

Chapter 16: Another Reason to Bring Cancer into the Realm of Global Public Health: The Insularity of Cancer Patients and How Global Public Health Might Get Them Better Connected

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As a cancer survivor and a Boston College faculty member, James Keenan, SJ, stresses how urgent it is to consider cancer a global health emergency and how this approach implies a necessary and beneficial change of perspective. In fact, cancer is usually experienced as a personal ordeal, centered on who is affected. As he indicates, shared accompaniment and advocacy—as in the case of women’s grassroots organizations of breast cancer survivors—further exemplify how new forms of collective support, social action, and lived solidarity contribute to change the patterns of cancers’ stories by giving voice and agency to the patients and survivors who are voiceless and disempowered.

In October 2006, my dermatologist discovered an anomaly on my lower back that turned out to be a thin melanoma. It was subsequently removed, and the border were checked. I was told that my borders were clear, that my stage 1 melanoma was caught early, and that I was very fortunate. I was assured that survival rates were very high and that only 3 percent ever advanced to higher stages.

On August 4, 2008, I discovered in my groin a swollen lymph node. On August 26th a three-inch tumor was removed and biopsied. On August 28th, I was informed that I was at a stage III, possible Stage IV melanoma.

In a lay person’s terms, I had not had a recurrence. Rather my original melanoma had migrated before it was removed. Though the borders were clear, I was not, in fact, melanoma free. Instead, the sentinel node had functioned well and collected these cells over the nearly two years since it

was discovered. But now I had to find out through a lymph node dissection that was scheduled for September 26 whether the cells were solely contained in the sentinel node or whether other nodes or other organs had become infected.

During the month of waiting, because of a variety of reported aches and pains, I had two scans for brain tumors, one for a pulmonary embolism, and another for a deep vein thrombosis. All were negative.

I was a white male, professional, living in Boston, being treated at Mass General Hospital (MGH). My oncologist was chair of melanoma at MGH, and my surgeon was incredibly regarded and informative. I could not have had better physicians. Still, even in this very privileged situation, I had a fifty percent chance of survival over the next five years, *if* the sentinel node had done its work and the cancer had not spread. My odds were much worse if the cancer had migrated elsewhere.

After my surgery when my lymph nodes in my left leg were removed and biopsied, I learned that no other cancer cells were discovered elsewhere, including my hip and pelvis. I would now begin a twelve-month treatment at MGH of interferon. For the first month, I would have daily infusions, and after that, I would inject myself three times a week with the drug that caused, as physicians told me, “flu-like symptoms.”

I have to say that every time I had an infusion or later every time that I injected myself, those three words seemed to minimize or even ridicule the actual impact of each injection. During the year, I had two extended hospitalizations occasioned by significant life-threatening bouts of cellulitis. In December 2009, I concluded my interferon treatment, and ten years later my oncologist informed me that we no longer needed to meet. Though a few weeks later, another stage one melanoma appeared on my arm and was removed, it seems that I have now “beaten” my original cancer.

Cancer as a Global Public Health Issue

When I learned that this conference was treating cancer as a global public health issue, I was surprised. I say this not only as a cancer survivor but also as one who accompanied my niece who fought three years against a

leukemia, to which she succumbed in 1999 at the age of 19. I did not see the connection between cancer and global public health. Moreover, as an ethicist, I have taught a fairly popular course, “HIV/AIDS and Ethics,” here at Boston College since I arrived twenty years ago. The course is fundamentally an introduction to Global Public Health through the lens of HIV.

I had thought that the overriding concern of Global Public Health was the risk of communicable infection. The rise of global public health awareness universally paralleled the emergence and on-going threat of HIV/AIDS.¹ In fact, in 2014, the Journal *Global Public Health* focused on the synergy between HIV/AIDS and Global Public Health.¹ In 2015, The World Health Organization narrated from 2000 to 2015 how the organization only began to implement a global public health strategy in response to HIV/AIDS in Africa in 2000 and then outlined all the different ways that such a strategy reframed the international response to local outbreaks of the virus.² HIV/AIDS taught the human community that we needed Global Public Health to get out the same message about matters of prevention. We could only subdue the virus if we cooperated globally. Indeed, prevention strategies for HIV/AIDS are critical. Thus, as a Catholic ethicist, I worked for some time arguing for a rationale that Catholics and their health care and educational institutions could support both condom use and needle exchange programs precisely as prophylactic strategies against the spread of HIV/AIDS.³

¹ Nora J. Kenworthy and Richard Parker, “HIV Scale-up and the Politics of Global Health. Introduction,” *Global Public Health* 9, nos. 1–2 (2014): 1–6, doi.org/10.1080/17441692.2014.880727; Christopher J. Colvin, “Evidence and AIDS Activism: HIV Scale-up and the Contemporary Politics of Knowledge in Global Public Health,” *Global Public Health* 9, nos. 1–2 (2014): 57–72.

