

The Price of Pain:

Examining Global Inequality in Palliative Care and a Human Rights Response

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First place, Robert D. Sparks Writing Contest

March 25, 2014

Uganda Cancer Institute, Kampala, Uganda, September 2012

“Surely this can’t be the patient”

That’s what raced through my head as I approached the bedside. I was supposed to be interviewing a 20 year old male with HIV who had recently been diagnosed with Kaposi’s sarcoma (KS), a cancer connected to an opportunistic infection, as data collection for my graduate studies.

Double checking the file confirmed that this was, in fact, who I was supposed to be interviewing. Emmanuel’s¹ file read 20 years old, but his withered, cancerous body looked to be no older than 10 years. His legs were twigs folded awkwardly beneath him, and his ribs and cheekbones were bony protrusions that stretched his spotted skin, creating depressions in places they did not belong.

A cough wheezed from his frail body, expelling infectious droplets into the crowded ward. A contorted wince and quick inhalation through a rounded mouth revealed the intense pain Emmanuel felt as he propped himself on to his elbows, swinging his legs around with his hands. His furrowed brow and determined pursed lips communicated to me that he wanted to be interviewed when I tried interjecting on account of his pain. But maybe getting the chance to tell his story provided the small victory he needed. I read the consent; he agreed, and we proceeded through nearly all the questions normally.

¹ Emmanuel is a pseudonym to protect patient identity.

“I have nobody. I have nothing. I am nothing.”

That was his answer. I did not want to ask the question, but part of my questionnaire focused on social support systems. “Does anyone know about your condition?”; “Have you told anyone other than the doctor about your illness?” I tried to focus on the remaining few questions, but the scowl on E’s face and his previous answer replayed themselves over and over again in my head. *I have nobody. I have nothing. I am nothing.* He later told me that he wanted to die. Not because he had no one left in this world, although that was true, but because he wanted to leave the pain he felt from the assault of HIV and cancer on his body. *Mycobacterium tuberculosis* had ravaged his lungs, Kaposi’s sarcoma had co-opted his skin’s connective tissue, exploding in painful lesions all over his body, and HIV had rendered his defense system useless, resulting in fatigue and body aches. But Emmanuel had received no pain management, and it seemed from his request to die that pain had taken his will to live.

Emmanuel died two days later. It is the fate that about 80 percent of the people that I interviewed will face before reaching old age. He had lived with HIV for seven years, somehow surviving without any therapy until TB and later KS attacked his compromised immune system. As a physician-in-training, I found the lack of social support system for Emmanuel to be devastating. Even more devastating, however, was the fact that Emmanuel died alone in excruciating pain and agony, a small but incredibly influential part of his medical history that could have been changed with proper care through palliative services.

Emmanuel’s story is not another narrative of suffering merely for the sake of further validating sensationalized stories of African poverty. Unfortunately, Emmanuel is not the

exception among cancer patients in Uganda; he is closer to the rule. Emmanuel is the reality of cancer, HIV, and lack of pain management in Uganda and throughout the world for marginalized patients without access to palliation and pain management. I believe his story needs to be told because he represents a severely under emphasized problem in medicine globally, namely, the unjust distribution of pain management and palliation that leaves the large majority of patients in the world with terminal illnesses with no form of end-of-life care.

“I’d rather have HIV a thousand times than get cancer.”

That is what I was told by a number of patients. “HIV I can deal with,” they told me. “But, cancer!.....”, trailing off for me to finish the rest. I might agree if I was Ugandan. Of course, I’m not. If I get cancer, I have access to early detection, surgical intervention, a myriad of tests, therapies, drugs, and pain management. Cancer is a painfully different story without these things.

Global inequality in palliative care persists as a reality that affects millions worldwide who face terminal illness, both chronic and acute. Emmanuel’s story is just one of many that can be told that chronicle death in extreme agony due to a lack of pain management within palliative services. A small fraction of the global population claims access to nearly the entire global supply of palliative services. The story of Uganda and Emmanuel is simply a reflection of one of the largest and most astonishing gaps in access to life-altering medications worldwide, a global injustice that cannot be ignored.

What is a proper response to a patient like Emmanuel? Does the global community, including physicians, have any responsibility for these outcomes? A human rights-centered

approach provides a basis for global palliative care equity. Grounded in ethics, law, and social theory, a human rights response provides impetus for action from the global community that includes everyone from the physician to the policy maker. Faced with the injustice of global palliative care inequality and motivated by human rights, a proper response will work to ensure that patients are no longer abandoned in agony.

The Problem: Global Palliative Care Inequality

Although palliative care is a relatively new advancement of modern medicine, it has come to be internationally implemented and holds many commonly accepted definitions. The World Health Organization has defined palliative care as

“an approach that improves the quality of life of patients and their families facing the problem 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” (1).

