

Chapter 14: From Compassion to Pragmatic Solidarity: Considering the Right to Health from the Margins

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Paul Farmer has been among the most influential figures in the growing movement to understand and underscore the relationship between health and human rights. Drawing from his experience as a physician to the poor and the marginalized in Haiti, Latin America, Russia, Africa, and the US, Farmer joined Jonathan Mann and others in exposing the necessary connections between poverty, inequality, and disease and between differential vulnerability to disease and systemic violations of human rights.¹ Arguing for a “right to health” grounded in advocacy for the protection and promotion of those social, political, economic, and cultural conditions that allow individuals and communities to flourish as human beings, Farmer challenged conventional human rights discourses as excessively legalistic and narrowly focused on theory over practice. Drawing from liberation theology, Farmer argued that it is not enough to acknowledge the reality of global health inequities or to assert a human right to health or health care; recognizing the interrelated social, political, economic, and cultural conditions that affect health and well-being and constrain access to care, particularly for the most marginalized, must be

¹ Jonathan Mann was an American physician who is widely considered a pioneer in the movement to recognize the relationship between health and human rights. He oversaw the World Health Organization’s Global Programme for AIDS and was a founding member of Project SIDA (devoted to understanding and addressing AIDS in Africa) and HealthRight (a research and advocacy organization for promoting global health and human rights). Mann was among the first to develop the implications of recognizing health as a human right for the field of global health and to articulate the connections between disease and the violation of human rights. For a helpful overview of developments in the field of health and human rights, see George J. Annas, Jonathan M. Mann, Michael A. Grodin, and Sofia Gruskin, eds., *Health and Human Rights: A Reader* (New York and London: Routledge, 1999).

linked to action in the struggle for social and economic rights. It is not enough merely to treat the diseases of the destitute poor; rather, respect for human dignity requires a lived commitment to improving the conditions that result in too many people around the world dying of preventable diseases. In his argument for “pragmatic solidarity” in the face of global health inequities, Farmer reminds us that caring for the poor is not just about exercising compassion. The willingness to “suffer with others” becomes pragmatic solidarity when it is joined with action to reduce their suffering. Pragmatic solidarity is about asking the question: “how much of this suffering is premature or even unnecessary and what might we do collectively to lessen it?”²

This essay explores the ways in which Catholic social thought informs the content of a “right to health” and asks how its understanding of the relationship between health and human rights is enriched by Farmer’s construction of “pragmatic solidarity.” What would it mean to incorporate attention to the patterns of structural violence that determine how disease and death are distributed and to whom the goods of science and medicine will be available? What would it mean, in other words, to acknowledge that death and disease have social causes and cannot be adequately addressed without also addressing those causes? What does it look like to join the affirmation of a right to health with action in the struggle for social, economic, and cultural rights?

Farmer’s influence on our understanding of the relationship between health and human rights has been most profound in the arena of global health and in the context of diseases that have long disproportionately affected the poor and marginalized, like AIDS and tuberculosis. He was also a strong voice for equitable access to vaccines as COVID-19 raged world-wide. Although the pandemic and its impact in the United States are not yet fully understood, it is impossible to ignore the differential course of the virus according to race, age, and economic status. It is

² See Paul Farmer, “Pragmatic Solidarity,” *The Center for Compassion and Global Health*, ccagh.org/conversations/editorials/paul-farmer.

instructive, even in a preliminary way, to bring the lens of pragmatic solidarity to bear on our experience of COVID-19, to ask what we might learn about existing patterns of structural violence, of socially constructed risk and resilience, that resulted in deaths both tragic and avoidable.

Interrogating Health and Human Rights

In his book *Pathologies of Power*, Farmer observed: “When children living in poverty die of measles, gastroenteritis, and malnutrition, and yet no party is judged guilty of a human rights violation, liberation theology finds fault with the entire notion of human rights as defined within liberal democracies.”³ This observation captures several key themes in Farmer’s analysis of the relationship between health and human rights. First, it raises up the focus on protections for civil and political rights in contemporary liberal discourses to the exclusion of social, economic, and cultural rights. Although Article 25 of the 1948 Universal Declaration of Human Rights holds that “everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care,” human rights protections, even in countries where a right to health care is constitutionally recognized, tend to take the form of freedom from interference and explicit discrimination.