² World Health Organization, “Global Health Sector Response to HIV, 2000–2015: Focus on Innovations in Africa,” 2015, apps.who.int/iris/bitstream/handle/10665/198065/9789241509824_eng.pdf?sequence=1&isAllowed=y.

³ James F. Keenan, ed., assisted by Jon D. Fuller, Lisa Sowle Cahill, and Kevin T. Kelly, *Catholic Ethicists on HIV/AIDS Prevention* (New York: Continuum, 2000); James F. Keenan, ed., assisted by Jon D. Fuller, Lisa Sowle Cahill, and Kevin T. Kelly, *Eticistas Católicos e Prevenção da AIDS* (Sao Paulo: Edicoes Loyola, 2006). See also James F. Keenan, “Prophylactics,

Furthermore, early on, in 2007, the connection between tuberculosis (TB) and HIV generated the need for a combined global public health policy in light of the emergent one on HIV. The *New England Journal of Medicine* specifically addressed the issue of tuberculosis as a global public health concern, seeing the issue of contagion and morbidity as mutually relevant.⁴

Toleration, and Cooperation: Contemporary Problems and Traditional Principles,” *International Philosophical Quarterly* 29, no. 2 (1989): 205–220; James F. Keenan, “Applying the Seventeenth-Century Casuistry of Accommodation to HIV Prevention,” *Theological Studies* 60, no. 3 (1999): 492–512; James F. Keenan, “Catholics Fighting the Spread of HIV: Exposing and Encountering the Same Problems in the Virgin Islands as around the World,” *Catholic Islander* 14 (1999): 13; James F. Keenan and Jon D. Fuller, “Condoms, Catholics and HIV/AIDS Prevention,” *The Furrow* 52 (2001): 459–467; James F. Keenan and Jon D. Fuller, “Tolerant Signals: The Vatican’s New Insights on Condoms for H.I.V. Prevention,” *America* 183 (2000): 6–7; James F. Keenan and Jon D. Fuller, “Church Politics and HIV Prevention: Why Is the Condom Question So Significant and So Neuralgic?,” in *Between Poetry and Politics: Essays in Honour of Enda McDonagh*, ed. Linda Hogan and Barbara FitzGerald (Dublin: Columba Press, 2003), 158–181, reprinted in James F. Keenan and Jon D. Fuller, “Church Politics and HIV Prevention: Why Is the Condom Question So Significant and So Neuralgic?,” in *30 Años de VIH-SIDA: Balance y Nuevas Perspectivas de Prevención*, ed. F. J. de la Torre Díaz, *Cátedra de Bioética* (Madrid: Universidad Pontificia Comillas, 2013), 207–228; James F. Keenan and Jon D. Fuller, “The Language of Human Rights and Social Justice in the Face of HIV/AIDS,” *Budhi: A Journal of Ideas and Culture* 8, nos. 1–2 (2004): 211–233; James F. Keenan and Jon D. Fuller, “Educating in a Time of HIV/AIDS: Learning from the Legacies of Human Rights, the Common Good, and the Works of Mercy,” in *Opening Up: Speaking out in the Church*, ed. J. Filochowski and P. Stanford (London: Darton, Longman and Todd, 2005), 95–113; James F. Keenan, “Four of the Tasks for Theological Ethics in a Time of HIV/AIDS,” in *Concilium: AIDS*, ed. R. Ammicht-Quinn and H. Haker (London: SCM Press, 2007), 64–74; James F. Keenan and Enda McDonagh, “Instability, Structural Violence and Vulnerability: A Christian Response to the HIV Pandemic,” in *Progressio* (London: Progressio, 2009): 1–10; James F. Keenan, “HIV/AIDS: The Expanding Ethical Challenge,” in *Beauty, Truth and Love: Essays in Honour of Enda McDonagh*, ed. Eugene Duffy and Patrick Hannon (Dublin: Columba Press, 2009), 126–148, reprinted in James F. Keenan, “HIV/AIDS: The Expanding Ethical Challenge,” in *30 Años de VIH-SIDA: Balance y Nuevas Perspectivas de Prevención*, ed. F. J. de la Torre Díaz, *Cátedra de Bioética* (Madrid: Universidad Pontificia Comillas, 2013), 51–70.