WHO has stressed the importance of palliation, insisting on its relevance in maintaining proper health. Palliative care has been shown to be associated with improved quality of life, reduced symptoms of depression, and longer survival (2), which are goals of palliative care that WHO advocates. These positive aspects become even more vital in settings where poor patients present with late-stage disease and palliative care could be the most beneficial and least burdensome treatment option. Unfortunately, palliative care services remain primarily a luxury of high-income countries, despite the fact that most painful terminal illnesses occur elsewhere.

While diseases in high-income countries (HICs) garner the most attention globally with respect to palliation, the reality is that the largest proportion of individuals in need of palliative care are those with HIV and terminal cancers in low- and middle- income countries. Globally, approximately 58 million people die each year, but 80% of the world population is underserved

with respect to treatment of moderate to severe pain (3, 4) The largest majority of these underserved patients are cancer and HIV patients; half of all cancer patients and 95% of all HIV patients live in areas with limited or no access to treatment for moderate to severe pain (5, 6). Emmanuel is the picture of global palliative care inequality; it is HIV and cancer patients who suffer the most from this misdistribution of care.

Thirty-five million people globally still live with HIV, and 1.6 million die each year from the disease with the vast majority of morbidity and mortality occurring in low- and middle-income countries without palliative services (7). Numerous sources have chronicled the pain HIV patients experience in death with 60-80 percent of all AIDS patients describing their pain as “moderate to severe” (8). In addition, many of these patients experience painful co-morbidities, such as TB and KS. In addition to a number of pain-causing symptoms like those seen in cancer, such as fatigue, weight loss, depression, anxiety, and co-infections, nearly a third of HIV patients also experience neuropathic pain due to low CD4 counts, the HIV infection itself, drug side-effects, and inflammatory responses from the infection (9). These aspects of HIV care, however, are rarely discussed or included in treatment regimens.

In addition to HIV, cancer represents a rapidly increasing global concern, as it contributes 12.7 million cases and 7.6 million deaths yearly (10). This represents a 14.2% increase from 2002, making cancer an increasingly salient disease as a focus of prevention and treatment. This trend is only expected to continue with an anticipated 50% increase in cancer prevalence by 2020 (11). In addition to the predicted increase in disease burden, cancer faces the challenge of global inequity, referred to as the “Cancer Divide” (12). Cancer represents a disease that reflects extreme inequity with respect to the global disparity in cancer incidence, cancer mortality, and access to essential cancer medications between the global North and the global South.

The majority of the global cancer burden already lies in low-income countries, and changing lifestyles alongside infections that cause cancer provide a combination that will result in a continually increasing cancer burden. Developing countries contribute 56% of all cases and 64% of all deaths, despite the fact that the incidence rate in these countries remains half of that compared to developed nations (13). Most of these deaths are due to cancers from infectious agents that can be prevented and controlled. Eighty percent of all preventable deaths from cancer (2.4-3.7 million) occur in low and middle-income countries (14), and this number is expected to grow.

These inequities can be traced to a lack of global funding and the international policy decisions made around cost and cost-efficacy of treating HIV and cancer in LMICs. Currently, gross inequalities exist in providing essential medicines, diagnostics, and training to combat cancer in low- and middle-income countries. Only 5% of the global expenditure on cancer is spent in LMICs, although they represent 80% of the burden, resulting in a 5/80 cancer disequilibrium (12). The inequality affects all aspects of cancer control and care, extending from prevention to palliation.

The lack of funding is reflected in the unequal cancer outcomes in these disadvantaged countries. A woman with cervical cancer who is in the lowest 10% in terms of wealth globally is 12 times more likely to die than a woman who is in the highest 10% (10). These rates are true across numerous types of cancers. While these numbers are startling, one of the greatest inequalities, however, is in the form of unequal global distribution of pain management and palliation.

While the divide between the rich and poor concerning systemic treatments and prevention is great, the divide for pain management medications for HIV and cancer is even

greater. Even though HICs have only 15% of the global population, they consume 94% of the total global morphine supply (16). The University of Wisconsin Pain and Policy Studies group found that the cumulative dosage of pain medication in milligrams per death due to HIV or cancer among the poorest 10% of countries was only 54mg compared to over 97,000mg per death due to HIV or cancer in the wealthiest 10% of countries (17, 18). The problem, however, is not only patients receiving inadequate doses of pain medication, but also entire populations who have entirely no access to pain medication for terminal diseases, as seen in the case of Emmanuel.

