

## Chapter 8: Social Inequities and Social Justice: Crafting Ethical Priorities for a Global Journey with Cancer

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Conor Kelly examines social inequities and, by strongly advocating for social justice, frames ethical priorities. In particular, he invites to focus not only on what we do not know about cancer (e.g., in terms of scientific understanding and medical know-how), but also on what we already know about cancer regarding its toll on human beings and societies, as well the continuing and even increasing inequities in cancer care across the planet. Hence, new ethical priorities for the ongoing global journey with cancer require a greater emphasis on combatting the disparities that shape peoples' experiences of cancer, expand access to the cancer treatments that are known to work and work well, and increase access to palliative care for patients with cancer.

There is a lot we do not know about cancer. Granted, the scientific understanding of cancer has come a long way, and the medical know-how needed to treat cancer has ballooned in the last fifty years (and truly exploded in the last twenty), but one cannot shake the feeling that we are still only seeing the proverbial tip of the iceberg when it comes to the human understanding of cancer. This is why so many contemporary cancer treatments are experimental, why the United States spends billions of dollars on cancer research every year, and why patients facing cancer diagnoses regularly seek out second opinions. There is much we do not know about cancer, and these knowledge gaps leave us searching for new answers.

This instinct—to search for understanding—is a good one. As a theologian grounded in a tradition that insists that an innate “desire to know the truth” (*Fides et Ratio*, Introduction) is a quintessential mark of our shared humanity, I would never deny the intrinsic good to be found

in the pursuit of knowledge and understanding, nor would I gloss over of the pragmatic benefits that emerge when more accurate assessments of a given problem lead us to more meaningful solutions. Nevertheless, as a theologian and ethicist, I believe our search for answers in the sphere of cancer, while commendable, has skewed our priorities and therefore left us ill-equipped to address the rising global cancer pandemic. We have let our thirst for knowledge get the better of us, and consequently we now put so much energy into what we do not know about cancer that we are losing sight of what we do know. This shift in focus is intolerable because what we do know about cancer reveals dramatic ethical insufficiencies.

The point of this chapter is to correct this imbalance, chiefly by articulating the ethical insufficiencies involved and then describing a new path forward that would allow us to avoid replicating the current injustices while we come to grips with the fact that cancer is not a Global North problem but a human one. To achieve these ends, the chapter has three parts. The first part emphasizes some of the most poignant “knowns” of cancer, including and especially what is known about the disparities in cancer rates and cancer treatments, because these facts reveal both our current priorities in the so-called fight against cancer and the inadequacy of those priorities from an ethical perspective. The second part explores how the framing of this approach as a fight dictates the priorities and contributes to the disparities, even though this framing builds upon a doubly false narrative that we must correct. The final part describes an alternative framing that can help us refocus on what we do know, stimulating new ethical priorities for the global cancer pandemic before us.

## **The Ethical Insufficiencies behind the Known Facts about Cancer’s Disparities**

Consider some of the basic facts that we know about cancer at this moment. One thing we know is that the incidence of cancer is on the rise and will continue to rise, not only in the wealthier nations of the Global North but also throughout the Global South. As a result, we know that cancer is and will continue to be an ever more common cause of death

across the globe. This simple fact offers one concrete way to capture the notion of a rising global cancer pandemic: there will be more people dying from cancer across the globe as time wears on.

Significantly, we also know something about how the burden of these deaths will be distributed. Deaths from certain forms of cancer will be concentrated almost exclusively in the wealthier nations of the Global North because they will be tied to affluence, either directly—as a result of behavioral factors such as sedentary lifestyles, red meat consumption, and obesity that are more common with more resources—or indirectly—for instance, if they primarily develop as a result of aging and are therefore more common in nations with the highest life expectancies, because this measure is highly correlated with Gross Domestic Product (GDP) per capita.<sup>1</sup> Deaths from other types of cancer, meanwhile, will be concentrated in the less economically rich nations of the Global South, or in the poorer communities found within the economically powerful nations of the Global North, because the mortality rates of some cancers are closely tied to socio-economic status.<sup>2</sup> In these latter cases, two distinct trends impact mortality.