Western bioethics maps on to this emphasis with human rights violations in medicine typically characterized as violations of individual liberty (as in undermining protections against unwanted medical treatment) or privacy (as in denying the right to determine the time and manner of one’s death). In the mainstream bioethics literature, human rights “dilemmas” almost exclusively focus on questions related to the state’s treatment of individuals, e.g., whether physicians may ethically participate in torturing prisoners of war. However, as Farmer argues, the children who die “stupid deaths,” that is, deaths that can be prevented by use of available therapeutic remedies, bear witness to the hardly visible

³ Paul Farmer, *Pathologies of Power: Health, Human Rights and the New War on the Poor* (Berkeley and Los Angeles: University of California Press, 2005), 142.

structures of violence (global as well as local) perpetrated by the powerful on the weak and marginalized. “Structural violence,” those deeply ingrained patterns of distributing power and resources, constrains not only what kinds of treatment will be required and available to those in need, but who has access to the conditions conducive to health and well-being: safe drinking water, sanitation, education, nutrition, and adequate housing.

As Farmer correctly argues, structural violence escapes analysis in human rights discourses because, unlike the protection of civil and political rights, achieving a “standard of living adequate for the health and well-being” of everyone requires substantive governmental investments. Although human rights are articulated as “universal,” they are broadly assumed to be protected by states. Thus, both the definition and the achievement of “an adequate standard of living” occur within a discrete context. Moreover, to a large extent, the promotion of human rights, in particular social, economic and cultural rights, requires good faith commitments. When those in power refuse to accept the responsibilities of stewardship, resulting in deep divisions between the haves and the have nots that threaten health and well-being, politicians and policy-makers may be subject to criticism but are seldom held accountable. Even international human rights organizations tend to treat poverty and inequality as “simply distracting background considerations” rather than as human rights violations, further undermining the protection of social and economic rights.⁴

When we acknowledge that the powers at work behind the unequal and multiple worlds of health and health care across the globe are not only political but economic, we see other interrelated manifestations of structural violence that often elude naming in debates over health and human rights. We cannot understand the course of the HIV/AIDS

⁴ See Paul Farmer, *Never Again? Reflections on Human Values and Human Rights*, delivered as The Tanner Lectures on Human Values, University of Utah, March 30, 2005, tannerlectures.utah.edu/_resources/documents/a-to-z/f/Farmer_2006.pdf.

epidemic, for example, without also exposing the reach of multinational pharmaceutical corporations and their impact on access to treatment, availability of testing, standards of care, and even the training of physicians. We cannot understand why some children in the Global South disproportionately die “stupid deaths” without acknowledging the impact of multinational corporations on the flow of money, technologies, goods and services, and, ultimately, on local economies and patterns of cultivation and distribution of resources.

Farmer’s observation that diseases make a “preferential option for the poor,” demanding a response from those who claim to be concerned about health and equity, points to his impatience with theory divorced from action. Admitting the often overwhelming character of global health challenges even for those charged with responding, he argued nonetheless: “Those who formulate health policy in Geneva, Washington, New York, or Paris do not really labor to transform the social conditions of the wretched of the earth. Instead, the actions of technocrats—and what physician is not a technocrat?—are most often tantamount to managing social inequality, to keeping the problem under control.”⁵

Given his commitment not only to providing the best possible care to the poor but transforming their social conditions, it is not surprising that Farmer was deeply attracted to liberation theology, a movement that arose within small Christian communities in Latin America. Liberation theology takes as its starting point the real situation of the most destitute. Citing influential Peruvian theologian Gustavo Gutiérrez’s critique of liberal human rights discourses, Farmer insisted that a commitment to human rights must be a commitment to the “rights of the poor,” to standing with the poor in the struggle to meet their basic human needs; otherwise, it is merely a defense of laissez-faire doctrine that pretends that one’s society enjoys an equality that it does not.⁶

⁵ Farmer, *Pathologies of Power*, 140.