Some of these populations are already the most vulnerable with respect to proper access to healthcare. Sub-Saharan Africa (SSA) consumes medicinal opioids necessary to treat only 85,000 people, despite the fact that 1.1 million will die each year in pain; they have access to only 1% of the total global supply of medicinal opioids (19). This is not a story of a global shortage, however; it is a story of global misdistribution. SSA has been left out of the global opioid consumption equation, seeing relatively unchanged rates of opioid usage even though the global usage has doubled in the last decade (20). These data clearly show a gap in palliation worldwide.

The access gap to proper pain medication and palliative services has been further measured by a number of groups. A report by the World Health Organization estimates that “5.5 million terminal cancer patients and one million end-stage HIV/AIDS patients are suffering without adequate treatment for moderate to severe pain” (21). In addition, the Worldwide Palliative Care Alliance reports that only 8% of the 100 million people eligible for palliative care actually have access to it, and only 6% of the global palliative care services exist in developing countries, despite the fact that 85% of the global population resides there (22). The problem is

not only low levels of palliation, but also areas with no palliative services whatsoever. In fact, a third of all countries worldwide have no palliative care services across the entire country (23).

Numerous reasons for these disparities have been posited.

Funding of and access to palliative services and pain medication are only part of the problem. Countries in similar income brackets report opioid consumption levels that are still orders of magnitude different, suggesting that there also exist inequities in health care infrastructure, cultural uptake, and distribution mechanisms (12). In fact, these issues may even be greater than cost, at least with respect to opioids. One source analyzing drug pricing data suggests that differential pricing in low-income countries has led to a 1 mg tablet of morphine sulfate costing less than one cent, and monthly supplies cost \$1.80-\$5.40 (97) (24). Populations remain severely underserved, however, leading to numerous questions surrounding the failure of pain medication to reach its targets. These problems further underscore the need for palliative care to become a priority for the global healthcare community so that needless suffering can be stopped.

Often statistics remain on the pages of policy briefs and recorded in large institutional reports. Emmanuel's story reminds us, however, that these numbers represent actual individuals that die every day in unnecessary pain and suffering. For healthcare providers, his lack of medical care can be seen as a failure when one considers a human-rights approach grounded in medical ethics. Viewing the stories of those who are neglected from palliative care from this perspective provides an undeniable conviction that even one unnecessary painful death is, in fact, an injustice that needs to be addressed.

A Response: Palliative Care as a Human Right for All

The discourse positing palliative care as a human right has been built on the robust foundation of health as a human right. This has been argued in numerous documents including the UN Declaration of Human Rights (UNDHR) that states: “Everyone has the right to a standard of living adequate for the health of himself and his family” (25) In addition, The International Covenant on Economic, Social and Cultural Rights (ICESC) states:

Article 12.1 “the State Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. 2. The steps to be taken.....to achieve the full realization of this right shall include those necessary for:

d) The creation of conditions, which would assure to all medical service and medical attention in the event of sickness” (26)

Building on this foundation and numerous writings of institutions and individuals, many have argued for palliative care as a facet of health as a human right. Physician, Frank Brennan has formulated a cogent defense of this position that employs legal, social, economic, and ethical frameworks.

An appeal to medical ethics in support of palliative care as a human right can be traced to Hippocrates who said that medicine was “to do away with the sufferings of the sick, to lessen the violence of their diseases and to refuse to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless” (27). This sentiment has been echoed in contemporary moral arguments by medical ethicists who call for the “same care and attention for those who leave life” as to “those who enter life” (3) and by Pope Benedict XVI who said palliative care was a “right belonging to every human being, one which we must all be committed to defend” (28). The root of a palliative care human rights approach is found additionally in medical ethics.

Ethicist Margaret Somerville has stated, “Nowhere are the concepts of an ethic of care, human ethics, human rights, and human responsibilities more important than in relation to human dying” (29). Somerville can largely be credited with establishing a theoretical grounding for palliation as a human right. She has argued that the medical ethics concept of negligence can be applied to cases of failure to provide pain-relief treatment and was forefront in grounding the concept of rights to palliation as a human right (30). She says the concept of respect for persons as a universal requirement is “inextricably linked to that of human ethics” and “legally enforceable human rights; and to leave people in avoidable pain and suffering is to show them great disrespect and to breach fundamental requirements of human rights and human ethics” (29). Contemporary policy and academia has furthered this position. Despite these advances, however, patients like Emmanuel continue die untreated in immense pain, as palliative care is ignored in the growing list of global social inequalities that receive international policy and aid priority.

Further on the point of medical ethics, Brennan looks at accepted medical ethics and asks physicians to reflect on their own principles (rooted in the bioethical principles of autonomy, beneficence, non-maleficence and justice) and their virtue ethics to think critically about end-of-life situations that he says have a “deep humanitarian core”. He says that if the physician feels in these cases strongly about an “ethical obligation to relieve suffering or act virtuously by doing so” that “from that obligation springs a right” (31). In other words, physicians need not look farther than the same medical ethics that they have already affirmed in numerous other cases for motivation to accept palliative care as a human right for all.