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<sup>1</sup> See Susan J. Curry, Tim Byers, Maria Elizabeth Hewitt, and National Cancer Policy Board (U.S.), eds., *Fulfilling the Potential of Cancer Prevention and Early Detection* (Washington, DC: National Academies Press, 2003), 41–86. On the link between red meat and certain cancers, see Cheryl L. Rock, Cynthia Thomson, Ted Gansler, Susan M. Gapstur, Marjorie L. McCullough, Alpa V. Patel, Kimberly S. Andrews, Elisa V. Bandera, Colleen K. Spees, Kimberly Robien, Sheri Hartman, Kristen Sullivan, Barbara L. Grant, Kathryn K. Hamilton, Lawrence H. Kushi, Bette J. Caan, Debra Kibbe, Jessica Donze Black, Tracy L. Wiedt, Catherine McMahon, Kirsten Sloan, and Colleen Doyle, “American Cancer Society Guideline for Diet and Physical Activity for Cancer Prevention,” *CA: A Cancer Journal for Clinicians* 70, no. 4 (2020): 245–271, at 254. For the links between cancer and age, see Mary C. White, Dawn M. Holman, Jennifer E. Boehm, Lucy A. Peipins, Melissa Grossman, and S. Jane Henley, “Age and Cancer Risk: A Potentially Modifiable Relationship,” *American Journal of Preventative Medicine* 46, no. 3 Suppl. 1 (2014): S7–15. For the correlation between income and life expectancy, see Samuel H. Preston, “The Changing Relation between Mortality and Level of Economic Development,” *International Journal of Epidemiology* 36, no. 3 (2007): 484–490.

<sup>2</sup> See Francis P. Boscoe, Christopher J. Johnson, Recinda L. Sherman, David G. Stinchcomb, Ge Lin, and Kevin A. Henry, “The Relationship between Area Poverty Rate and Site-Specific Cancer Incidence in the United States,” *Cancer* 120, no. 14 (2014): 2191–2198.

First, because the “lack of options” is one of the key features of poverty, people living in poverty often find themselves facing conditions that increase their risk of cancer even as they simultaneously have fewer opportunities to extricate themselves from these circumstances.<sup>3</sup> Thus, although the lifestyle risk factors identified a moment ago are accurately associated with the choices of luxury, they are also experienced by those in poverty, but usually by force of imposition rather than election. For example, the “poor diet” of someone in poverty can often be traced to the fact that food deserts are heavily concentrated in the poorest neighborhoods in the United States, limiting access to the fruits and vegetables known to reduce cancer risk and instead forcing people with lower incomes to rely on processed foods that expose them to carcinogens and contribute to other risk factors like obesity.<sup>4</sup> In these ways and more, the lack of options accompanying poverty shapes cancer burdens for the poor.

Second, in addition to the increased exposures to risk factors that influence whether someone develops cancer, poverty also influences what happens after cancer arrives, because access to early diagnosis and treatment is directly correlated with wealth.<sup>5</sup> People living in poverty,

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<sup>3</sup> Sandra M. Schneiders, “A Vow of Poverty,” in *Poverty: Responding Like Jesus*, ed. K. R. Himes and C. M. Kelly (Brewster, MA: Paraclete Press, 2018), 41–48, at 46.

<sup>4</sup> See Andrew Deener, “The Origins of the Food Desert: Urban Inequality as Infrastructural Exclusion,” *Social Forces* 95, no. 3 (2017): 1285–1309. For a metanalysis of the diets known to have the most preventative impact on cancer, see Mark T. Williams and Norman G. Hord, “The Role of Dietary Factors in Cancer Prevention: Beyond Fruits and Vegetables,” *Nutrition in Clinical Practice* 20, no. 4 (2005): 451–459. Notably, the environmental injustices of concentrating green spaces in richer areas and concentrating polluting industries in poorer ones offer a second illustration of the structural influences shaping the lifestyle “choices” of individuals living in poverty. Philip Landrigan’s work highlights these unjust tendencies. See, for instance, Philip J. Landrigan, et al., “The *Lancet* Commission on Pollution and Health,” *Lancet* 391, no. 10119 (2018): 462–512, at esp. 474 and 487–492.

