

## Applying Lessons Learned From Low-Resource Settings to Prioritize Cancer Care in a Pandemic

Rebecca J. DeBoer, MD, MA; Temidayo A. Fadelu, MD, MPH; Lawrence N. Shulman, MD; Katherine Van Loon, MD, MPH

**IMPORTANCE** The coronavirus disease 2019 (COVID-19) pandemic has forced oncology clinicians and administrators in the United States to set priorities for cancer care owing to resource constraints. As oncology practices adapt to a contracted health care system, expertise gained from partnerships in low-resource settings can be used for guidance. This article provides a primer on priority setting in oncology and ethical guidance based on lessons learned from experience with cancer care priority setting in low-resource settings.

**OBSERVATIONS** Lessons learned from real-world experiences are myriad. First, in the setting of limited resources, a utilitarian approach to maximizing survival benefit should guide decision-making. Second, conflicting principles will often arise among stakeholders and decision makers. Third, fair decision-making procedures should be established to ensure moral legitimacy and accountability. Fourth, proactive safeguards must be implemented to protect vulnerable individuals, or disparities in cancer treatment and outcomes will only widen further. Fifth, communication with patients and families about priority setting decisions should be intentional and standardized. Sixth, moral distress among clinicians must be addressed to avoid burnout during a time when resilience is critical.

**CONCLUSIONS AND RELEVANCE** Although the need to triage cancer care may be new to those who underwent training and now practice oncology in high-resource settings, it is familiar for those who practice in low- and middle-income countries. Oncologists in the United States facing unprecedented decisions about prioritization can draw on ethical frameworks and lessons learned from real-world cancer care priority setting in resource-constrained environments.

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**Author Affiliations:** Division of Hematology/Oncology, University of California, San Francisco (DeBoer, Van Loon); UCSF Helen Diller Family Comprehensive Cancer Center, San Francisco, California (DeBoer, Van Loon); Department of Medical Oncology, Dana-Farber Cancer Institute, Boston, Massachusetts (Fadelu); Abramson Cancer Center, University of Pennsylvania, Philadelphia (Shulman).

**Corresponding Author:** Rebecca J. DeBoer, MD, MA, UCSF Helen Diller Family Comprehensive Cancer Center, University of California, San Francisco, 505 Parnassus Ave, M1286, San Francisco, CA 94143-1270 (rebecca.deboer@ucsf.edu).

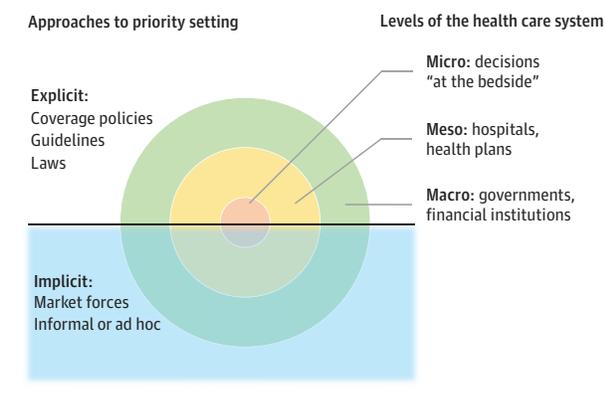
The coronavirus disease 2019 (COVID-19) pandemic has forced transformations of oncology practice to limit patient volumes, increase availability of hospital beds, reduce use of personal protective equipment, and reallocate the health care workforce. Changes in day-to-day practice have been fast and dramatic; in a short time, oncology clinicians have converted their practices to telemedicine, canceled or postponed procedures, altered treatment plans to minimize visits, and delayed routine follow-up. The triage process has required clinicians and administrators in the United States to think about cancer care in an entirely different way. For many, it is the first time that external circumstances demand that they ask, "Is this [visit, procedure, intravenous drug administration, scan, laboratory test] truly essential? If so, can it wait, and for how long? How is *essential* defined in this new reality?"