Legal arguments can also be made based on the numerous international governance bodies that have drafted policy describing palliative care as a human right. In addition the

UNDHR and ICESCR documents, The Cape Town Declaration of 2002 that advocated specifically for palliative rights for HIV/AIDS patients, the 2004 International Working Group of the European School of Oncology, The Korea Declaration of 2005, and the 2005 Montreal Statement on the Human Right to Essential Medicines all contain assertions that palliative care is a human right (31-33). Collectively, these documents have provided a basis for legal obligation that has allowed scholars to advance the legal discourse surrounding palliation as a human right. They also reflect a larger social movement generally and also within medicine that increasingly sees global human rights and distribution of medical care as linked. The patient-physician relationship that mediates the distribution of care, including palliation, is no longer simply between two individuals, but between communities, groups, governments, institutions and influenced by policy.

The realm of social theory helps describe this transition in understanding. In particular, the field of medical anthropology provides a social theoretical framework and argument for understanding the role of the physician and medicine in alleviating human suffering experienced through pain. From this perspective, suffering and pain experienced by individuals is not reflective of the bio-physical manifestation of the disease in the individual, but also the larger social and economic forces that bring about human suffering. For physicians who may be accustomed to operating on an individual to individual level, this theoretical argument that links the individual to the structure is an important one when considering global inequality in palliative care. Medical anthropologist and psychiatrist, Alex Keinman, iterates,

Anthropologists now configure suffering as much more than deep subjectivity of the afflicted person, the psychology of the individual.... It includes the individual level but also transcends it as cultural representation, as transpersonal experience, and as the embodiment of collective memory. That is to say, one can speak of suffering as being social...[connecting] the moral to the medical, the political to the emotional, and the religious to the physiological (34).

Suffering of the individual, especially needless suffering of the individual in pain without palliative care can then be understood to reflect the psychological disposition as well as the political and economic forces that put an individual in a situation of suffering. Physicians can play a role in alleviating this suffering at all levels.

Critical medical anthropologist and physician, Paul Farmer, draws this connection between the suffering experiences of individuals and the political economy that determines their position by writing on the realities of HIV/AIDS and TB among marginalized communities in Haiti. Farmer describes this phenomenon as “structural violence,” a term borrowed from Latin American liberation theology (35). For Farmer, social forces, such as poverty and racism, are so salient in society that they become embodied in the individual experience (36). He calls structural violence, relative to healthcare, as “violence that is exerted systematically—that is, indirectly—by everyone who belongs to a certain social order....a social machinery of oppression” (37). These forces are far more than powers that cause divisions and inequality; they are methods of instigating violence and suffering on populations, a dynamic underpinning of society that often goes unchecked until suffering is met face to face. Farmer chronicles the stories of his Haitian patients to show the connection between political and economic structures and the suffering experience of individuals afflicted with preventable, but deadly, diseases.

When one takes these assertions seriously, he or she can arrive at the conviction that delivering palliative care is not simply about treating the individual, but is also about treating all individuals justly and equitably. These arguments also force one to consider their own responsibility in alleviating palliative care injustice. Failure to treat patients equitably is a failure on both the public level of governments and policy-makers, but also on the personal level of the physician who takes medical ethics and the obligation to alleviate suffering seriously.

Next Steps

Global inequality in palliative care is an underrepresented phenomenon that is not only one of the greatest injustices in our global society, but is also an issue that carries significant ethical and moral implications. Statistics can only reveal a part of the problem; stories like Emmanuel's elucidate the humanistic aspect that paints a very real picture of the too common reality of death without pain alleviation that disproportionately affects entire populations of people, particularly those with HIV and cancer in low-income countries. As global citizens, we have increasingly responsibility to respond.

We live in a global society, and physicians have increasing influence to reach communities around the world. A consequence of this reality is that ethical obligations no longer apply solely to the immediate physical community, but rather to the entirety of the community in which the physician finds him or herself, a global community. Our technology, information, resources, and consumption increasingly draw us closer, which has implications for the practice of medicine. The patient is not only the one seen face to face in the clinic in a given day, but also the patient never seen across the world.

Alleviation of pain can be one of the greatest gifts a physician can give to a patient facing death. If we truly believe in the alleviation of pain as the best medical practice and that denying this to some patients is a violation of human rights, then we have an obligation to these marginalized patients. Armed with these convictions, we can move to act so that stories of needless suffering in death like Emmanuel's can be eradicated.

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