<sup>5</sup> See Paul C. Pearlman, Rao Divi, Michael Gwede, Pushpa Tandon, Brian S. Sorg, Miguel R. Ossandon, Lokesh Agrawal, Vinay Pai, Houston Baker, and Tiffani Bailey Lash, “The National Institutes of Health Affordable Cancer Technologies Program: Improving Access to Resource-Appropriate Technologies for Cancer Detection, Diagnosis, Monitoring, and Treatment in Low- and Middle-Income Countries,” *IEEE Journal of Translational*

then, are less likely to benefit from the new technologies and new treatment plans that have sprung from our perennial fixation on what we do not know about cancer. As a result, the cancers that are concentrated among those in conditions of poverty are much deadlier than those that are concentrated in higher-income areas, a trend that holds both within nations and between nations.<sup>6</sup>

The best way to express the influence of all these trends on the disparate experiences of the burden of cancer is to recognize that, “when it comes to cancer, the poor are more likely to die of the disease, while the affluent are more likely to die with the disease.”<sup>7</sup> This is the state of affairs that has emerged from pouring so much time, energy, and money into the question of what we do not know about cancer at the expense of what we do. Those efforts have translated into an increased attention on the cancers concentrated in richer nations and richer communities while limiting the attention paid to cancers concentrated in less wealthy nations and less wealthy communities. This has, helpfully, lowered mortality rates in those wealthier regions but at the cost of a growing gap that reflects implicit priorities that we cannot maintain if we are going to confront the rising global cancer pandemic appropriately.

The fundamental flaw in our current set of priorities, as reflected in these disparate burdens, is that they are unethical. In concrete terms, they represent a violation of social justice. Our current set of priorities transgresses social justice because it maintains a state of affairs in which the burden of cancer’s mortality is distributed not just unevenly but unfairly. Norman Daniels, the philosopher and bioethicist, provides the theoretical

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*Engineering in Health and Medicine* 4 (2016): 2800708, doi.org/10.1109/JTEHM.2016.2604485.

<sup>6</sup> See Boscoe et al., “The Relationship between Area Poverty Rate and Site-Specific Cancer Incidence in the United States,” 2194; Mahshid Ghoncheh and Hamid Salehiniya, “Inequality in the Incidence and Mortality of All Cancers in the World,” *Iranian Journal of Public Health* 45, no. 12 (2016): 1675–1677.

<sup>7</sup> Dr. Francis Boscoe, quoted in Hematology Times Staff, “Wealth Appears to Affect Distribution of Cancer Types,” *MD Edge*, May 28, 2014, www.mdedge.com/hematology-oncology/article/185896/lymphoma-plasma-cell-disorders/wealth-appears-affect-distribution-cancer.

resources to justify this claim, for he explains in *Just Health* that “a health inequality is an inequity if it is the result of an unjust distribution of the socially controllable factors affecting population health and its distribution.”<sup>8</sup> Appealing to John Rawls’s famous *Theory of Justice*, Daniels further clarifies that a just distribution of these burdens would be one that leaves the least well-off in their best absolute position.<sup>9</sup> Unquestionably, the current situation of disparate cancer burdens is not the best we can achieve for the least well-off. There is little room to assert that the “socially controllable factors affecting population health and its distribution” are shared in what Rawls would describe as a fair and equitable fashion when it comes to cancer. It is hard to imagine an abstracted moral agent behind the “veil of ignorance” agreeing to a system in which environmental carcinogens are the almost inevitable lot of communities of color and people with the smallest incomes and lowest educational attainments.<sup>10</sup> Likewise, the current distribution of income (a key social determinant of health) between the Global North and the Global South is hardly to the benefit of the least well-off. On the contrary, there is an injustice to our current social inequalities, and thus they constitute social inequities violating social justice. Insofar as our current priorities for responding to cancer reinforce these connections, they are unethical.

The violations identified by Daniels’s procedural account of social justice are not, however, the only flaws in our existing priorities. They are similarly indicted by a substantive account of social justice, like the one found in the Catholic theological tradition, which describes social justice

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<sup>8</sup> Norman Daniels, *Just Health: Meeting Health Needs Fairly* (New York: Cambridge University Press, 2008), 101.