⁶ Farmer, *Pathologies of Power*, 142; Gustavo Gutiérrez, *The Power of the Poor in History* (Maryknoll, NY: Orbis Books, 1983), 87.

Pathologies of Power follows liberation theology's "observe, judge, act" method.⁷ Farmer's analysis is rooted in the concrete struggles of the destitute poor for survival, challenges a status quo that is fundamentally unperturbed by their suffering, and calls for action by the powerful in response to the demands of the poor to meet their basic human needs. Farmer often began with a story, an introduction to a patient who led him not only to treat the presenting illness but to observe the circumstances of his patients' lives and the shape of their suffering and from there to question the structures of violence at work. His critique of international efforts to address multi-drug resistant tuberculosis (MDRTB), for example, starts with Sergei, who contracted tuberculosis while enduring more than a year in pretrial detention in Russia. After transfer to a penal TB colony, Sergei received erratic treatment and faced chronic shortages of basic medical supplies, overcrowded living conditions, and inadequate nutrition. Farmer meets Sergei as he is preparing to be released, most likely carrying infectious, multidrug resistant TB home to his family and his community.⁸ In Farmer's hands, Sergei's story is a window into seeing clearly how the failure to invest in effective, comprehensive second-line drug treatment, along with failure to address the conditions under which prisoners are detained in unsafe conditions, feeds a widespread TB epidemic that results in an undeclared death penalty extending beyond the prison walls.

In the method of liberation theology, observation leads to judgment: "We look at the lives of the poor and are sure, just as they are, that something is terribly wrong."⁹ Farmer's analysis of what exactly is terribly wrong has several levels. At the root is the willingness to accept the proposition that some lives are worth more than others. To the extent that we allow the policies and practices by which life-saving therapies are not available to the poor in many parts of the world to go unchallenged, we

⁷ See Leonardo and Clodovis Boff, *Introducing Liberation Theology* (Maryknoll, NY: Orbis Books, 1987), for a helpful treatment of this method.

⁸ Farmer, *Pathologies of Power*, 113–121.

⁹ Farmer, *Pathologies of Power*, 142.

have made a commitment to an ideology of fundamental inequality. In Sergei's case, and the case of the thousands of other Russian prisoners and staff infected with MDRTB, decisions to provide only standard, short-course therapy are declarations that their lives are worth less than the lives of those who are not imprisoned or who are able to access effective drugs, adequate nutrition, and supportive care. In addition, when we treat health care as a commodity to be distributed on the market, we are ratifying the belief that those who have resources are entitled to protection against physical vulnerabilities not available to others with the same vulnerabilities but insufficient resources. The high cost of comprehensive treatment for MDRTB is a result of pricing decisions made by drug companies along with the unwillingness of international public health authorities to use moral pressure to bring down drug prices as proved effective in facing other emergencies such as HIV/AIDS.

Farmer acknowledges that the process of observation and judgment is difficult in the arena of global health, both because the voices of the poor seldom enter into discussions regarding policies and practices in development or international health and also because vested interests "have an obvious stake in shaping observations about causality and in attenuating harsh judgments of harsh conditions."¹⁰ He cites as examples of the latter the prevailing wisdom in international development circles that AIDS could not be successfully treated in very low resource areas even after effective and affordable drugs became available. His work with Partners In Health in Haiti directly challenged powerful, unquestioned assumptions that the destitute poor in countries such as Haiti could not comply with medication protocols that involved multiple, carefully spaced daily doses taken with meals (assumptions that, not surprisingly, shore up arguments for "cost-effective treatment" that is inferior to the standard of care in resource-rich countries). Farmer's patients did well when offered an approach that combined individual assistance from community health workers in taking medications with financial and nutritional support. A

¹⁰ Farmer, *Pathologies of Power*, 144.

