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ABSTRACT



The COVID-19 pandemic has raised a host of ethical challenges, but key among these has been the possibility that health care systems might need to ration scarce critical care resources. Rationing policies for pandemics differ by institution, health system, and applicable law. Most seem to agree that a patient's ability to benefit from treatment and to survive are first-order considerations. However, there is debate about what clinical measures should be used to make that determination and about other factors that might be ethically appropriate to consider. In this paper, we discuss resource allocation and several related ethical challenges to the healthcare system and society, including how to define benefit, how to handle informed consent, the special needs of pediatric patients, how to engage communities in these difficult decisions, and how to mitigate concerns of discrimination and the effects of structural inequities.

KEYWORDS

Decision making; end-of-life issues; health care delivery; health policy; public health; rationing/ resource allocation

On March 11, 2020, the World Health Organization declared that the global spread of the novel coronavirus disease, COVID-19, was a pandemic. At the time of this writing, it is estimated that in the United States 20–60% of the population could become infected with COVID-19, over 20 million people might require hospitalization, and over 4 million could require intensive care unit (ICU)-level care (Tsai et al. 2020). The initial surge of COVID-19 has already overwhelmed health systems across the globe, sparking international discussion about the ethics of triage, allocation of scarce resources, and medical decision-making under crisis standards of care. These

conversations are not new. Discussions of appropriate criteria and processes for the allocation of scarce critical care resources during pandemics have been ongoing among ethicists, healthcare institutions, and public health agencies such as the Centers for Disease Control and Prevention (CDC), for years (Biddison et al. 2014; Persad et al. 2009; Travers et al. n.d.; White et al. 2009). However, each pandemic has its own unique features, occurs in an evolving health care environment, and is embedded in a particular historical and political moment. Thus, the COVID-19 pandemic raises a particular set of concerns for our

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healthcare systems, for North American society, as well as the global community.

The COVID-19 pandemic has raised a host of ethical challenges, but key among these has been the possibility that health care systems might need to ration scarce critical care resources. Rationing policies for pandemics differ by institution, health system, and jurisprudence. Some states have uniform policy, while some systems and states have no policies at all.

Where policies exist, most seem to agree that a patient's ability to benefit from treatment and to survive are first-order considerations. But there is debate about what clinical measures should be used to make that determination and to what extent subjective clinical judgment should be allowed. There is also disagreement about other factors that might be ethically appropriate to consider. In this paper, we will discuss resource allocation and several related ethical challenges to the healthcare system and society, including how to define benefit, how to handle informed consent, the special needs of pediatric patients, how to engage communities in these difficult decisions, and how to mitigate concerns of discrimination and the effects of structural inequities.

These present real ethical challenges that arise when health systems reach the end of their capacity to handle the influx of patients during a pandemic. As COVID-19 has spread globally, bioethicists have been working with physicians and other health professionals to create or revise policies, engage in clinical consultation, and help develop appropriate criteria for allocation decisions. In this paper, members of a task force of the Association of Bioethics Program Directors review some of the difficult challenges facing clinicians and health care systems during the COVID-19 pandemic. This is not an exhaustive list of the ethical challenges arising during the COVID-19 pandemic. Rather, we focus on issues that are most pressing as the US approaches the first peak of this pandemic.

HEALTHCARE SYSTEM ISSUES

Appropriate Use of Prognostic Scoring Systems

Ethical guidance on allocation of scarce resources generally hinges on determining who is most likely to benefit. However, the appropriate definition of benefit has been debated. Defining benefit using quality of life considerations (for example, considering the quality of life-years saved) has been widely condemned on grounds of disability discrimination (Fins 2020). More defensibly, benefit has been defined in terms of short-

term prognosis, namely likelihood of survival to hospital discharge. More controversy arises when benefit is considered in terms of long-term survival, since this systematically disadvantages patients on the basis of age, disabilities that may lead to shorter life, and underlying health disparities that can also affect life-expectancy. Yet, even assessing likelihood of short-term survival can raise challenges, especially in the context of a new disease such as COVID-19, with data still emerging relevant to predicting who is likely to survive in the critical care context.

Most allocation guidance suggests using a clinical scoring system, typically incorporating the Sequential Organ Failure Assessment (SOFA) score for adults (or Pediatric Logistic Organ Dysfunction (PELOD) for children), to estimate the probability of a patient's short-term survival. The advantages of SOFA-type scoring systems are apparent—they generate mortality predictions based on objective data; they integrate several physiologic and biochemical metrics; they attempt to avoid stereotyping and other cognitive biases; and because they aggregate several data types, they avoid the possibility that any single factor (such as age or a disability) will be used to deny a patient access to a scarce resource.

