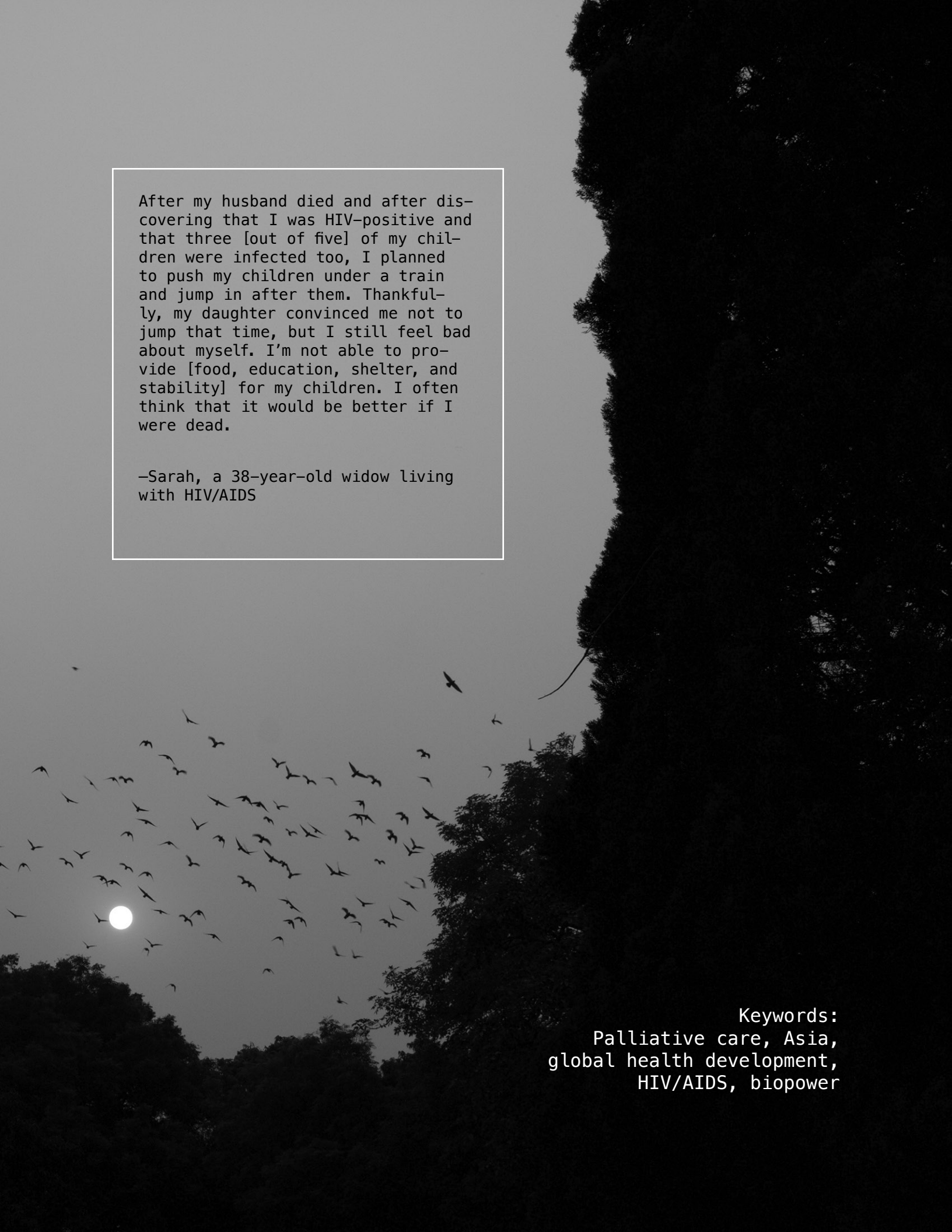


The Politics of Palliative Care in Resource-Limited Settings

Kalei Richard James Hosaka

Journal of Undergraduate Ethnography
Vol. 7 No. 1 47–66
ISSN 2369–8721



After my husband died and after discovering that I was HIV-positive and that three [out of five] of my children were infected too, I planned to push my children under a train and jump in after them. Thankfully, my daughter convinced me not to jump that time, but I still feel bad about myself. I'm not able to provide [food, education, shelter, and stability] for my children. I often think that it would be better if I were dead.

-Sarah, a 38-year-old widow living with HIV/AIDS

Keywords:
Palliative care, Asia,
global health development,
HIV/AIDS, biopower

Abstract

Whose lives are valuable? Whose lives are worth living? This essay examines these questions by investigating the ways in which global health development programs deal with palliative care, specifically care for people living with HIV, in resource-limited settings. Through interviews and participant observation, I explore the concept of worth as expressed by a particular funding agency and the Central Hospital Network's (CHN) palliative care staff in an Asian country (not specified due to ethical considerations). Based on six months of ethnographic investigation conducted during an internship from February through August 2015 in a palliative care hospital and organization associated with CHN focused on caring for the poor living with HIV/AIDS, I argue that decisions regarding funding for people with incurable diseases are inseparably tied to understandings of whose lives are more valuable than others. I argue that palliative care that seeks to improve the quality of life for persons with life-threatening illness—especially in resource-limited settings—will continue to face barriers to its development as long as it is judged by utilitarian, neo-liberal development standards.

Whose lives are valuable? Whose lives are worth living? These questions have been central to debates in anthropology, sociology, philosophy, economics, and other fields. Whether in Agamben's (1998) explanation of bios and zoe or Foucault's (1979) articulation of biopower, we find that worth is almost always indelibly inscribed on bodies. In a world of asymmetrical power relationships, globalization, and growing inequality, the question of the worth of human lives is increasingly important.