similar approach to treating TB outbreaks in Haiti and Peru called into question a simple reliance either on biological factors (e.g., the inability to overcome mutations that create drug resistance) or psychological factors leading to patients' discontinuing treatment (e.g., confidence in sorcery). Rather, Farmer's work demonstrated that removing structural barriers to compliance with drug regimens, by addressing economic factors that affect initial exposure, stage at diagnosis, access to therapy and length of convalescence, resulted in greatly improved outcomes.¹¹ In both cases, the act of judgment exposes what is invisible in a focus on patient behavior (e.g., when the course of an infection is blamed on ignorance about hygiene) that becomes visible when the lens widens to the conditions that structure patients' risk (e.g., lack of access to adequate nutrition and clean water, economic opportunities and safe shelter).¹²

Just as observation leads to judgment, observation and judgment lead to action. As Farmer argues, the goal of reflecting, studying, and gaining the local knowledge borne of listening deeply to the poor is not to produce more books or articles or reports or even witness to standing with the poor. Rather, the point of joining the poor in understanding their experience is to change the world, to act with them for their liberation. Thus, for Farmer, liberation theology demands "yok[ing] all of its reflection to the service of the poor."¹³

Farmer's liberation ethic is most compelling for health care here, as observation and judgment turn to action in the form of what he calls "pragmatic solidarity." He describes "pragmatic solidarity" in various ways. It is first a way of practicing medicine: "Medicine becomes pragmatic solidarity when it is delivered with dignity to the destitute poor."¹⁴ At its most basic level, this involves insisting that goods and services reach those who need them the most, not only those who can afford to pay. This commitment is visible throughout his work, in finding innovative ways to

¹¹ Farmer, *Pathologies of Power*, 151.

¹² Farmer, *Pathologies of Power*, 121–122; 151.

¹³ Farmer, *Pathologies of Power*, 138; 144–145.

¹⁴ Farmer, *Pathologies of Power*, 138.

treat HIV/AIDS or MDRTB in areas of the world and in certain populations in which it was widely argued that it could not be done. As we have seen, however, once the connections between vulnerability to disease and death and the failure to protect social and economic rights are acknowledged, tending to the medical needs of the poor also involves acting to address the impact of structural violence. It is not only medical care that expresses solidarity but the “rapid deployment of our tools and resources to improve the health and wellbeing” of the poor.¹⁵

Pragmatic solidarity also describes the turn from compassion as sentiment to joining the poor in their struggle for liberation. This involves recognizing, as Gutiérrez expressed it, that “the poverty of the poor is not a call to generous relief action, but a demand that we go and build a different social order.”¹⁶ In the context of global health, Farmer interprets this sense of pragmatic solidarity as a challenge to question the strong, if unstated, belief that charity is the answer to the problems of poverty and access to care.¹⁷ Reliance on the generosity of those of means to address the longstanding needs of the destitute poor is dangerous insofar as it assumes that poverty and disease are random or happen to certain people and not to others because of some combination of personal choices. Quoting theologian Jon Sobrino, he argues that poverty is not the inevitable result of history or geography or personal behavior; rather, poverty and other forms of structural violence result from the actions of other human beings, and the poor are victims of these actions.¹⁸ Charitable relief efforts are often tinged with an assumed superiority on the part of those bestowing their charity; moreover, medical missions tend to be sporadic or piecemeal and offer care that would not be offered to those with means, e.g., expired

¹⁵ Farmer, *Pathologies of Power*, 220.

¹⁶ Gutiérrez, *The Power of the Poor in History*, 45.

¹⁷ Farmer acknowledges that charity can be a powerful expression of love of neighbor for religious believers. His critique is leveled at the type of charitable response that substitutes either money or “helicopter treatment” for accompaniment.