As the COVID-19 pandemic unfolded in China, Italy, and other parts of the world earlier this year, health care professionals and the public grappled with projections of the need to ration medical resources in the United States.<sup>1,2</sup> Oncologists began preparing for the need to ration care that is essential for patients with cancer, anticipating that hospital admissions, cancer surgery, radiotherapy courses, systemic chemotherapy, and palliative treatments would be compromised by overwhelmed health care systems. Patients with

cancer voiced alarm that their care needs would be neglected during the pandemic. Frameworks were rapidly developed to guide cancer care triage decisions,<sup>3-5</sup> and the National Comprehensive Cancer Network compiled disease-specific guidelines from panels of experts.<sup>6</sup> Moreover, the presumed vulnerability of patients with cancer to COVID-19 based on early data from Wuhan, China,<sup>7,8</sup> incited concern among oncology clinicians. The American Society of Clinical Oncology published ethical recommendations for the oncology community pertaining to rationing scarce critical care resources, emphasizing that a cancer diagnosis alone was not a defensible justification to deny patients access to scarce resources.<sup>9</sup>

As of August 2020, the state of the COVID-19 pandemic and its implications for cancer centers vary considerably across the United States. Fortunately, projections of health care resource scarcity have not materialized in many places. Although epicenters around the country remain in a crisis phase, other cities have reopened. The recent COVID-19 resurgence, as well as the massive economic toll that the pandemic has already taken, will pose ongoing constraints to health care systems and cancer care for an indefinite period. Although the need to triage cancer care may be new to those who underwent training and now practice oncology in high-resource settings, it is familiar for those who practice in low- and middle-income

Figure. Dimensions of Health Care Rationing and Resource Allocation



countries (LMICs). As oncologists in the United States face unprecedented prioritization decisions, ethical frameworks and lessons learned from cancer care priority setting in resource-constrained environments are highly relevant.

## Priority Setting in Oncology

*Priority setting* is an umbrella term that encompasses both health care rationing and resource allocation.<sup>10</sup> *Rationing* refers to health care distribution in a setting of absolute scarcity (eg, ventilators, organs, or blood bank supply). *Resource allocation* refers to distribution in a setting of relative scarcity, and is reflected by budgeting decisions (eg, funding for emergency preparedness vs cancer care). Both have reverberated at all levels of the health care system in the current pandemic (Figure). The need to ration valuable medical interventions is as old as the interventions themselves, and generations of ethicists, economists, and policy makers have developed ethical principles to guide this process. Researchers have also endeavored to assess the public's values regarding how limited resources should be prioritized (eg, deliberative democracy), typically premised on hypothetical scenarios rather than real-world experience.<sup>11</sup> In the absence of explicit policies or procedures for priority setting, implicit rationing based on default market forces or morally arbitrary realities such as who is first in line often occurs.

In oncology, increasing costs of care have fueled discourse about priority setting. Efforts such as the American Society of Clinical Oncology Value Framework<sup>12,13</sup> and the European Society for Medical Oncology Magnitude of Clinical Benefit Scale<sup>14,15</sup> aim to provide objective assessment of the benefit of anticancer therapies to inform resource allocation. Single-payer health care systems in several high-income countries have implemented explicit prioritization systems for expensive novel therapeutics and radiotherapy.<sup>16-18</sup> Even in the United States, with its relatively abundant resources and plurality of payers, explicit rationing is required periodically in oncology, primarily in cases of drug shortages. Ethical frameworks have been proposed to guide the prioritization of limited chemotherapy supplies and scarce resources such as proton therapy and cellular therapy<sup>19-23</sup>; however, to our knowledge, reports of real-world applications of these frameworks are lacking.

Although discourse regarding priority setting in oncology in high-income countries has historically focused on expensive interven-

tions and rare drug shortages, it plays a central role in routine clinical decisions and policy making in LMICs. As oncologists who practice in the United States and are also involved in oncology capacity building, clinical guideline development, and patient care in LMICs, we are accustomed to the shift in mindset required to prioritize cancer care in a setting of limited resources. We are actively engaged in research to examine and improve the process of priority setting and communication with patients about resource limitations in Rwanda and Tanzania. In recent months, we have found ourselves drawing on this expertise in discussions about prioritizing care at our home institutions in the face of the COVID-19 pandemic.