Is peace in living with life-threatening illness a right for all or a privilege for the wealthy? This paper explores the question '*whose lives are worth living?*' by investigating the ways in which global health development programs deal with palliative care in resource-limited settings. The field of palliative care — specialized medical care that seeks to holistically improve the quality of life for people and their families living with life-threatening illnesses such as various cancers and HIV—has gained traction in the U.S. and Europe in both medical and academic circles, due in part to aging populations. Yet discussion of the realities of palliative care in resource-limited settings is rarer. In contexts of scarce resources, how can the terminally ill be worth caring for? While nursing homes and hospice care institutions in rich countries are being reformed, palliative care teams (including those working with cancer and HIV) in poorer places are struggling to stay afloat. In the case of the site for this investigation, situated in

a county in Asia that I leave unnamed to protect the identities of the organizations and individuals involved, there are at least a couple of reasons for this: first, the central government has significantly cut its health care budget in recent years, and the effects of decreased funding are most felt in specialties like HIV care. Second, as one of my informants told me, with an increasing middle class, international donors and transnational agencies "have decided to contribute less [financially] to health care programs."

This article analyzes the question, "Who decides if care for the terminally ill is worthwhile in resource-limited settings?" by investigating how decision-makers understand the concept of the worth of persons living with terminal and/or life-limiting illnesses in poverty in resource-constrained settings. This analysis is grounded in two experiences: (1) participant-observation during six months as an intern with *Life Centre* from February through August 2015, a palliative care unit of the Central Hospital Network (CHN); and (2) an ethnography of interaction between CHN's palliative care practitioners in rural areas and a neoliberal funding agency (RFM¹) which was conducted when these two groups met during a three-day proposal-writing meeting and workshop to discuss funding for CHN's palliative care program. In exploring these two experiences, I describe the dissonance that palliative care practitioners in resource-poor rural parts of the country feel in articulating the worth of caring for people at the end of their lives

to the funders of programs for health and development.

Broadly speaking, I make the case that contemporary global health development based on neoliberal principles of limited government and objectivity allows global health funders to distance themselves from moral and ethical considerations (see Rottenberg 2009; Ferguson 2006). On an applied level, I argue that palliative care and any kind of healthcare that seeks to improve the quality of life for persons at the end of life—especially in resource-limited settings—will continue to face barriers to its development as long as it is judged by utilitarian, neoliberal development standards that see health care in terms of a cost-benefit framework. Because the terminally ill and those living with HIV/AIDS or other life-threatening illnesses have less worth in the global health discussion, where every dollar spent is expected to produce a return, palliative care cannot and should not be “sold” as a development initiative. Instead, palliative care must be engaged culturally in the sense that it must be articulated both at the local level and to the international aid community as the product of an understanding of humanity where people are valuable regardless of their economic contribution to society.

* * *

As with any ethnography that “studies up” (in this case, writing about the interactions between staff members of CHN and RFM), ethical representation poses an enormous challenge. My intent is not to investigate the actions of specific organizations but instead to explore the topic of palliative care in resource-limited settings. Thus, some details throughout the narrative have been changed to protect the privacy of the people I met, balancing anonymous characterizations with the integrity of important ethnographic details. In any case, my goal is to critique not individuals but sociopolitical systems and widespread narratives of development.

I support this paper’s central arguments by describing one particular narrative of how decision-makers interact with the development of palliative care in resource-limited settings that draws from ethnographic experiences from my fieldwork. Acknowledging that the main argument in this paper—namely, that palliative care does not fit into mainstream “development” ethos—is based on a subjective interpretation of the ethnographic data, I organize this paper to allow the reader to understand the rationale behind my interpretations. For this reason, I intentionally place ethnographic descriptions prior to theoretical considerations and my own interpretations.

I begin by introducing Life Centre, the site of my primary fieldwork, and briefly discuss palliative care generally. I then describe the interaction between a Western funding agency, which I call

'RFM', and CHN in a three-day meeting, and present the experiences one palliative doctor, with whom I had a close rapport throughout my stay, had of that meeting. Next, after exploring theoretical frameworks of global health and development, I provide an ethnographic narrative that counters RFM's approach to global health funding. In the final section, I consider the implications of some of the paper's central themes.

Palliative Care At Life Centre

I spent six months with my college's development studies program as an intern with Life Centre, a palliative care unit primarily focused on HIV/AIDS, based in the Central Hospital Network (CHN). My time with Life Centre was focused on building relationships with people living with HIV/AIDS or other terminal illnesses in situations of poverty, as well as with local professionals trying to ameliorate living conditions for those living with the illnesses. I spent the majority of my days traversing the city to visit families affected by HIV and cancer as a part of Life Centre's home-based care team, working on projects with staff, and conversing with patients in the HIV ward.

The six months that I spent living and working with staff at Life Centre provided ample opportunities for understanding palliative care in the country, particularly from the perspective of indigenous palliative care practitioners. In addition to attending a meeting on the future of CHN's palliative care funding

between the head of a European funding agency and CHN's palliative care staff from across the countryside, I also participated in a nationally certified course on palliative care, as well as an "End of Life Care Workshop" run by the palliative care directors of a large cancer hospital. Aside from informal conversations and participant-observation, I conducted in-depth qualitative interviews with roughly fifteen staff members and patients who were a part of Life Centre's home-based care program.

For the duration of my internship, Dr. Joseph, director of Life Centre and later the director of CHN's palliative care program provided a room for me to stay with his family in their apartment located twenty minutes from Life Centre's clinic. Given our shared interests in palliative care, we quickly formed a strong mentor-mentee relationship, and he treated me as a student and a son. In addition to our shared professional interests, coincidentally, I look like one of his wife's relatives; which allowed me to fit in as a part of his extended family. On many occasions, he would give me lectures on topics such as the socioeconomic struggles his patients go through in living with HIV/AIDS, clinical tips on pain management for people with late-stage cancer, the difficulties of raising support and awareness for palliative care, and the joy of raising a family in an urban setting.