¹⁸ Farmer, *Pathologies of Power*, 143; Jon Sobrino, *Spirituality of Liberation: Toward Political Holiness* (Maryknoll, NY: Orbis Books, 1988), 31.

drugs or cast-off medical goods. Not only is this a failure to respect the human dignity of the poor; it ignores or attempts to erase the history of inequality and unequal opportunity that have led to current conditions. Charitable relief efforts often assume as well that the structures of inequity are fixed or inevitable. In its most pernicious form, those in power choose charity so as to protect their self-interest while commending themselves for their efforts to mitigate the suffering of the least well-off.

The challenge to build a different social order extends to asking difficult questions of the prevailing models of international development. Farmer is critical of development models that measure overall gains in health, income, or national productivity and declare success while ignoring persistent gaps in income levels. Farmer recognizes that there have been wondrous advances in science and technology, advances that have great potential for addressing the suffering and death of millions of people, and that the lives of many poor people have been improved. But advances in knowledge or skill alone do not guarantee equitable development without redistribution of goods and services, nor is development necessarily either linear or inevitable. Although he does not use the language of integral human development as found in contemporary Catholic social thought, he argues that genuine development depends upon guaranteeing the conditions for the dignified participation of all members of a society. When the dominant values in development discourses are “cost effectiveness” and “market responsiveness” and development efforts accept gross income gaps as temporary or culturally specific, development efforts will not lead to a different social order.

Sobrinho insisted that “the only correct way to love the poor will be to struggle for their liberation. This liberation will consist, first and foremost, in their liberation at the most elementary level—that of their simple, physical life, which is at stake in the present situation.”¹⁹ It is fair to say that, for Farmer, the only correct way to care for the poor is to join them in the struggle for their dignity against all that threatens their survival and

¹⁹ Sobrinho, *Spirituality of Liberation: Toward Political Holiness*, 32.

well-being. “Caring for the poor” takes many forms in Farmer’s work, from making medical goods and services available to the destitute poor, to challenging political, economic, and social dogma that justifies the present world order, to reorienting research to include the social and economic determinants of health, to changing the way medical students are taught to think about medicine. In all these forms, pragmatic solidarity becomes possible (and necessary) when the conviction that “the world is not as it should be” leads to accepting responsibility for one’s own role in maintaining the structures of violence and committing to the path of liberation.

Pragmatic Solidarity, Catholic Social Thought, and the Challenge of COVID-19

The clearest defense of a right to health care and the related importance of social, economic, and political rights in Catholic social thought is found in Pope John XXIII’s encyclical *Pacem in Terris*. There he argues: “Every man (*sic*) has the right to life, to bodily integrity, and to the means which are necessary and suitable for the proper development of life”; these means, he goes on to state, “are primarily food, clothing, shelter, rest, medical care, and finally the necessary social services” (no. 11).²⁰ Pope John XXIII praised the United Nations’ *Universal Declaration of Human Rights* for its attention to the full range of subsidiary rights—and responsibilities—invoked in the right to a dignified life. He recognized, as Farmer does, that articulating a “right to health” is an empty gesture if not accompanied by the will to promote and safeguard access to the range of goods and services that protect individuals and communities from the conditions that impede human development. The biblical mandate to care for the poor and the most vulnerable foregrounds the needs and longings of the least well-off or the most marginalized in what has come to be called the “preferential option for the poor.”

²⁰ See also, Louis F. Buckley, “Catholic Social Thought Concerning the Right to Health and to Health Care,” *Linacre Quarterly* 87, no. 2 (2020): 138–146.

The *Ethical and Religious Directives for Catholic Health Care Services* (ERD), issued periodically by the United States Catholic bishops to provide guidance for care in Catholic health care institutions and health care systems, also assert a universal right to health care grounded in four central values: respect for human dignity, the preferential option for the poor, concern for the common good, and the responsible stewardship of resources.²¹ As was the case for Pope John XXIII, the ERDs presume not only that suffering people should be cared for as a dimension of Christian discipleship but also that all human beings have a right to health care by virtue of being human. To acknowledge the fundamental and universal equality and dignity of all persons is to recognize both their equal potential for human flourishing and their shared vulnerability before the threat of illness, disability, and death. Drawing from Catholic social thought, access to health care is held to be important in a just society for the same reason that access to a range of political and economic goods is important. They are conditions, or in some cases, avenues for social participation, self-determination, and the pursuit of opportunity.²²