However, although scoring systems strive to be objective, they are not ethically-neutral nor free of bias. First, the predictive validity of the SOFA score in the context of COVID-19 respiratory insufficiency has not been validated (Hick et al. 2020). This has led to the recommendation that only large differences in such scores should ground allocation decisions comparing patients' likelihood of benefit through survival, and that such scores need to be combined with clinical judgment (National Academies of Science, Engineering, and Medicine, Standing Committee on Emerging Infectious Diseases and 21st Century Health Threats 2020). Indeed, aggregate scores are not always more accurate than professional judgment and some scores, like SOFA, were developed decades ago for purposes other than triage (Rubinson et al. 2010). In fact, SOFA did not perform very well for pandemic influenza (Khan et al. 2009). Although efforts are underway to develop scoring systems with better predictive accuracy, these too must be scrutinized; to the extent they consider comorbidities, even these will carry risks of disability discrimination and perpetuating or exacerbating underlying inequities in the health care system. For example, because minorities have more comorbidities and greater risk of death from COVID-19 (The Associated Press 2020), scoring that deprioritizes patients with comorbidities may cause

resources to be directed away from them—a serious ethical problem. In addition, scoring systems can be alluring but by generating a numerical outcome in a seemingly objective fashion, they risk false precision in claiming a difference in risk of mortality between patients who are, in fact, clinically indistinguishable.

Scoring systems should maximize predictive validity and ethical fairness. In the context of the evolving COVID-19 pandemic, with predictive validity not yet firmly established, scoring systems should be combined with clinical judgment. Both must be scrutinized for prognostic accuracy (which should increase with collection of data in the COVID-19 context), as well as for ethical acceptability and fairness. There are opportunities in this big data era to make use of health information technology to evaluate and improve prognostic judgments as to which patients are likely to benefit through survival to discharge.

Pediatric Standards of Care

Although the vast majority of individuals with diagnosed COVID-19 are adults, the pandemic surge will also impact pediatric or neonatal environments. Both free-standing children's hospitals and pediatric and neonatal units within larger adult facilities may have excess resources in proportion to those affected. To maximize survival and treat individuals fairly, these facilities could share needed resources, such as ventilators, and treat older patients than they usually do. Treating older patients could be done by accepting patients of greater age with COVID-19 diagnosis and should be based on the ability to provide care at least equivalent to that provided in adult facilities, while maintaining fiduciary obligations to all pediatric patients.

If the surge overwhelms available resources, the question of whether children should be given priority in allocation protocols arises. Reasons for doing so include increased life-years saved as well as the life-cycle principle, whereby all persons should have the same opportunity to live through the various stages of life (Persad et al. 2009). While prioritizing children has been endorsed by community focus groups in less pressing times (Biddison et al. 2019; Public Health—Seattle and King County “Health Care Decisions in Disasters: Public Engagement Project on Medical Service Prioritization during an Influenza Pandemic” 2009), allocating resources based on age has prompted lawsuits and complaints alleging discrimination (Department of Health and Human Services 2016). Incorporating existing

comorbidities or mortality risk—both of which are greater in older adults (Verity et al. 2020)—into an allocation protocol may indirectly prioritize children, but the absence of a validated method for comparing adult and pediatric outcomes may require significant reliance on expert clinical judgment, itself susceptible to bias.

Finally, children are not little adults and their developmental needs should be recognized in the pandemic context. For example, many institutions have significantly restricted visitation in an effort to reduce infection risks and to conserve personal protective equipment (PPE). However, continuing to permit visitors is necessary for children and patients with developmental disabilities due to their inability to give informed consent and the need to address their fears and anxieties. Visitors may also free staff, who may be in short supply, to focus on essential tasks.

Protection and Prioritization of Healthcare Workers

Disaster response and public health emergency protocols traditionally prioritize essential personnel in the allocation of scarce resources, for the success of the response and the good of society, and are grounded on a duty of reciprocity to those accepting greater risk for the public good. Prioritization can mean anything from immediately being placed in the highest priority group to access scarce resources, to being given special consideration in the event that other relevant factors are equal (as a tie-breaker) (Emanuel et al. 2020; White and Lo 2020). Policies also differ in what scarce resources to allocate in this manner; in some policies, essential personnel priority is limited to preventives such as vaccines and medication treatments, but does not include critical care resources such as mechanical ventilators, as a patient requiring ventilator care is unlikely to return to service in the near term.

What this means for healthcare workers in the context of the COVID-19 pandemic is controversial. There is widespread agreement that everyone should be treated fairly in allocating scarce resources, but what constitutes fair treatment is far from obvious. If prioritization is based on health status alone—a combination of likelihood of benefit and need—then allocation decisions should be blind to concerns of who constitutes essential personnel or whether they are owed a debt of reciprocity by society (Berlinger et al. 2020).

Fairness, however, also requires that those who bear the greatest burdens and sacrifice the most should be among those who reap the benefits. Healthcare workers clearly are among the front-line defenders in the fight against COVID-19 (Adams and Walls 2020). Analogous to soldiers on the battlefield in wartime, healthcare workers are essential for fighting the COVID-19 pandemic. Furthermore, front-line healthcare workers have taken on significant increased risk in the face of the unusually high infection and mortality rates of COVID-19, inadequate supplies of personal protective equipment (PPE), and in some communities an overwhelming surge of infected patients. Society certainly owes them adequate PPE and arguably owes them a debt of reciprocity. This may prioritize them for vaccines and medication treatments. More controversial is whether they should receive priority for scarce critical care resources like ICU beds and ventilator support.