* * *

Palliative care has been the subject of growing global discussion. The global inequalities in access to palliative care are stark, and most of those with the privilege to access palliative care are living in high-income countries. A 2014 UN Health report stated that “only 1 in 10 people who need medical care to relieve the pain, symptoms and stress of serious illness is currently receiving it” (UN 2014, n.p.). Somewhat skeptically, as if to suggest that there is little hope for palliative care’s development globally in the near future, one of the main authors of the report explained:

Our efforts to expand palliative care need to focus on bringing relief of suffering and the benefits of palliative care to those with the least resources... will take courage and creativity as we learn from each other how to integrate palliative care into existing but very limited health-care systems.

Megacities in Asia offer a unique vantage point from which to view palliative care development at both local and global levels. With large-scale rural-to-urban migration, where world-class malls are built adjacent to sprawling slums and packed 1940s-style military jeeps drive past BMWs, social inequality is palpable. For the bottom half of the socioeconomic ladder, high quality healthcare is a rarity. For an observer, it seems as though the city’s sheer population size and its surrounding areas render adequate healthcare for the non-elite majority nearly impossible. Throughout the course of my fieldwork, Mark—a 20-year-old man

HIV-positive from birth—often expressed to me his feelings of discontent with government-funded Antiretroviral Therapy (ART) centers:

The counselor will just ask about my [antiretroviral] medicine—how many tablets I have left. If the patients say that they have some problem, the doctor or counselor will say: ‘It happens.’ If you talk too long about the problems with HIV/AIDS, they’ll interrupt you and say ‘Please leave now!’ The lines are long, and there are too many people.

With the city’s population rapidly increasing and the central government cutting back on its health care budget, adequate health care for the masses continues to prove difficult. As one of the physicians at Life Centre related to me, “I don’t know how my friends do it in the government hospitals. They see patient after patient every single day.” In a context of scarce health care resources—including capital, workforce and infrastructure—where does palliative care fit into the picture? In the next section, I outline a brief history of palliative care and how it is understood in the country where this study was conducted.

Contextualizing Palliative Care

The origins of the contemporary palliative care movement are often traced back to physician Cicely Saunders’ pioneering hospice care in the United Kingdom in the mid-1900s. At a time in medicine when patients diagnosed with incurable disease were left to die, Saunders sought

to improve the quality of life of her patients, regardless of how many days they had left to live. From its beginnings, palliative care has often been synonymous with ‘end of life’ or ‘hospice’ care. Because of this, palliative care has widely been viewed as the medical option of last resort, the antithesis of curative care. I argue that this understanding of palliative care affects how health care workers, government officials, and aid organizations understand the worth of palliative care.

Most palliative care practitioners today see palliative care as a medical approach integrated with curative care, which improves quality of life for people with life-threatening illness. Harding (2008) articulates that palliative care has always been demonstrably effective alongside curative treatment. Improving the quality of life for patients and their families is a matter that deeply depends on social and interpersonal engagement. This line of thought runs throughout physician-anthropologist Paul Farmer’s writings on HIV/AIDS, in which he argues that patients living in poverty with HIV/AIDS need accompaniment—home-based therapy, social and psychological support, and everyday help—as much or more than antiretroviral treatment and symptom control (Farmer et al. 2013). The ethos of the modern palliative care physician or nurse is summed up in Atul Gawande’s *Being Mortal* (2014, p. 259): “We think our [doctors’] job is to ensure health and survival. But really it is larger than that. It is to enable well-being.”

According to a recent UK “Quality of Death” report, the Asian country where this study was conducted is nowhere near one of the best countries in the world in which to die (Economist Intelligence Unit 2015). While the history of palliative care services in this country goes back to the mid-1980s, a number of factors have limited its reach to and development in the general population, especially in rural areas. In many places throughout Asia, “population density, poverty, geographical diversity, restrictive policies regarding opioid prescription, [and] workforce development at base level” as important limiting factors affecting the development of palliative care services (Khosla et al. 2012).² Where palliative care exists, it exists in small niches. As cited in organizational literature, CHN palliative care practitioners operate under the World Health Organization’s (WHO) current definition of palliative care (2016):

Palliative care is 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.

In many ways, palliative care is the practical postmodern response to modern medical practice. By acknowledge the inevitability of death, palliative care practitioners confront the limits and consequences of the best scientific practice. Palliative care strives to cope with

the limits of modern medicine while holistically seeking to improve the well-being of patients, unlike most medical specialties, which seek to push as much as possible against the constraints of our biology to make patients better (Gawande 2014). While palliative care practitioners understand the great importance of palliative care for patients suffering from life-threatening illnesses, they are deeply aware of the financial limitations that affect the kinds of services they can provide. How might palliative care providers in places with limited resources access funding, and what sorts of strategies can be employed to access global health funding for improving palliative care services? In the section that follows, I address these questions by describing the interactions between CHN's palliative care practitioners and a Western funding agency in the summer of 2015.

A Case Study—What To Do With The Terminally Ill

In late July, Dr. Joseph took me with him to a three-day proposal-writing meeting and workshop that would also discuss the next steps for CHN's palliative care program. A funding agency (RFM) from a Western country intended to continue its partnership with CHN in providing financial support for its palliative care program, and Christopher, the head of RFM, attended the meeting, along with fifteen CHN staff, including several physicians, two nurses, the CHN director for palliative care, and a CHN secretary. Christopher flew in the day before the

meeting convened. Raised in the West and having lived there for almost all of his professional life, Christopher is an expert in strategic planning and proposal writing with years of experience working in the world of development funding. RFM had been a major contributor since CHN's palliative care services began in 2010, funding roughly thirty percent of the overall budget.