The ERDs value health care as a contribution to the common good: “Catholic health care ministry seeks to contribute to the common good. The common good is realized when economic, political, and social conditions ensure protection for the fundamental rights of all individuals and enable all to fulfill their common purpose and reach their common goals.”²³ It is presupposed that health care is a social or public good rather than a private good, in part because science and medicine are maintained by social investments. But it is also public in the sense of being necessary for realizing the opportunities and obligations of the common good, e.g.,

²¹ United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 6th edition, www.usccb.org/about/doctrine/ethical-and-religious-directives/upload/ethical-religious-directives-catholic-health-service-sixth-edition-2016-06.pdf.

²² For a fuller discussion of the implications of a right to health care in Catholic social thought in the context of COVID-19, see Maura A. Ryan, “Tragic Choices, Revisited: COVID-19 and the Hidden Ethics of Rationing” *Christian Bioethics* 28, no. 1 (2022): 58–75.

²³ *Ethical and Religious Directives*, Introduction to Part One.

governance, work and leisure, family life, and intellectual development. Health care should be available to all in need without regard to the ability to pay.

Despite the longstanding defense of a “right to health and health care” in Catholic social thought and its incorporation in the ERDs, Catholic bioethics has been slow to make the connections between access to health care and structural violence or to engage directly the implications of social, economic, and political inequality for health and well-being. Indeed, as M. Therese Lysaught and Michael McCarthy argue in the introduction to their volume, *Catholic Bioethics and Social Justice*, despite the long tradition of Catholic social thought as a resource for reflection on the conditions for human flourishing, Catholic bioethics and Catholic social thought have remained largely siloed. Moreover, “Catholic bioethics has remained virtually silent—with a few notable exceptions around inequalities in accessing health care services and HIV/AIDS—with respect to social determinants of health, environmental effects on health, and broader questions in global health.”²⁴

As Lysaught and McCarthy note, the near-blindness of Catholic bioethics to the social construction of health and illness can be attributed to several factors including a preoccupation—visible in the ERDs—with moral issues in clinical medicine, particularly with bedside decision-making at the beginning and end of life. Also in the background is the persistent gap between theory and practice in human rights discourses described by Pope John Paul II in *Evangelium Vitae*, a gap he linked to false accounts of human freedom: “The roots of the contradiction between the solemn affirmation of human rights and their tragic denial in practice lies in a notion of freedom which exalts the isolated individual in an absolute way, and gives no place to solidarity, to openness to others and service of them” (no. 19).

²⁴ M. Therese Lysaught and Michael McCarthy, eds., *Catholic Bioethics & Social Justice* (Collegeville, MN: Liturgical Press Academic, 2019), 4.

John Paul II shared Farmer's critique of notions of "solidarity" that fail to move beyond "feeling(s) of vague compassion or shallow distress at the misfortunes of so many people, both near and far." Rather, solidarity is a "firm and persevering determination to commit oneself to the common good; that is to say, to the good of all and of each individual, because we are all really responsible for all" (*Sollicitudo Rei Socialis*, no. 38). But it is precisely as the challenge of solidarity moves from feelings of vague compassion to the assumption of responsibility that Farmer's development of pragmatic solidarity is most compelling. The Catholic Church has a long tradition of delivering health care to the poor. However, as Farmer repeatedly argued, delivering health care to the poor is a necessary but not sufficient practice of solidarity. If we are unwilling to address the patterns of structural violence that account for differential vulnerability to disease and death, if we fail to put human and financial resources to bear on the social causes of disease, if we do not call powerful actors to accountability, whether local or global, we are simply managing inequality. We are not working toward a new social order on behalf of the poor and marginalized.