<sup>9</sup> See Daniels, *Just Health: Meeting Health Needs Fairly*, 92–97. He refers to John Rawls, *A Theory of Justice* (Cambridge, MA: Belknap Press of Harvard University Press, 1971).

<sup>10</sup> For one study into the clustering of pollution in relation to race, poverty, and educational attainment, see Michelle L. Bell and Keita Ebisu, “Environmental Inequality in Exposures to Airborne Particulate Matter Components in the United States,” *Environmental Health Perspectives* 120, no. 12 (2012): 1699–1704. For the importance of the “veil of ignorance” in Rawls’s theory of justice, see Rawls, *A Theory of Justice*, 118–123.

in relation to participation and insists “*that persons have an obligation to be active and productive participants in the life of society and that society has a duty to enable them to participate in this way*” (USCCB, *Economic Justice for All*, no. 71). According to this definition, social justice can be measured against people’s ability to contribute productively to the common good of their communities. This has immediate implications for the disparate burdens of cancer that result from our current priorities because, as anyone who has accompanied someone with cancer can attest, cancer has a dramatic effect on a person’s ability to engage in social life.<sup>11</sup> Notably, Daniels alludes to this idea when he describes health as “necessary to protect opportunity” and explains that good health is a prerequisite to pursuing one’s life projects and engaging in society more broadly.<sup>12</sup> Insofar as our current priorities in relation to cancer treatment reinforce the limited participation of certain groups in social life, they undermine society’s duty to enable all its members to participate in an active and productive way and thus violate the substantive norms of social justice. They are unethical.

## **Root Causes behind the Warped Priorities to Date**

Granted, it is easy to cast stones, but the real value of a critical diagnosis like this can be measured by its ability to contribute to the development of an alternative, and improved, approach. Such a contribution can emerge from this analysis, provided we are willing to explore what has allowed us to respond to cancer in a way that violates both procedural and substantive accounts of social justice. While the astute reader already has some sense of where I think the roots of this problem lie, given my comments about the

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<sup>11</sup> Researchers note these trends and highlight the fact that their impact extends far beyond the person with cancer: “The burden of cancer extends beyond mortality. Individuals who are affected by a diagnosis of cancer experience physical suffering, distress, and diminished quality of life associated with disease-related symptoms, diagnostic procedures, cancer therapies, and long-term/late adverse effects of treatment. Moreover, quality of life can also be substantially reduced for family, caregivers, and friends of patients with cancer.” Rock et al., “American Cancer Society Guideline for Diet and Physical Activity for Cancer Prevention,” 245.

<sup>12</sup> Daniels, *Just Health: Meeting Health Needs Fairly*, 30. See also 31–46 more broadly.

impact of our focus on the unknowns of cancer over its knowns, this second part of the chapter will push that point even further. It is not simply that we are focusing on a narrow set of questions to the exclusion of others, it is also that we are approaching those questions with a narrow set of assumptions about what we should be trying to achieve by asking them. Specifically, we have let unethical priorities shape our approach to cancer because we are framing the appropriate response almost exclusively in the combative terms of a war that must be won instead of using a more honest analogy.

I am, of course, not the first person to raise concerns about the use of war metaphors for the “fight” against cancer. Physicians and bioethicists have long raised alarm about the impact of military metaphors in medicine, arguing in both scholarly contexts and popular publications that it is problematic to describe a patient’s treatment process as a battle because of the disassociations this language evokes.<sup>13</sup> Psychologists, meanwhile, have shown that military metaphors can increase apprehension and fatalistic thinking and decrease a person’s overall willingness to pursue treatment.<sup>14</sup> These important criticisms, however, tend to focus on patients’ experiences, and what I want to highlight is that this framing extends far beyond the doctor-patient relationship and actually influences the priorities of our collective approach to cancer more broadly, causing us to overemphasize some of the costliest pathways for addressing cancer while shying away from the ones that might do the most good.