⁴ Mario C. Raviglione and Ian M. Smith, “XDR Tuberculosis—Implications for Global Public Health,” *New England Journal of Medicine* 356, no. 7 (2007): 656–659.

In both these instances the status of those infected or at risk to infection became a significant issue for HIV/AIDS and tuberculosis, not least because there was not a cure for either. While one is a virus and the other an illness communicated by droplets of bacteria, the two came together precisely by the risk of communication among vulnerable populations. As if to mark the expanding interests of global public health, *The Lancet* in a 2008 essay entitled, “Global Public Health: A Scorecard,” opened with these words: “Global health is attracting an unprecedented level of interest.”⁵

Of course, the more recent outbreak of Ebola in 2014 again brought together through global public health the issues of risk, communicability, and social vulnerability of that highly infectious virus.⁶ And after that, the value and relevance of global public health increased again as Ebola entered into the narratives.⁷

Then came COVID-19.

I was in fact teaching my course on HIV/AIDS when COVID broke out. Students studying one pandemic were encountering first-hand a new one. The global public health issues came to the fore; the students quickly sought out the emerging congruencies between the two pandemics, including their modes of transmission, incubation, vulnerability, and those most at risk.

Not surprisingly the precarity that COVID prompts in the world dovetails the lessons learned from HIV. Global Public Health has evidently emerged today as having greater contemporary social relevance with

⁵ Robert Beaglehole and Ruth Bonita, “Global Public Health: A Scorecard,” *Lancet* 372, no. 9654 (2008): 1988–1996, at 1988.

⁶ Paul Farmer, *Fevers, Feuds, and Diamonds: Ebola and the Ravages of History* (New York: Farrar, Straus and Giroux, 2021); James F. Keenan, “Paul Farmer Went to Africa to Fight Ebola. He Found a People Devastated by War and Racism,” *America*, March 12, 2021, www.americamagazine.org/arts-culture/2021/03/12/paul-farmer-book-review-ebola-africa-health-240206.

⁷ Shamimul Hasan, Syed Ansar Ahmad, Rahnuma Masood, and Shazina Saeed, “Ebola Virus: A Global Public Health Menace: A Narrative Review,” *Journal of Family Medicine and Primary Care* 8, no. 7 (2019): 2189–2201.

COVID-19, but again it emerges significantly because of its impact as a highly communicable illness.

It was in 2009 that the medical community with public health officials began recognizing the relevant interdependency between two communicable illnesses with a third non-communicable, but infectious one. The linking of HIV/AIDS and tuberculosis with malaria helped us to see how the social, economic, and political context of human vulnerability needed to be coordinated. Bringing malaria more clearly under the tent of global public health helped us to see that we should think beyond the risk of infection from one human being to another as the gateway to public health.⁸

Still, malaria's infectiousness is what brought it into the purview of global public health. From the 1950s, the social sources that bred the risk of malaria came to the attention of early global health workers.⁹ Similarly, infectiousness becomes the group heading for other global health concerns like dengue fever that are in the air in these years.

In 2020, global health concerns focus on the infectiousness of different epidemics, as was noted in a recent article in the *AMA Journal of Ethics* where Abraar Karan, in "Responding to Global Public Health Crises," implicitly presumes that global public health epidemics are rooted in infectiousness as he notes: "Epidemic outbreaks such as Ebola, dengue, Zika, measles, and influenza have all made international headlines within the last few years."¹⁰

Bringing Cancer into Global Public Health

⁸ Marco Vitoria, Reuben Granich, Charles F. Gilks, Christian Gunneberg, Mehran Hosseini, Wilson Were, Mario Raviglione, and Kevin M. De Cock, "The Global Fight against HIV/AIDS, Tuberculosis, and Malaria: Current Status and Future Perspectives," *American Journal of Clinical Pathology* 131, no. 6 (2009): 844–848.

⁹ Ambrose O. Talisuna, Peter Bloland, and Umberto D'Alessandro, "History, Dynamics, and Public Health Importance of Malaria Parasite Resistance," *Clinical Microbiol Review* 17, no. 1 (2004): 235–254.