Recent experience with COVID-19 provides an opportunity to ask what pragmatic solidarity might look like in the context of health care in the United States. It is not possible in this space to explore all the ethical dimensions of the pandemic. Nor is it possible to acknowledge all of the factors—political, religious, social, economic—that turned a public health emergency into a public health disaster. However, it is possible, even in a preliminary way, to bring the lens of pragmatic solidarity to bear and to ask what we might learn from COVID-19 about the role of structural violence in risk and resilience.

Pope Francis called the COVID-19 pandemic "the moment to see the poor."²⁵ In an editorial published in the journal *Science* in April 2020,

²⁵ Inés San Martín, "Pope Says Pandemic a Chance to 'See' the Poor and Rethink Production, Consumption," *Crux*, April 8, 2020, cruxnow.com/covid-19/2020/04/pope-says-pandemic-a-chance-to-see-the-poor-and-rethink-production-consumption.

leaders of the Pontifical Academies of Science and Social Science pleaded for acknowledgment of the ways in which COVID-19 both revealed and exacerbated long-standing inequalities in access to information, medical care, safe employment, and decent housing.²⁶ COVID-19 drew attention to the acute vulnerability of some people on both a global and a national scale. In the United States, COVID-19 had a disproportionate impact on older Americans and communities of color, especially in the early stages. While the higher incidence of death and disability can be explained in part by the higher likelihood of co-morbidities in people over the age of 65 and among African-Americans, unequal vulnerability to infection, serious illness, and death from COVID-19 is the product of a complex set of social, political, and economic choices made and reaffirmed for decades.

An article in the *New England Journal of Medicine* described nursing homes in the United States in March 2020 as “tinderboxes, ready to go up with just a spark” and attributed the then unfolding tragedy in nursing homes to “decades of neglect of long-term care policy.”²⁷ By May 2020, COVID-19 had claimed the lives of twenty-eight thousand nursing home residents, accounting for 35 percent of the nation’s deaths. In February of 2022, the Centers for Disease Control reported that more than two hundred thousand long-term care facility residents and staff had died due to COVID since the start of the pandemic. According to the authors, both in-home and institutional long-term care is underfunded by Medicaid and insufficiently monitored. In the height of the COVID-19 crisis in urban areas such as New York City, nursing homes faced critical shortages in PPE, respiratory support and equipment, medications, and staff. Low wages for nursing home staff meant many held more than one job, spreading the virus from one facility to another.

²⁶ Joachim von Braun, Stefano Zamagni, and Marcelo Sánchez Sorondo, “The Moment to See the Poor,” *Science* 368, no. 6488 (2020): 214.

²⁷ Rachel M. Werner, Allison K. Hoffman, and Norma B. Coe, “Long-Term Care Policy after Covid-19—Solving the Nursing Home Crisis,” *New England Journal of Medicine* 383, no. 30 (2020): 903–905.

As compared to White Americans, especially in the early stages of the pandemic in the fall of 2020, Black Americans were 2.6 times more likely to contract COVID-19, 4.7 times more likely to require hospitalization, and 2.1 times more likely to die; American Indian or Alaskan Native Americans were 2.8 percent more likely to contract COVID-19, 5.3 times more likely to require hospitalization, and 1.4 times more likely to die; Hispanic or Latinx Americans were 2.8 times more likely to contract COVID-19, 4.6 times more likely to require hospitalization, and 1.1 times more likely to die.²⁸

In testimony before the US House of Representatives Committee on Education and Labor, labor economist Valerie Wilson explained the disparate racial impact from COVID-19 as rooted in deeper, longstanding disparities in health status, access to health care, wealth, employment, wages, housing, and income.²⁹ In the COVID-19 economy, there were three main groups: those who had lost their jobs; those who were essential workers and faced health insecurity as a result; and those who could continue working safely from home. As Wilson notes, Black, Latinx, Native Americans, and low-income workers were the most likely to be in the first two groups. Moreover, access to high quality health care, including preventative care for comorbid conditions such as hypertension and diabetes, differs significantly by geography and ability to pay.

