

## **Quality of Life for the Sick and Dying: Challenges in Ugandan Palliative Care and its Relation to Disease-Modifying Care<sup>1</sup>**

Palliative care in Uganda has reached great heights in providing quality medical care to cancer and HIV/AIDS patients. However, I questioned how the struggling infrastructure of palliative care in Uganda affected the population's access to disease-modifying treatments, especially in a time where cancer rates in Uganda are at their highest. I also wanted to explore how better access to palliative care over other forms of care affected local perceptions of medical need and illness. Although palliative care in nature provides some disease-modifying treatments, their relationship requires exploration to address equitable access for a range of services. Providing sustainable health initiatives and strengthening its support will create a tangible improvement in Ugandan healthcare.

During the summer of 2011, I examined the accessibility and allocation of palliative as well as other forms of disease management in the Central and Eastern regions of Uganda. I spent six weeks investigating the conditions of various palliative care units across the country to examine: (1) its working relationship with disease-modifying services; (2) the challenges faced by health care workers; (3) the locals' experiences, knowledge, and medical need. I conducted semi-structured interviews with patients, medical staff, administrators, and governmental officials to analyze the local need in cancer and palliative care, as well as the local understanding of illness and suffering. My research inspected the discrepancy between medical services and

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<sup>1</sup> The title was originally "Quality of Life for the Sick and Dying: Challenges in Ugandan Palliative Care and its Relation to Curative Services." The language has been altered in order to adequately convey the language used in Uganda with regard to "curative services." Whereas the US would often call such services curative, the British palliative care system addresses them as "disease-modifying" in Uganda because oftentimes the procedure is unfortunately more palliative than curative.

further explores the development of palliative care. I also utilized participant-observation, a critical technique for anthropological research. I observed how the patients interact with one another as well as how the doctors interact with the patients.

Overall, my interviews and participation-observation proved successful. I found that it was easy to communicate with the patients and healthcare workers, and share their experiences in palliative care. Conducting my research at a variety of palliative care units, I was able to not only learn about the challenges in providing disease-modifying treatments, but also to act as their voice and advocate upon return to my base, Palliative Care Association of Uganda (PCAU), and for their US partner, Center for Hospice and Palliative Care (CHPC).<sup>2</sup> Additionally, while observing the efficiency of palliative care units in Uganda, I found a great importance of community participation in local health priorities. For example, it was evident that the hard work of community health volunteers in advocating early detection of cancer as well as providing basic nursing skills on daily visits to patients better enabled facilities to evaluate the community's needs for cancer treatments. Community health care workers also sensitize the community and assist in referring patients to the palliative care units and other health facilities. Essentially, the community health care volunteers' role as advocates and liaisons for each patient meant that providing different forms of disease management for cancer patients were better controlled. However, more facilities and especially rural locations need better funds and human resource management in order to maintain and support community health care workers. Further inspection on the logistics may prove to be a useful step to bringing better access to medical services to local populations.

I was intrigued by the holistic success of palliative care in Uganda, especially for their

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<sup>2</sup> A relationship between Notre Dame, CHPC and PCAU is working throughout the year as we analyze my data and conduct geospatial analysis on where and how to improve palliative care in Uganda for the upcoming year.

ability to address the patients' physical, psychological, social, and spiritual aspects, in the face of the lacking resources and severe suffering. Despite the inability to access some essential disease-modifying treatments, the holistic care they provide to the patient and his or her family is incredible. They are committed to continuing education and teaching one another to better their care. Our less patient-centered care in the US has much to learn from the Ugandans.

Although many other accomplishments may be named, addressing the challenges faced during this research most resonate the intricate cultural and social issues at hand. First off, one challenge was the issue of language barrier. Most villagers speak a local dialect so using a translator inhibited my relationship with the informants. Also, I found that some questions would not translate adequately for the patients. Mostly this is due to the inherent nature of questionnaires being limited artificial structures for interviews but also because the cultural understanding of hospice and palliative care between the US and the UK (used in Uganda) is complexly divergent. There are many explanations for the role of palliative care in the patient's medical care aside from curative. However, patience and implementation of semi-structure in interviews provided more ease in the sharing of stories. Lastly, we cannot deny that an inevitable limitation to the participant-observation is that my presence inevitably changed the local interaction.