¹⁰ Abraar Karan, "Responding to Global Public Health Crises," *AMA Journal of Ethics* 22, no. 1 (2020): E3–4, at E3, doi.org/10.1001/amajethics.2020.3.

Bringing cancer into the Global Public Health tent is a significant act. As a matter of fact, in 2011 cancer came into sight with global public health officials when, after recognizing AIDS defining cancers like Kaposi sarcoma (KS) and aggressive non-Hodgkin lymphoma (NHL) as well as cervical cancer (CC), they made connections between HIV/AIDS and cancer in Africa.¹¹

Since then, cancer has been emerging as a global public health concern. Still, when one Googles “When did Cancer become a Global Public Health pandemic,” the first item proffered is the Global Cancer Center of the American Cancer Society,¹² and the second item is the announcement of the Boston College conference that generated these papers.¹³

There are many reasons to bring cancer under the tent of Global Public Health. Above all the global numbers are daunting. As one of the world’s leading killers, there were in 2018 more than 18 million new cases and 9.5 million deaths. In 2040, there are predictions of 29.5 million new cases and 16.4 million deaths.¹⁴ Second, global public health would heighten attention to the enormous disparity regarding treatment resources available around the world. Third, universal preventative educational strategies could bring behavioral changes, from routine and periodic check-ups to greater awareness of environmental impact on cancer rates.

Inasmuch as I was invited to contribute to this conference and collection precisely because of my own personal history of cancer, I would like to add a fourth reason by arguing how much the life of the cancer patient could improve if cancer care and treatment learned lessons from

¹¹ Sam M. Mbulaiteye, Kishor Bhatia, Clement Adebamowo, and Annie J. Sasco, “HIV and Cancer in Africa: Mutual Collaboration between HIV and Cancer Programs May Provide Timely Research and Public Health Data,” *Infectious Agents and Cancer* 6, no. 1 (2011), 10.1186/1750-9378-6-16.

¹² American Cancer Society, “Our Global Cancer Control Work,” 2021, www.cancer.org/health-care-professionals/our-global-health-work.html.

¹³ Ed Hayward, “Conference to Address Rise in Global Cancer,” *BC News*, September 2021, www.bc.edu/bc-web/bcnews/science-tech-andhealth/biology-and-genetics/global-cancer-pandemic-conference.html.

¹⁴ National Cancer Institute, “Cancer Statistics,” September 25, 2020, www.cancer.gov/about-cancer/understanding/statistics#.

global public health. Under the umbrella of public health, regardless of the illness, the patient is pre-eminently considered under a social context. The strategies for a person at risk to COVID, HIV, Ebola, TB, or malaria are well rehearsed. If those at risk of infection become infected, automatically others in their circle are affected. There is a constitutive social impact to whatever developments happen in the course of a patient's diagnosis, quarantine, care, or treatment. At every phase of their being under the umbra of whatever social health threat there is they are socially considered, understood, or treated.

Significantly, the social contextualization of the patient does not mean that issues of the patient's own personal autonomy are overlooked. Though the patient is seen in a social context, the decision-making capabilities of the patient are not necessarily compromised. Without a doubt, the gay community kept the at-risk or HIV-infected person as autonomously in charge of decision-making as one could be, but they were also part of a community of people. As Anthony Pinching and Kenneth Boyd noted twenty years ago, "This infection is so intensely private in its transmission, the disease so isolating and so personally devastating in its impact, it readily distinguishes the reality of what people are and do, from the rhetoric of what others may feel they should be and do. AIDS has forced us to recognize that respecting individual rights is a critical safeguard for the health of the community, as well as for the person."¹⁵

Moreover, their own personal decisions in a social context eventually became matters of the public agenda through advocacy. Reflecting on the first 20 years of AIDS in the *New England Journal of Medicine*, New York's Kent A. Sepkowitz commented,

In the 1970s, Washington-based, organized advocacy groups that focused on particular diseases were few; now at least 150 organizations exist.... Activism by patients with AIDS has

¹⁵ Anthony J. Pinching, Roger Higgs, and Kenneth M. Boyd, "The Impact of AIDS on Medical Ethics," *Journal of Medical Ethics* 26, no. 1 (2000): 3–8, at 3. See also Keenan, "Developments in Bioethics from the Perspective of HIV/AIDS."

influenced advocates for patients with other diseases, including breast cancer, Parkinson's disease, Alzheimer's disease, and juvenile diabetes. Using creative approaches rather than following the established rules of lobbying, AIDS activists created a new model. ... Today, patients are routinely consulted regarding the design of studies, and community-based research is conducted across the country.¹⁶