Rwanda is a small, densely populated country in East Africa that has recovered remarkably from the 1994 genocide, including rebuilding a once-devastated health care system and adopting a national health insurance system that is free for individuals with the lowest incomes.<sup>24</sup> Through government investment and equity-oriented national policies, mortality rates have decreased precipitously and life expectancy has doubled since the mid-1990s. In 2012, the Ministry of Health established the country's first cancer treatment center, the Butaro Cancer Center of Excellence, at a district hospital with support from the nongovernmental organization Partners In Health and others.<sup>25</sup> Basic services across the cancer care continuum, including pathologic diagnosis, surgery, chemotherapy, and palliative care, are available at the Butaro Cancer Center of Excellence. More than 11 000 patients have been enrolled to date, and the program continues to evolve as oncology capacity expands in the rest of the country.

Tanzania is a country of nearly 60 million people in East Africa, reputed for its stability in the region since gaining independence in the 1960s. Despite a strong commitment to socialism and universal health care in the postindependence era, increasing health care costs and a struggling economy led to reforms in the 1990s that introduced cost sharing in the form of user fees. Today, a minority of the population is covered by public or private health insurance. In 1996, Ocean Road Cancer Institute (ORCI) in Dar es Salaam was established as the national referral center for cancer, with a mission to provide equitable, accessible, and high-quality cancer services.<sup>26</sup> The government of Tanzania sponsors free care to approximately 5000 new patients per year at ORCI, providing radiotherapy, chemotherapy, and palliative care. Built on a longstanding partnership between ORCI's affiliate Muhimbili University of Health and Allied Sciences and the University of California, San Francisco, the Muhimbili University of Health and Allied Sciences-ORCI-University of California, San Francisco Cancer Collaboration was established to strengthen cancer research, training, and clinical systems in Tanzania.

Rwanda and Tanzania are both classified as low-income countries but are among the fastest-growing economies in Africa.<sup>27</sup> As specialty health care services, such as cancer care, expand in both countries, resource allocation is associated with macro-level and meso-level budgeting by government agencies and hospitals, as well as by market forces. In oncology, persistent resource constraints include: unavailability of key cancer therapies; drug shortages; overburdened imaging machines, operating rooms, and radiotherapy machines; limited blood supply; private sector costs that are prohibitive to most people; and inadequate numbers of trained oncology clinicians. These constraints force oncology clinicians to make micro-level resource allocation and rationing decisions on a regular basis.

## Lessons Learned From Experiences in LMICs

The growing global cancer burden outpaces resource availability in many LMICs, obliging oncology clinicians and policy makers to prioritize resources at all levels of the health care system. These prioritization decisions inherently mean that some patients with cancer receive standard treatment while others do not. In the absence of explicit systems for making these difficult prioritization decisions, distribution typically occurs haphazardly or based on a patient's ability to pay, further exacerbating already stark disparities in cancer mortality based on socioeconomic status. Global oncology collaborations have worked to set priorities for cancer care to ensure that resource use is both optimal and equitable. As cancer centers in the United States adapt to a contracted health care system during the COVID-19 pandemic, the expertise gained from partnerships in LMICs can be used for guidance.

First, in a setting of limited resources, a utilitarian approach to maximizing survival benefit should guide decision-making. Overall survival is the universally accepted standard measure of clinical benefit in oncology. Recent efforts to develop national cancer control plans and clinical guidelines in resource-constrained settings affirm the pre-eminence of survival. For example, the World Health Organization Model List of Essential Medicines<sup>28</sup> and resource-stratified guidelines developed by the Breast Health Global Initiative, American Society of Clinical Oncology, and National Comprehensive Cancer Network identify the most cost-effective anticancer interventions as measured by survival.<sup>29-31</sup> Other forms of clinical benefit, such as quality of life and avoidance of toxic effects, are incorporated into these systems as well, but survival is commonly prioritized.<sup>32</sup> In the context of limited hospital beds, supplies, and health care workforce, as can occur in a pandemic, survival benefit should be the foremost benchmark used to prioritize resources.