Earlier that year, RFM had helped CHN to pilot a large, multi-site study on the impact of palliative care on household poverty, which showed that in general, adequate palliative care reduces household poverty: the logic was that palliative care could prevent households from exhausting savings on unnecessary treatment, and could allow family members who would otherwise accompany their sick loved one to go back to work. An Asia-based public health researcher with ties to an American university had been tasked with carrying out this study, the goal of which was essentially to investigate the link between palliative care and reduced poverty. Following the study, all parties agreed that this link does in fact exist. The argument was this: suppose a farmer discovers he has late-stage lung cancer in a rural area. Not knowing his chances of recovery, he spends all of his savings on treatment and medication, which are almost always futile, and his children or grandchildren may even leave their jobs to care for him. A palliative care program could prevent this by providing medical care and helping the farmer's family cope with the loss.

Most in attendance at the three-day workshop understood that the meeting would focus on future funding options for CHN's palliative care programs. RFM provided the financial support for the meeting so that the directors and a staff member from each of CHN's palliative care programs could attend. Christopher, the representative from RFM, led nearly all of the discussions; when he did so, he sat on a chair facing the rest of the group as if he were a lecturer in a small classroom. Behind him was a hotel-supplied projector screen. The rest of the group sat on chairs facing the front of the room around five separate tables.

Dr. Angela, central director for CHN's palliative care programs, opened the meeting, emphasizing the value of palliative care and highlighting the good work that CHN is doing. "We value people over programs and we strive to maintain dignity ... We realize that most who access our services have lost dignity and hope." Dr. Angela reiterated that CHN's palliative care brings visibility to the cause of caring for the terminally ill in the country, promoting or providing holistic care for the poor, high quality end-of-life care in resource-limited villages, and awareness of terminal disease. She maintained that the meeting would address the question: "how can we improve the social impact of our services?" Dr. Joseph then followed with a brief summary of the main conclusions of the CHN-RFM collaborative study on palliative care and reduced household poverty. He articulated the ways in which CHN's palliative

care programs have the potential to improve quality of life for poor terminally ill patients and their families, in ways many of the staff members had not considered:

Most of our patients are daily wage earners, a quarter of patients lost their livelihood following illness, only a tenth receive government benefits, and most of our patients do not plan for inheritances . . . CHN has helped 85% of patients to cut spending on medicine and travel, provided livelihood support in some of its locations, and increased education and awareness of life-limiting diseases in families and community leaders.

After Dr. Angela and Dr. Joseph opened the discussion, Christopher took the "stage," and from that point on, it became clear that he would facilitate the rest of the three-day meeting. Christopher revealed his plan to apply for a prestigious multi-year grant from the Global Synergy International Fund (GSIF) – a development fund supported by various government and private sources in the US and UK. To the surprise of many, Christopher intended the meeting to be centered on gathering details to apply for this grant.

Christopher presented himself as able to re-present CHN's palliative care program into one attractive for donors. He made it clear: "Donors in the UK want to improve the economy and improve companies.... Organizations in London and others like USAID are becoming more rightwing and neoliberal." In line with GSIF's institutional culture of neoliberalism, Christopher explained that the pro-

posal for the grant must be “innovative, have the potential to impact, and able to be scale up,” and the three-day meeting about “finances” became a three-day group proposal-writing workshop. Logistically, the workshop aimed to create a “log-frame,” an extremely important component of GSIF applications, which consisted of four sections: “objectives,” “specific objectives,” “results,” and “activities.”

Christopher’s plan for getting funding from these increasingly “right-wing” funding agencies was simply to sell palliative care as a poverty-reduction strategy, which would: (1) make the palliative care programs economically sustainable by investing in medical specialties (i.e. cardiology, surgery, anesthesiology) whose income could support palliative care, and (2) convince other hospitals that this work is important in reducing poverty, and in doing so, (3) increase the number of palliative care programs across the country. By doing this, Christopher argued, “we [could] get governments on board” and show them that providing palliative care is a core part of running a country. The argument was that such palliative care activities would lead to reduced household poverty in the country, as expressed in an early draft of the “goals” section of the log-frame: “By 2021, fewer people are living below the Below Poverty Line (BPL) OR fewer people living on \$2/day or less.”

Although the CHN staff members understood the substantial sums they could receive through this grant, they questioned the feasibility of Christopher’s vi-

sion at every turn: how could they truthfully say that their palliative care services would be financially sustainable and scalable? Indeed, conflict ensued from the moment Christopher presented the plan to apply for the GSIF grant. As one CHN staff member asked incredulously, “Can we reasonably reach millions with palliative care?” While some were more outspoken than others, over the course of the three-day meeting, nearly every CHN staff member present argued that it is not really possible to convince other hospitals of the value of palliative care when most other health care workers in the country view the terminally ill with less dignity than the CHN staff do. Nor, they argued, is it possible to make palliative care services sustainable when specialty doctors like anesthesiologists and cardiologists, who would perform operations that could generate hospital income to support palliative care, would not want to work in rural or poor urban areas. (This relates, in a sense, to the point made earlier that palliative care is a kind of antithesis to medical specialization.) Moreover, they maintained, it would not be possible to scale up palliative care services with so few physicians willing to engage in this kind of work. The staff kept returning to the fact that they work in palliative care primarily because they seek to improve the quality of life of the patients they serve, not necessarily to reduce poverty on a nationwide scale. For instance, one of the physicians, Dr. George, reminded Christopher: “We are in places where there are no other places around,” point-

ing to the fact that they first and foremost want to serve communities' needs. Another physician chimed in: ““We’re serving in desperately poor areas. Every time there’s a salary rise, it’s going to affect the patient. We’ve made a decision to choose to work with low salaries to work among the poor.”