Although a more substantive analysis is necessary to understand fully the differential path of the virus, it is possible to glimpse the patterns of structural violence that determine how disease and death are distributed in a pandemic. We can see, for example, how overinvestment in end-stage

²⁸ See Centers for Disease Control and Prevention, "Risk for COVID-19 Infection, Hospitalization, and Death by Race/Ethnicity," www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html. The demographics of COVID-19 morbidity and mortality shifted over time as vaccine resistance accounted for more White Americans becoming ill or dying.

²⁹ Valerie Wilson, "Inequities Exposed: How COVID-19 Widened Racial Inequities in Education, Health, and the Workforce: Testimony Before the US House of Representatives Committee on Education and Labor," *Economic Policy Institute*, June 22, 2020, www.epi.org/publication/covid-19-inequities-wilson-testimony/.

rescue care undermines preventative care and how decisions to fund hospitals versus community clinics determines what kind and quality of care is available in particular communities. As Farmer often observed in his work in under-resourced areas of the world, those who are already at risk of poor health due to their living conditions and inadequate access to health care are more likely to have a bad outcome from exposure to a highly transmissible virus. We can also see, in the toll COVID-19 took on nursing home patients, the consequences of a longstanding failure to invest in long-term care in the United States. At the most fundamental level, practicing pragmatic solidarity involves addressing the disparities that underlie differential vulnerability under pandemic conditions and making a genuine commitment to treat health care as a human right rather than a commodity. We practice pragmatic solidarity when we turn commitments to the common good into investments in guaranteeing equity in employment, education, and housing.

Paul Farmer's Legacy for Theological Ethics

Much could and will be said about the impact of Farmer's work for theological ethics. Here I will highlight three features that are particularly significant for theological bioethics. First, very few have articulated what Lysaught and McCarthy called "bioethics in a liberationist key" as powerfully as Paul Farmer.³⁰ Not only was Latin American liberation theology deeply woven into his scholarship, but he lived his commitment to standing with the poor in his medical practice and challenged the powerful to see and actively respond to the social, economic, and political conditions that rendered his patients subject to unnecessary suffering, whether in a Russian prison or a rural Haitian village. Not only did he care for the bodies of the poor, he struggled with them for their liberation.

Second, in foregrounding the promotion of social, economic, and cultural rights in the context of global health, Farmer breaks out of the focus on the individual and on rights of non-interference that has

³⁰ Lysaught and McCarthy, *Catholic Bioethics & Social Justice*, 16.

dominated both international human rights discourses and debates within contemporary bioethics. He effectively shifts the subject and context for theological bioethics—from the individual patient in the clinical setting to the communities and conditions within which health and disease are experienced—and in so doing expands what counts as a moral question. It is not only decisions about when to stop treatment that should capture our theological and moral imaginations but the many-layered choices that explain why no treatment or inferior treatment is available for some people in some places. In the process, he suggests what shape a rapprochement between Catholic bioethics and Catholic social thought might take.

Finally, Farmer's challenge to practice pragmatic solidarity lends explicit content to the movement from compassion to solidarity. His call to uproot those patterns of structural violence that render some individuals and communities disproportionately vulnerable to disease and death, to unnecessary suffering, traces the path from "vague compassion" to a genuine "commitment to the common good," from managing inequality to advancing a new social order. He shows us what it looks like to practice works of mercy that are also works of justice.

Conclusion

Paul Farmer dedicated his professional life to advocating for a universal right to health grounded in the protection and promotion of those social, political, economic, and cultural conditions that allow individuals and communities to flourish as human beings. Committed not just to the care of the destitute poor but to honoring their full human dignity, he made it impossible for proponents of human rights to ignore the realities of structural violence and the connections between poverty, inequality, and disease and between differential vulnerability to disease and systemic violations of human rights. Deeply indebted to liberation theology, his development of pragmatic solidarity resonates with and expands the call to solidarity in the Catholic social tradition. He leaves contemporary theological bioethics with both a challenge and a roadmap: to see clearly what connects poverty, inequality, and disease and to go beyond by

bringing all our resources (moral, theological, financial, intellectual, medical) to the creation of a new social order.



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