In oncology practice, maximizing survival benefit may mean prioritizing curative vs palliative treatment, long-term vs short-term disease control, and higher magnitudes of benefit. Ideally, these decisions should be made based on objective estimates accounting for an intervention's cure rates or disease-free survival as well as patient factors such as age, performance status, and comorbidities. However, even with the best data and prognostic tools, these calculations are challenging within cancer types. Work developing prioritization guidelines for limited radiotherapy resources in Rwanda has based decisions on estimated incremental curative benefit by cancer type and stage.<sup>33</sup> Objective comparison across cancers has proven to be extraordinarily complicated, even without accounting for mitigating factors through metrics of quality- or disability-adjusted life-years. Thus, while maximizing survival is useful as a general principle, operationalizing it in a real-world setting poses numerous methodological challenges.

Second, conflicting principles will often arise among stakeholders and decision makers. Although utilitarianism is widely accepted as the dominant driver of public health priority setting, several competing values and principles may be invoked as cancer care is prioritized in a real-world context. For oncology clinicians, the tension between the population-oriented principle of maximizing benefit and more familiar patient-centered approaches may be pronounced.<sup>9</sup> Oncologists often feel strong moral and ethical obligations to patients, as well as a legal duty to act in the patients' best interests. They

may assert a claim on resources based on deontology, the theory that moral action is based on the rightness or wrongness of an action itself (eg, treating an individual patient) rather than its consequences (eg, inefficient use of resources). Similarly, respect for persons and human dignity may compel us to prioritize symptom palliation and end-of-life care during the COVID-19 pandemic. In qualitative research examining the values associated with radiotherapy prioritization in Rwanda, oncology clinicians highlighted the tension between their role as stewards of limited radiotherapy resources and their obligations to individual patients.<sup>34</sup> They emphasized the difficulty of not being able to send patients for palliative radiotherapy, but upheld that it would be unacceptable for a curable patient to lose a chance of cure because an incurable patient received priority.

Another key category of competing allocation principles is prioritarianism, or favoring the worst off.<sup>35</sup> Treating the sickest patients first appeals to the intuitive "rule of rescue" to alleviate identifiable and avoidable suffering, regardless of the patient's prognosis. During the COVID-19 pandemic, emergency cancer surgeries (eg, neurosurgical decompression for a patient with spinal cord compression) have been prioritized even in the absence of a clear survival benefit. In addition, treating the youngest patients first gives priority to those who would otherwise die having had the fewest life-years, similar to the "fair innings" approach of prioritizing the young to promote equal chances of a reasonable life span. Given the clear association between age and case fatality from COVID-19, the role of age in resource allocation has been a subject of controversy.<sup>36,37</sup> In Rwanda, clinicians and program leaders widely agreed that life expectancy and potential life-years gained by curing disease should be considered in the allocation of limited radiotherapy resources, although opinions varied about the appropriateness of age cutoffs.<sup>34</sup> Recognizing that no single principle sufficiently captures all morally relevant considerations, multiprinciple allocation systems have been developed, such as the United Network for Organ Sharing<sup>35</sup> or priority scores for ventilator allocation during the COVID-19 pandemic.<sup>2</sup>

Third, fair decision-making procedures should be established to ensure moral legitimacy and accountability. In the absence of a consensus about which normative principles should guide health care rationing and resource allocation, the focus has shifted to decision-making processes. One procedural approach to priority setting is the Accountability for Reasonableness framework, which requires the following: (1) transparency: decisions and rationales must be publicly accessible; (2) relevance: rationales must appeal to reasons and principles deemed relevant; (3) appeals: there must be a mechanism to revise decisions; and (4) enforcement: this process must be regulated to ensure these conditions are met.<sup>38</sup> Applying this framework, cancer care prioritization decisions during a pandemic should be transparent, relevant to stakeholders including patients, and revisable under a regulated process. Upholding these standards will be particularly important given that capacity for oncology care will remain intact but services may not be offered as a result of deliberate decisions. In our experience, implementation of a fair process requires dedicated effort and resources. Although challenging during a time of resource constraints, attention must be paid to procedural considerations to ensure legitimacy and accountability.