In response, Christopher continually pressed upon CHN staff members his conviction that their programs must be scalable or financially sustainable in order to be worthwhile. He claimed that CHN was too thinly spread, and that if they wanted to continue with palliative care, they must either cut back on their palliative care services (concentrating palliative care in a couple of hospitals) or increase the investment for it to be worth doing. On more than one occasion, feeling the weight of the pushback, he reminded CHN that he is an expert at strategic planning and proposal writing. He continued that “the days of our organization just investing is in the past,” and that CHN must model its programs to fit what donors have in mind.

As in much of the post-1990s literature on donor-driven development, Christopher as the representative of a particular funding agency alternates between pushing an agenda onto “passive” recipients of foreign aid and “empowering” local NGOs to identify and address problems they see (see Rauh 2010, Rottenburg 2009). To sum up the meeting, while both sides agreed that palliative care is valuable and has the potential to reduce household poverty, they diverge

in their perceptions of which programs are worthwhile. Christopher argued that palliative care is worthwhile only if the programs are self-sustaining economically and if similar services can be scaled up so that all who need palliative care can be served. In other words, palliative care programs must be modeled into something that today’s donors want to fund. On the other hand, CHN’s palliative care practitioners saw palliative care as worthwhile even if it is neither self-sustaining nor scalable. Their commitment to the dignity of the patients they serve—especially at the end of life—outweighs their commitment to donor organizations’ “common sense.”

It is clear that CHN operates under a very different understanding and definition of worth than funders who want to see a return on investment. Furthermore, the ways in which both parties articulate the worth of palliative care in turn sheds light on how they arrive at an account of whose lives are worthwhile and valuable. For CHN’s practitioners, the practice of palliative care in resource-limited settings is also a symbolic statement about human value: for them, healthcare and “health investment” should not be just for those who can afford it or for those who can contribute economically to a society but for all.

Conceptualizing Worth

From the moment we left the meeting and stepped out of the hotel, I could tell that Dr. Joseph was enraged with how things had gone. This became especially

apparent when we were returning home from the second day of the proposal-writing workshop. As the head representative of RFM, Christopher had, shockingly, spent the afternoon berating CHN for the way that it handled its resources and physicians. In Christopher's view, palliative care should be based on rational cost-benefit analyses, not some kind of moral commitment to human dignity. That afternoon, he had made his position quite clear:

Your ethos is that doctors get little pay. In other places, doctors are given much better conditions, which includes pay... You people never listen to us. It's your decision if you want your people to work out of a particular ethos.

Christopher's systematic belittling of the desire of CHN doctors to serve the poor through medicine was indicative of the stark contrast in ethos (to use Christopher's word) between funder and recipient. For Christopher, the motivation for doctors to use their resources to serve the poor was keeping them back from running sustainable programs. His argument was that if doctors' salaries were increased, CHN could attract more specialty physicians (such as anesthesiologists and cardiologists) whose work could in turn help fund the palliative care programs. What Christopher could not understand was the extent to which the physicians felt that the quality of care they were able to give to their impoverished patients necessitated a modest

lifestyle.

On that second day, Dr. Joseph and I took three city trains before we reached home. It was rush hour; even though the trains ran every few minutes, each one that came was packed beyond capacity. Knowing my interest in long-term palliative care work in resource-limited settings, Dr. Joseph often sought opportunities to teach me while we were in transit. Despite the crowding on the trains and hectic streets, the noise around us gave our conversations a sense of privacy.

My conversation with Dr. Joseph on that rainy afternoon was much different than usual. The topic was donor-driven funding; he specifically wanted me to understand what it felt like for him as a palliative care physician to interact with foreign funders like Christopher. While much of what Christopher said deeply offended Dr. Joseph, what insulted him most was Christopher's demeaning attitude towards CHN doctors who pass up jobs with lucrative salaries in order to serve the poor. He said:

CHN doctors should get equal [pay] to others? Doctors in CHN should work because we want to serve the poor. What other doctors get is deeply unjust. Should we follow that unjust system? Is this what donor-driven policies look like? They should live among the poor, then they would understand. Because you studied more, that's why you deserve a higher salary? Your studies are meant to serve the need; and salaries push you away from the need.

Salaries push you away from the need. Dr. Joseph's words swirled around

in my mind as we flowed out of the first train onto the platform and briskly walked toward the North-South line platform at Central station. Outside of the disembodied and rational approach to funding embodied by Christopher and the sterile hotel environment, we passed by scores of people—largely from the bottom half of the socioeconomic ladder—engaged in their day-to-day endeavors to make ends meet.

Once we got to the next leg of our

“Global health funding agencies [who] deal with palliative care in resource-limited settings... are committed to narratives of economic sustainability and profitability”

commute, Dr. Joseph elaborated on what he had meant earlier. He explained that Christopher’s criticism of the deeply personal commitment to serving the poor revealed a misunderstanding. For Dr. Joseph, practicing palliative care among the poor has implications for his own lifestyle. “I can’t help but question how much *heart* there is for the people we serve [in Christopher’s talk]. Imitating Christopher, he went on to parody his condescending attitude: “‘You stubborn CHN doctors’.... For him, it is all ‘rotten’ and he needs to teach us how to run things. I hate that kind of patronizing attitude.”