Despite the strain of enduring challenges, these experiences were part of what constructed the depth of my findings. Through participant observation and semi-structured interviews, I investigated the influence of palliative care in Uganda. Overall, palliative care has achieved great improvements in providing access to a wide range of health care services for Uganda's population. Medical care in Uganda has undergone significant advancement preventative to curative to rehabilitative and then to palliative care. However, thinking that I was

going to return home with more questions answered than asked, I was ironically mistaken. I came home with even more questions. Straddling the complexity of the “connective tissue” regarding national health care in a developing country as well as international relations and understanding such realities from the lens of locals on the ground of a developing country as a Western outsider is, needless to say, perplexing.

I found that limited local drug access strongly disfavors national consideration for development in cancer treatments and prevention efforts than in HIV/AIDs treatments. In a reactionary sense, one would think that this is inequitable, but many of the cancers are associated with HIV/AIDs. Although many resources exist for HIV/AIDs patients (antiretroviral medications and counseling), less resources exist for cancer patients. This may be explained by a range of reasons. One factor is that there was great stigma towards cancer. Many uneducated people believe that cancer is caused by witchcraft through curses put upon them. Also, cancer treatments are much more expensive. The nature of cancer as chronic and most times incurable makes investing in HIV treatment more attractive as it is easier to control.

I also investigated a variety of general logistical issues that affect medical care in Uganda. I found that Uganda’s health care struggles due to geographical isolation; many patients live in rural areas that are too far away from the nearest clinic or transportation proves too costly. Also, there is a lack of material and professional resources, political corruption, no organized national healthcare system, high poverty rates, and the high cost of drugs, all of which prove detrimental to managing and accessing medical services. Additionally, there are issues in drug distribution, lacking endowments and funding for sustainable services, and poor knowledge about cancer and palliative care. An important logistical issue for providing disease-modifying treatments to disparate populations is “brain drain.” There are few trained doctors in Uganda and

many are working for the government, not practicing. They seek better pay and schooling for their children so they work in Kampala and/or with governmental positions for pensions. Many rural communities thus do not have access to these professionals. If patients were referred to the national hospital, Mulago in Kampala, many would go for initial testing or treatment but not continue follow-up. The distance and subsequent cost of accessing proper medical professionals and equipment is overwhelming. We need to encourage medical students to practice in rural areas, and find ways to compensate them for this effort to expand medical support.

Possible considerations for the increase in cancer rates include better detection, adoption of a more Western lifestyle (smoking, alcohol, poor eating habits), as well as poor waste management. Since Uganda does not have a national waste disposal system, most of the population disposes of waste by burning the garbage. The combustion of industrially-processed materials is carcinogenic in that the chemical by-products produced as emissions are hazardous.<sup>3</sup> Advocacy and governmental consideration for better management is necessary.

Although a disparity exists, we cannot deny the ethical requisite of promoting and improving palliative care. Patients cannot be left to suffer while development for better prevention, advocacy, and treatment of cancer continues. Additionally, it is vital that local conception of illness, cancer, and palliative care needs to be addressed. Since only 50 of the 112 districts of Uganda currently support structured palliative care, we need to increase support for palliative care so that more cancer patients can be reached. While national policies change to improve access to cancer treatments, with increased advocacy and support for palliative care, greater early access to disease-modifying treatments can be achieved.

During the fall of 2011, I will continue analyzing my results and to discussing proposed

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<sup>3</sup> These emissions are also known to cause a variety of respiratory diseases. This is probably the cause of the pneumonia I suffered from during my stay in Uganda.

resolutions with collaboration from PCAU and the CHPC. This will be executed through regular meetings with my faculty mentor Prof. Smith-Oka as well as in classwork for an Anthropology elective titled “Cultural Difference and Social Change” which is taught by my faculty mentor. In addition, I will meet regularly with the COO of the CHPC for assistance in implementation of ideas for improvement in palliative care. Also, I will present my findings at the Annual Meeting of the American Anthropological Association in Montréal this November and I will begin writing a Senior Honors Thesis. As a final product to my research, my Senior Honors Thesis will address the development of Ugandan palliative care and the disparity between accessibility and allocation of medical services in the context of sustainable international development.

With this research, I hope to increase awareness and discussion of the relationship between palliative care and other disease-modifying services, particularly those that produce health disparities for the Ugandan population. Most crucial is the immediate significance of my findings for the CHPC who holds a partnership with PCAU. They plan to use my data in their efforts to develop a new “re-districting formula” in aims of providing more efficient and effective palliative care services to the Ugandan population. I hope that my results will better direct social change to benefit these most under-represented communities. Addressing the results of this research across international borders will renew a universal belief in healthcare. This belief upholds that healthcare, including palliative and disease-modifying services, is a right and not a commodity by asserting that need rather than privilege should be the appropriate foundation for allocation of resources.