With the notable exception of breast cancer, however, other cancer patients are still very much operating in a private, personal, fairly insular context. Admittedly, I did think of the social significance, not of my cancer, but of my treatment in one way. I knew how privileged I was with my insurance and access to Boston-area facilities. I often thought that others should have access to the treatment that I had. When someone “catches” any of the more socially connected illnesses, we think, yes, it could happen to anyone. Not so with cancer. Perhaps because it is not infectious, there is a certain distancing with cancer. Ask almost any cancer victim or survivor (other than breast cancer), they will acknowledge an awkward silence or an experiential distance between others and the cancer carrier. Unlike other illnesses, cancer is not something you catch, it is not something that merits the estimation, anyone could get it. Rather, if you get cancer, you are the unlucky one. The cancer survivor is a particular individual; not a class. And your passage to treatment is much more personal, tailor-made (and private) than those with the illnesses mentioned above. Google cancer treatment and immediately you find the options or individualized treatment plans that you can make. It is remarkable the marketing of cancer as an autonomous, take-charge affair.

Indeed, one of the ways that I survived was becoming familiar with my cancer. I do not mean melanoma; I mean, my melanoma. It was mine, and I was personally going to subdue it. Many people accompanied me in my

¹⁶ Kent A. Sepkowitz, “AIDS—the First 20 Years,” *New England Journal of Medicine* 344, no. 23 (2001): 1764–1772, at 1770. On breast cancer, see Elizabeth Williams's chapter in this volume.

fight, but not fellow cancer patients. I was a lone patient. I never met others with melanoma except during my first month of treatment when I received daily infusions in a common space. But, after that first month, I never spoke again with another person who had melanoma. Nor did I meet one. At no time did any caregiver, professional or otherwise, refer to the experience of another cancer patient. I was in a category of one.

I did not hide my cancer, but no one really engaged it either, not at least the way I have encountered the phenomenon that other patients do who have HIV, COVID, TB, or malaria. In my fourteen months of treatment and in my subsequent nine years of treatment, I never met or was introduced to another cancer patient, nor was I offered anything to read that reflected at all the experiences of another cancer patient.

My relations were always singularly with my caregivers. Though I injected myself with interferon for eleven months three times a week knowing each time that I was inducing “flu-like symptoms,” I never met another person who had to manage their health in a similar way, who could share what they may have learned to make the affair more doable. In fact, I never met another person who took interferon, even though I am sure my doctors read plenty of accounts of their patients who discussed at length the experience of taking interferon. It was helpful for my doctors, but not for me?

I have no idea of what other cancer survivors did when they got cellulitis.

I learned that I had to protect myself from sun, but I never met others who developed their own strategies for sun protection.

Like other cancer victims and survivors, I could underline the singularity of my experience by highlighting how insular my own cancer-care was. I am not complaining about the care I received from MGH. How could I? My team of caregivers was remarkable. But my treatment was never socialized as other patients of other illnesses were. The only people I shared my experiences with were those who did not have similar experiences. And, therein, even the act of sharing became even more an insular occasion.

Placing cancer under global health makes the phenomenon of fighting cancer much less a personal struggle and much more a social one. Not only does it bring the caregivers and research under the tent of global public health, but it brings the more isolated patient there too, a place where the patient could learn from others about strategies of understanding, accepting, and surviving. In this way, other cancer patients could have the experience that women with breast cancer have of meeting, learning from, and standing with others in similar situations, grappling with life and death matters. Now, more than fifteen years after I was first diagnosed with cancer, I realize that socializing cancer and providing social encounters to cancer victims could provide a support as well as other benefits that I never had. Again, the lessons from HIV and breast cancer are notable.

Five years ago, I was diagnosed with prostate cancer, and though I am in only a regular, but vigilant, monitoring stage, having undergone three biopsies and three scans, I have never met another such cancer patient as part of my treatment. Informally, I now have learned to ask men my age, do they have it and how do they manage it, but my caregivers have never suggested that my treatment should be other than my singular engagement with them, the caregivers. Bringing cancer under the tent of global public health will offer the cancer caregiver and researcher the benefit of shared, collective, and reported experiences. Hopefully, the same opportunities will be shared with their patients.¹⁷

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¹⁷ want to thank my research assistant Aidan O'Neill for his very helpful work in preparing and editing this essay.

The Insularity of Cancer Patients

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