The day before, I happened to be sitting with Christopher during the lunch break at the hotel—a typical hotel buffet combining local and Western food. Waiters with filtered water jugs in hand moved from table to table, taking orders

and catering to the wishes of customers. Christopher sat across from me. In response to hearing me talk about Life Centre’s work among the HIV-positive population in poverty, he shared his deep disdain for the country’s cultural and socioeconomic hierarchy. Blaming poverty on broad generalizations about the country’s culture and society, Christopher explained that if he had all of the money and power in the world, his next project would be to eradicate this hierarchy from

existence.

A few days later, I asked Dr. Joseph about his motivation for working with Life Centre and practicing palliative care among persons living with HIV/AIDS. I wondered what kept him going in spite of tight finances and tremendous obstacles to wellbeing for his patients. He replied:

I want to share love in a place of so much brokenness, among our patients who feel that their lives are worthless. What keeps me going is the extent of human suffering, and the fact that you can’t move away from that and you share what they’re going through. I want to work towards their restoration and healing.

Perhaps the reason why Dr. Joseph feels that Christopher could not understand is simply that Christopher does not experience first-hand the extent of human suffering and the barriers to flourishing

that Dr. Joseph sees every day. To Christopher's ears, these words probably would have seemed like naïve clichés. Yet I am convinced that Dr. Joseph's response to Christopher, "[He] should have lived among the poor," is his way of expressing that Christopher's insistence on cost-benefit analysis in palliative care does not get at the true experience of suffering that the terminally ill endure. Could Dr. Joseph adequately provide care for patients in the depths of poverty yet live in wealth himself? Perhaps. But Dr. Joseph's preferred answer to this question gives us a clue to interpreting the difference between his and Christopher's approaches to funding palliative care.

Discourses in Global Health Funding

I have tried above to demonstrate that palliative care fundamentally concerns questions of human worth. Is it morally right to dedicate "unsustainable" or "unprofitable" resources to care for the dying? And if so, why? In the search for objective principles for creating the best care institutions, the morals and ethics that shape these principles are not always explicit. Here, I make the case that neoliberalism and cost-benefit economics are one outcome of a specific type of moral commitment. Farmer et al. (2013) argue that the global health apparatus operates in a Weberian "iron cage", in which rational economic calculations "trump human decency and common sense." In Farmer et al.'s view, the global health bureaucracy wields significant influence because of the

immense *biopower* it holds, having the power to define whose lives are worthy of treatment. They conclude that biopower is present "any time a quantification of life leads to a categorization of life."

Farmer et al.'s understanding of the "iron cage" wielding *biopower* is helpful in understanding how global health funding agencies deal with palliative care in resource-limited settings. They are committed to narratives of economic sustainability and profitability. This commitment becomes controversial when funders refuse to acknowledge that their economic approach is rooted in moral positions. The global health funding apparatus in which RFM finds itself is committed to a neoliberal model of development and is part of a particular institutional culture detached from the contexts of the people they hope to help. This analysis is consistent with Ferguson's (2006) conclusion that scientific capitalism is morally loaded even as its proponents insist it is impartial. Moreover, the institutional culture of global health development gives its members a sense of infinite power to reform, as when Christopher supposed that he could simply eradicate the country's cultural and socioeconomic hierarchy.

Global health funding discourse appears to blend a kind of utilitarian logic with themes of 'survival of the fittest' in discussions surrounding funding for programs like palliative care in resource-limited settings. Rooted in the work of Darwin, survival of the fittest is a concept biologists use to describe the matter-of-fact ways in which life oper-

ates: species (including humans) survive because of their ability to adapt to local conditions and thrive with success, securing dominion or providing offspring. These fundamentally biological ideas were arguably first systematically applied to social policies in the West at the turn of the 20th century with the rise of the eugenics movement, which focused on promoting better breeding and preventing the risk of inferior offspring, and continued throughout the 20th century even after the fall of Nazism (Stern 2005; Sussman 2014). Although the agenda of the eugenics movement is now largely renounced as unscientific and ethnocentric, some of the ideas of social Darwinism are embedded in our post-colonial world of perceived limited resources.

The institutional culture of global health development seems to broadly perpetuate a self-serving philosophy of social Darwinism and utilitarianism in resource-limited settings. Many theorists and development professionals assert that utilitarianism is a central tenet of development practice (Sen 2000). Because the role of modern medicine has historically been to cater to those who will benefit the most from its interventions (Gawande 2014), utilitarian logic is also ingrained in modern medicine. According to the utilitarian approach, palliative care would be distributed according to likely return on investment: resources would be diverted away from people who likely will not produce a positive return, toward those who would. Christopher's emphasis on the questionable worth of palliative care

for households in resource-limited settings implicitly goes along with the utilitarian narrative that tends to reinforce social and economic hierarchies with the language of natural inevitability. I argue that such narratives are not impartial but deeply moral.

In this vein, Blinderman (2009) argues that health priorities in resource-poor settings are, at their core, based on particular moral commitments. The worth of palliative care, therefore, implies particular understandings of what is right. Yet the picture Blinderman paints of moral commitments in resource-limited settings misses a nuanced understanding of how decision-makers conceptualize resource availability or scarcity. In regions like the ones where CHN's palliative care practitioners work, these moral commitments have everything to do with the perceived and actual reality of scarce resources. For Christopher, the priority of reducing household poverty led him to relentlessly articulate the worth of palliative care as economically sustainable and important for creating an economically productive environment.