At this broader level, the problem is that envisioning humanity’s engagement with cancer as a war to be won undergirds an entire system

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<sup>13</sup> See, for instance, Abraham Fuks, “The Military Metaphors of Modern Medicine,” in *The Meaning Management Challenge: Making Sense of Health, Illness and Disease*, ed. Z. Li and T. L. Long (Oxford: Inter-Disciplinary Press, 2010), 57–68; Dhruv Khullar, “The Trouble with Medicine’s Metaphors,” *The Atlantic*, August 7, 2014, [www.theatlantic.com/health/archive/2014/08/the-trouble-with-medicines-metaphors/374982](http://www.theatlantic.com/health/archive/2014/08/the-trouble-with-medicines-metaphors/374982).

<sup>14</sup> See David J. Hauser and Norbert Schwarz, “The War on Prevention II: Battle Metaphors Undermine Cancer Treatment and Prevention and Do Not Increase Vigilance,” *Health Communication* 35, no. 13 (2020): 1698–1704.2



dedicated not so much to the wellbeing of individual persons with cancer but to the eradication of cancer as an abstract cause of death. While this may not seem particularly problematic at first glance, the truth is that it has led to the priorities that support our current system of social inequities instead of social justice. This framing simply is not sufficient for crafting the priorities we need to manage the rising global cancer pandemic ahead of us.

Here it will be useful to mine the war imagery a little more deeply. In modern warfare, victory typically belongs to the most technologically advanced nations with the greatest economic resources to pour into their war effort, yielding the concomitant assumption that loss is inevitable for anyone who lacks these tools. Describing cancer in military terms encourages us to translate these assumptions into the “war on cancer,” where we similarly imagine that investment in the newest technologies is the only way to make any real progress, and we likewise accept that some nations (and, although we are loath to admit it, maybe even some patients) will get left behind as a matter of necessity. Thus, we arrive at the current unjust state of affairs, where novel treatments make big differences for those nations and patients with the most resources, while other cancers and other cancer patients fade from view.

If this process were ultimately to propel us to that final miracle cure—the silver bullet technology that would allow us to treat every form of cancer in every patient—perhaps we would be able to say that the sacrifices were worth it. In fact, we might even use Rawls’s difference principle to insist that these sacrifices were just.<sup>15</sup> But as with real-life wars, this military framing assuages our consciences far too quickly, glossing over real losses with an appeal to the same “*dulce et decorum est*” assertions that the poet Wilfred Owen savaged after World War I.<sup>16</sup> Much like that “old Lie” (to borrow Owen’s description of the phrase), the analogical allusions to “the greater good” found in the war against cancer similarly fall apart upon further review, for two reasons.

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<sup>15</sup> See Rawls, *A Theory of Justice*, 72.

<sup>16</sup> “Dulce et Decorum Est,” in Wilfred Owen, *Poems* (New York: Viking Press, 1921), 15.

First, the military framing misunderstands the human condition, prioritizing the annihilation of mortality despite the fact that death is a fundamental part of our human experience. Appeals to transhumanism aside, this is a quixotic quest, for even if we eliminated cancer as a cause of mortality, we would still die of something. The military metaphors obscure this reality, causing us to pursue the prolongation of life at all costs. Certainly, I have theological reasons for interpreting this as an untenable outcome, but I am fundamentally asserting a human point rather than a theological one: mortality is a defining feature of our human condition and any approach that fails to grapple honestly with our mortality is not an approach that will lead to good human priorities.<sup>17</sup>

The second shortcoming of the military framing is that it overstates the value of our resources. In part, because there is a limit to the benefits we can expect to achieve as mortal beings, there is a real limit to what our money can buy. On this point, I want to speak from a personal perspective and share that in the span of approximately fourteen months (from 2019 to 2020), I lost both my mother-in-law and my mother to two different types of cancer. Both women had the benefits of some of the most positive social determinants of health leading up to their diagnoses and both had access to the highest levels of cancer care available in this country. By all accounts, they had tremendous advantages in their “battles” with cancer. They were the ones who, based on the disparities described earlier, should have died with cancer, not from it, and yet they both died as a direct result of their disease. Their stories are, of course, anecdotal, but their particulars reveal a more universal truth, namely that however much superior firepower may prove decisive in actual warfare, there is no guaranteed way to “win” a “war” with cancer.