Fourth, proactive safeguards must be implemented to protect vulnerable individuals, or cancer treatment and outcome dispari-

ties will only widen further. In a setting of short- or long-term resource constraints, low-income and marginalized communities are at particularly high risk. Cancer treatment poses financial burdens for many families<sup>39</sup> and can present insurmountable burdens for people facing more immediate threats of poverty such as food insecurity, homelessness, addiction, and violence. Supporting vulnerable patients through cancer treatment requires a comprehensive package of resources and coordination of services. The governments of Rwanda and Tanzania, in collaboration with partners, have striven to fully cover or subsidize the out-of-pocket costs of cancer treatment for individuals with low incomes. In both settings, social support for food and transportation, patient navigation systems, and innovative mobile health technology strategies have been used to combat treatment abandonment.

The COVID-19 pandemic has already exposed social inequalities and health disparities, and this gap will widen as the economic fallout continues.<sup>40,41</sup> Adaptations to oncology practice may pose additional formidable barriers for low-income and marginalized communities. For example, cancer centers are urged to adopt telemedicine,<sup>42</sup> yet many patients, particularly older adults, rural residents, and low-income families, may not have access to a smartphone, computer, or reliable internet. Restrictions on visitors in clinics and infusion centers, where important information is often exchanged, disproportionately affect patients who rely on family members for health literacy or language translation. As society reopens and clinical services gradually resume, people who are financially secure and well informed are more likely to receive uncompromised care. Meanwhile, people who have lost jobs and health insurance are more likely to experience delays in cancer diagnosis or treatment interruptions. Safeguards must be proactively taken to ensure that disadvantaged patient populations are not forsaken, such as expanding access to internet and devices for telemedicine,<sup>43</sup> strengthening outreach and tracking systems for vulnerable patients, and increasing social work and supportive care services.

Fifth, communication with patients and families about priority setting decisions should be intentional and standardized. High-quality patient-clinician communication is associated with significantly reduced patient anxiety and depression; conversely, poor communication is associated with increased patient anxiety and depression.<sup>44,45</sup> During a time when fear related to COVID-19 and its consequences is rampant and predictions of health care ration-

ing have permeated the news, clear and consistent communication with patients is critical. Work in Rwanda and Tanzania has found that discussions with patients regarding resource limitations and prioritization decisions are among the most dreaded communication tasks that oncology clinicians face, but standardization across clinicians, skills training, and transparent objective criteria may mitigate the burden.<sup>34</sup> A playbook of COVID-19-ready communication skills, including tips for discussing rationing, has been published by VitalTalk, a nonprofit organization that disseminates evidence-based communication skills training for serious illness.<sup>46</sup>

Sixth, moral distress must be addressed to avoid burnout during a time when resilience is critical. Moral distress arises when one is unable to pursue a morally right action owing to external constraints, resulting in negative emotions and burnout.<sup>47</sup> Oncologists in high-income communities are often used to providing the highest standard of care, and therefore they will be particularly susceptible to moral distress when they are obliged to limit care. Interventions to address burnout range from individual-level coping and resiliency programs to organization-level changes that mitigate structural factors.<sup>48</sup> In our experience, activities that build community and camaraderie among interprofessional oncology clinicians serve as an important antidote to the moral distress of practicing within resource constraints. Moreover, specific triggers of moral distress can be addressed by the aforementioned recommendations: replacing subjectivity and arbitrariness in decision-making with principled guidelines, mediating value conflict through fair deliberative procedures, mitigating inequities by deliberate safeguards for the vulnerable, and standardizing communication approaches for difficult discussions with patients.

## Conclusions

After an initial push to triage cancer care quickly in the face of the emerging COVID-19 pandemic, oncology clinicians and administrators now must approach practice changes with a long-range view. A prolonged period of macroeconomic effects, such as unemployment and reduced public-sector health care expenditures, may lead to excess cancer-related deaths on a large scale.<sup>49</sup> As oncology practices adapt to a contracted health care system, using principled approaches and the wealth of experiences in oncology resource prioritization from LMICs may help guide decisions and implementation.

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