Delivery models of palliative care can and should be explained and understood in terms of their moral and philosophical commitments (Adinolfi 2012). For Christopher, palliative care would only be viable if it were able to fit in with the GSIF's goals for poverty eradication: reduced household poverty, scaled-up services, and economic sustainability. The moral commitment of the CHN staff

to quality of life must also be examined. The quality of life of the patients and of the CHN staff members is intertwined (as seen in their voluntary choice of a modest lifestyle), and their lives are linked in a close relationship. The difficulty of quantifying “quality of life” makes it difficult for palliative care to get recognition, and because of this, many argue that the phrase should be reformed to make it more understandable in the larger universe of international development (Nantais and Kuczewski 2004). Regardless, CHN’s palliative care nurses and physicians bear substantially different moral and philosophical commitments than Christopher, underlying the disparities in their approaches to articulating the worth of palliative care. Furthermore, the power difference and physical distance established in the meeting allowed Christopher to remove himself from his moral commitments in a way the CHN staff members could not.

The Application Of Palliative Care Principles: An Ethos For Health Care

Many of the CHN staff members with whom I spoke saw palliative care not so much as a medical specialty but as a medical approach. From the numerous conversations and lectures I attended with CHN staff members, it became clear that they take the WHO’s definition of palliative care as improving the quality of life seriously, seeking to address all barriers to quality of life that their pa-

tients encounter. As one of the doctors in the meeting mentioned, “palliative care is more of a heart issue.” For the CHN physicians, palliative care is a lens through which they come to see the holistic needs of the patients they serve. What Christopher misses in his commitment to addressing palliative care through macro-scale improvements in economy and health services delivery is the holistic expression of care for patients’ self-worth at the heart of the palliative care approach that CHN staff members strive to embody.

Throughout the course of my fieldwork, I spent many days at Life Centre’s “livelihood program,” a pilot program that seeks to improve the quality of life of women in poverty affected by HIV/AIDS. This is the kind of whole-society economic improvement that Christopher would seek, except that Life’s work in this arena is not about money but self-worth. Understanding that work and providing for one’s family are important aspects of quality of life for women affected by HIV/AIDS, the livelihood group provides a space for women who are HIV-positive to regain a sense of the worth of their lives. Below are my fieldnotes from an August day, written while sitting on the steps outside of the livelihood program’s main location:

With a white fabric in her hands, Sarah stops her work and gazes across the room. It is a Thursday afternoon; the sun filters through the window behind her.

The blue-painted door to Life Centre's newly launched "livelihood initiative" is cracked open, allowing air to flow into the room. The women earn the equivalent of 3 USD per day in local currency; they are part of a pilot livelihood program that Life Centre has recently started, hoping to provide a stable source of income and social support for women affected by HIV/AIDS. For these women, the cost of one pair of sandals would be roughly 1 USD; a round-trip bus ticket, 0.5 USD; average rent for a tiny room, 40 USD/month; adequate food for one's family, another 40 USD/month. The numbers don't seem add up financially, and I wonder how they make ends meet.

It is an overcast afternoon in mid August; the day this picture is taken [Figure 1], there are five pairs of footwear sprawled near the doorstep. There are fewer participants today than usual. Two of the slippers are the staff members', while the other three are the program participants'. The city dust visibly collects on the surface of the footwear, forming foot-like imprints on the rubber.

From the women's physical appearance, one would never be able to tell that the women in the group are

in any way different, that a disease as dreaded as HIV affects them. Indicators like height, skin-color, and clothing-type are ways that the local population distinguishes between the rich and poor; yet footwear choice almost never conveys one's socio-economic status (much less HIV status). Yet while footwear choice does not tell us much about these women's background, these slippers point us to life-experiences, stories of trauma, grief, loss, and occasionally, hope, all invisible to all but a few

trusted individuals in whom these women confide their stories. The everyday struggles of fear, insecurity, hunger, sickness, and financial security are inscribed in the dust on the surface of the footwear, just as the toll of HIV-infection is inscribed in the bodies and minds of the women and their families. And yet slippers also represent movement, reminding the observer that life continues for these women in the midst of seemingly unbearable conditions. Slippers

bear witness to everyday activities of cooking, working, running errands and spending time with friends. Slippers tell stories of pain, but they also provide glimpses of hope.

With the money earned from the group, perhaps Sarah can begin to provide adequate food for her children; and maybe one day soon, a new pair of slippers.

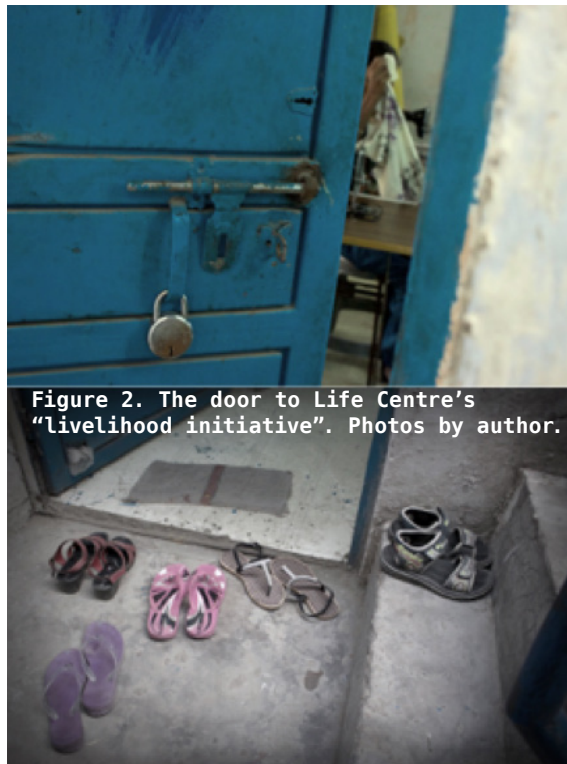


Figure 2. The door to Life Centre's "livelihood initiative". Photos by author.