## **Toward Renewed Ethical Priorities**

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<sup>17</sup> For one explanation of the theological rationale for critiquing the tendency to fight mortality at all costs, see the republished Pius XII, “The Prolongation of Life: An Address to an International Congress of Anesthesiologists, November 24, 1957,” *National Catholic Bioethics Quarterly* 9, no. 2 (2009): 327–332, at 329.

The sooner we can come to terms with both these realities—the inevitability of mortality and what can be described as the nonlinear relationship between resources and outcomes—the sooner we will be able to respond to the global cancer pandemic in a more just and equitable fashion. One way to start this shift is to re-envision the framing for our response. One reason for our current unjust prioritization of treatments for the cancers that have the highest prevalence in the richest areas (again, defined comparatively between nations and within nations) is our reliance on military metaphors, which allow us to accept that certain fronts in the war (and certain types of “soldiers”) are worth fighting for while others simply are not. If we swapped out metaphors, however, and envisioned humanity’s relationship with cancer as a journey, just as practitioners, patients, and researchers advocate, then we would be less apt to build our response around the assumption that exclusions are an inevitable, and therefore acceptable, cost of success.<sup>18</sup> Instead, we would be better able to acknowledge the contours of our present condition and thus would have a more honest engagement with what we do know about cancer, especially what we know about its disparate impact.

In practical terms, I think this shift in focus can lead to new ethical priorities for our ongoing global journey with cancer, and so I conclude with a brief outline of the two that I think are the most important. First, a journey built around an honest appreciation of what we do know about cancer should put greater emphasis on combatting the disparities that shape peoples’ experiences of cancer and not just combatting the cancer itself. Certainly, the rebalancing of prevention and treatment should be one part of this expanded project, but this is not the only option. Another avenue includes social interventions designed to increase access to the social determinants that have the most positive impact on health outcomes. Public policies promoting things like education can have a dramatic impact on health and well-being, even in the poorest nations.<sup>19</sup> In

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<sup>18</sup> For the comparative benefits of journey metaphors in cancer treatment, see Hauser and Schwarz, “The War on Prevention II: Battle Metaphors Undermine Cancer Treatment and Prevention and Do Not Increase Vigilance,” 1701–1702.

<sup>19</sup> See Daniels, *Just Health: Meeting Health Needs Fairly*, 142–143.

other words, the first priority must be to increase the attention paid to the structural factors undergirding the disparate burden of cancer so that we can begin to tackle the inequities and violations of social justice that we have tolerated for so long under our present paradigm.

Second, building further on what we do know about cancer, another priority that must be included in our global journey is to expand access to the cancer treatments that are known to work and work well, so that they are no longer the exclusive property of the richest patients and the richest nations. Importantly, I want to acknowledge that most of these treatments only came about as a result of research into the unknowns about cancer. We should not abandon cancer's unknowns altogether, but we should ensure that we do not ignore the ethically impactful knowns in the process. A related way in which we can do this is to increase access to palliative care for patients with cancer. As Alexandre Martins has argued persuasively, "Palliative care is not a privilege of high-income countries but a global health commitment that must be part of the agenda of public health actions and advocacy for health care as a human right."<sup>20</sup> In fact, this might be the most important priority to come out of the revised framing, for if we truly see the experience of cancer as a journey, then palliative care's holistic approach will be an essential tool. After all, if fighting against mortality is no longer the main goal, then accompanying one another in a rejection of isolation must become our top priority.<sup>21</sup>

Undoubtedly, there are other priorities we can add, but if we make these two shifts, we will go a long way in developing a more ethical, and more effective, response to the rising global cancer pandemic, in large part because we will be accounting for and attending to what we do know about cancer and not just what we do not yet understand.

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<sup>20</sup> Alexandre A. Martins, "Non-Communicable and Chronic Diseases in Developing Countries: Putting Palliative Care on the Global Health Agenda," in *Catholic Bioethics and Social Justice: The Praxis of US Health Care in a Globalized World*, ed. M. T. Lysaught and M. P. McCarthy (Collegeville, MN: Liturgical Press Academic, 2018), 329–341, at 332.

<sup>21</sup> For the contrast between mortality and isolation as the fundamental challenge of human existence, see Samuel Wells, "Rethinking Service," *The Cresset* 76, no. 4 (2013): 6–14.

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