Sarah and the other women enrolled in the program have faced innumerable and scarcely believable challenges, and yet these are the kinds of people for whom CHN's palliative care practitioners holistically care—namely, those who continue to experience the hardship of living in poverty with a life-threatening illness like HIV. Even beyond the WHO's conception of palliative care, CHN's palliative care staff understand it as more than a medical program for the terminally ill and see it as a call to care deeply about the quality of life of their patients. For CHN staff, palliative care represents an ethos that seeks to care about the wellbeing of patients at the margins of society, whoever they may be. Palliative care is an extension of their understanding that patients with life-threatening illnesses are inherently worth caring for.

Reimagining Worth

Is Sarah's life valuable? Is her life worth living? The answers to these questions depend on whom we ask. I have shown above that the various decision-makers attempting to articulate the importance of caring for persons with life-threatening illnesses in resource-limited settings operate with fundamentally different conceptions about how value is calculated. The question at hand is not whether poverty a good thing to address; instead, the conversation is about the different ways that decision makers articulate what palliative care should be, and indeed the impetus for its very existence. This discussion highlights how sustainability is a

constant goal in development initiatives, yet how the definition of sustainability often implies ideas of limited resources and efficiency. CHN's palliative care practitioners differ from their funders in their deep commitment to maintaining the dignity of human life above all else—whether or not this life is “sustainable” or generates “sustainability”. The interaction between RFM and CHN in mid-2015 reveals the ways in which global health funding agencies often prioritize economic sustainability over human worth. Moreover, this ethnographic work as a whole illuminates the concept of biopower, particularly regarding its cultural and ethical commitments in resource-limited settings.

Palliative care cannot and should not be “sold” as a development initiative in resource-limited settings. There is an urgent need to create a new paradigm for health funding in palliative care that provides care on the basis of human dignity even in situations of life-long and terminal illness. Anthropologists are uniquely positioned to articulate the ways in which narratives about human worth in settings of development inform understandings of moral practice. If the terminally ill are to be accorded the dignity that they deserve, such that peace at the end of life for people of all economic levels becomes a reality, then we must offer a new paradigm that counters the global health development narratives of cost-efficiency and sustainability that is pervasive in the contemporary world.

Acknowledgements:

The publication of this article was made possible by the mentorship of numerous individuals throughout my undergraduate years. I would like to foremost thank Dr. Laura S. Meitzner Yoder, director of Wheaton College's Human Needs and Global Resources program, for her commitment to my professional growth and her encouragement to write this article at the highest possible level. From Dr. Yoder, I learned to use ethnography to advocate for communities. Special thanks also to the professors of Anthropology at Wheaton College for their selfless dedication and service.

This work is licensed
under a Creative Commons
Attribution-NonCommercial-
NoDerivatives 4.0
International License.



REFERENCES

- Adinolfi, Paola. 2014. "Philosophy, Medicine and Healthcare: Insights from the Italian Experience". *Health Care Analysis : An International Journal of Health Care Philosophy and Policy* 22 (3): 223–244.
- Agamben, Giorgio. 1998. *Sovereign power and bare life*. Stanford, Calif: Stanford University Press.
- Blinderman, Craig. 2009. "Palliative Care, Public Health and Justice: Setting Priorities in Resource Poor Countries". *Developing World Bioethics* 9 (3): 105–110.
- Economist Intelligence Unit, "The 2015 Quality of Death Index," 2015, Economistinsights.com. Accessed 25 April 2016.
- Farmer, Paul, Jim Yong Kim, Arthur Kleinman, and Matthew Basilio. 2013. *Reimagining Global Health: An Introduction*. Berkeley: University of California Press.
- Ferguson, James. 2006. *Global shadows: Africa in the neoliberal world order*. Durham, NC: Duke University Press.
- Foucault, Michel. 1979. *Discipline and punish: the birth of the prison*. New York: Vintage Books.
- Gawande, Atul. 2014. *Being Mortal: Medicine and What Matters in the End*. New York: Henry Holt and Co.
- Harding R. 2008. "Palliative care in resource-poor settings: fallacies and misapprehensions". *Journal of Pain and Symptom Management* 36 (5): 515–7.
- Khosla D, FD Patel, and SC Sharma. 2012. "Palliative care in India: current progress and future needs". *Indian Journal of Palliative Care* 18 (3): 149–54.
- Nantais D, and M Kuczewski. 2004. "Quality of life: the contested rhetoric of resource allocation and end-of-life decision making". *The Journal of Medicine and Philosophy* 29 (6): 651–64.
- Rauh, Karen. 2010. "NGOs, Foreign Donors, and Organizational Processes: Passive NGO Recipients or Strategic Actors?" *McGill Sociological Review (MSR)* 1 (2): 29–45.
- Rottenburg, Richard. 2009. *Far-Fetched Facts: A Parable of Development Aid*. Cambridge, MA: MIT Press.
- Sen, Amartya. 2000. "A Decade of Human Development". *Journal of Human Development* 1: p. 1.
- Stern, Alexandra. 2005. *Eugenic nation: faults and frontiers of better breeding in modern America*. Berkeley: University of California Press.
- Sussman, Robert Wald. 2014. *The Myth of Race The Troubling Persistence of an Unscientific Idea*. Cambridge, MA and London: Harvard University Press.
- United Nations. 2014. "New UN Report Identifies Unmet Need for Palliative Care Worldwide." <http://www.un.org/apps/news/story.asp?NewsID=47024>. Accessed 14 February 2016.
- World Health Organization. 2016. "WHO Definition of Palliative Care." <http://www.who.int/cancer/palliative/definition/en/>. Accessed 25 April 2016.

¹ All names of individuals and organizations and some other details have been changed in order to protect participants' privacy.

² Khosla et al.'s research was National Institute of Health (NIH) funded and can be seen on the NIH website, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3573467/>, accessed January 31, 2016.