Delimiting who is in the category of essential personnel and determining what reciprocity demands is fraught with problems. The difficulty in defining and selecting essential personnel should give us pause. Physicians, nurses, social workers, respiratory therapists, pastoral care providers, emergency medical technicians, and pharmacists are all healthcare workers, as are those who work in hospital transport, environmental services, and security. All have taken on significant increased risk in the face of COVID-19. Going beyond healthcare, police and firefighters, as well as grocery cashiers, stockers, and baggers have also taken on increased risk, some with only modest compensation and little social standing. If healthcare workers ought to be prioritized, why not these other groups as well? If not these, then why healthcare workers? A question is raised as to whether the reciprocity owed is due to risk taken or life-saving services rendered. In the latter case, first responders and bedside healthcare workers would arguably have higher priority than cashiers, but this is controversial.

There is also an argument that those on the front lines need to be returned as quickly as possible to the fighting force. Our hospitals must be as functional as possible to keep up the battle against COVID-19. The absence of highly skilled healthcare workers in ICUs, emergency departments, and other areas of healthcare multiply the negative effects of the COVID-19 pandemic. Scarcity applies not just to PPE, ICU beds, and ventilators but also to personnel. Although infection may preclude healthcare workers from returning to work for several weeks, or even months, the fight against COVID-19 is expected to last at least

12–18 months with several waves of high hospitalization rates. Arguably, prioritizing healthcare workers for medical care means returning them to the front lines as soon as possible, even if severe illness means there will be a delay in their return (Emanuel et al. 2020).

Prioritizing healthcare workers for their instrumental value in the fight against COVID-19, however, involves an assessment of their relative social value. These assessments, while problematic in themselves, are notoriously susceptible to hidden biases and prejudices that may further exacerbate existing health, racial, and social disparities. Prioritizing healthcare workers in a system that they control, raises additional concerns that this will be seen as moving beyond prioritization (e.g., as a tie breaker when likelihood of benefit is equal) to privilege (e.g., where social worth moves a person to the front of the line).

Preserving the morale of healthcare workers also matters. In prior epidemics some healthcare workers have chosen to stay home rather than come to work for fear of exposing themselves or their families (Huber and Wynia 2004; Oberholtzer et al. 2004; Zuger and Miles 1987). COVID-19 has been distressing for front-line healthcare workers due to long hours, dwindling PPE, and an overwhelming surge in the hardest hit communities. Providing some priority for healthcare workers in the event that they become infected may help to buttress flagging morale and allay current anxiety (Adams and Walls 2020).

Community engagement studies indicate some public support for prioritizing healthcare workers, but the data are sparse (Biddison et al. 2018; “Health Care Decisions in Disasters: Public Engagement Project on Medical Service Prioritization During an Influenza Pandemic” 2009). In the absence of a better understanding of whether this support is widespread, prioritization of healthcare workers may feed concerns that the privileged, wealthy, and connected are unfairly accessing scarce medical resources, thereby reducing access for marginalized communities. COVID-19 testing of asymptomatic politicians, sports stars, and celebrities when tests were not available even to sick patients from the broader community has understandably raised such concerns.

Provision of Non-Critical, Non-COVID-19 Care

The need to preserve resources (PPE, hospital beds and equipment, and personnel) and practice physical distancing has forced clinicians to triage access to many diagnostic, therapeutic, and supportive care

interventions that would ordinarily be provided for patients with illnesses unrelated to the COVID-19 pandemic. Allocating limited healthcare resources in a rational, ethical, and integrated fashion to support the greatest good for the greatest number requires the deferral of nonemergency care and implementation of alternative delivery methods (e.g., telehealth). However, the delay or omission of routine health services can lead to morbidity or mortality.

Guidance is emerging about the allocation of specific treatments for serious conditions. For example, the American College of Surgeons suggests hospitals discontinue elective surgery during the pandemic (American College of Surgeons “COVID-19 Guidelines for Triage of Cancer Surgery Patients” 2020). The United Kingdom’s National Institute for Health and Care Excellence (NICE) has issued guidelines for prioritizing patients for treatments such as bone marrow transplants, systemic cancer treatments, and radiotherapy in the context of COVID-19 (National Institute for Health and Care Excellence (NICE) “COVID-19 Rapid Guideline: Haematopoietic Stem Cell Transplantation” 2020; National Institute for Health and Care Excellence (NICE) “COVID-19 Rapid Guideline: Dialysis Service Delivery” 2020; National Institute for Health and Care Excellence (NICE) “COVID-19 Rapid Guideline: Delivery of Radiotherapy” 2020; National Institute for Health and Care Excellence (NICE) “COVID-19 Rapid Guideline: Delivery of Systemic Anticancer Treatments” 2020). Similarly, Cancer Care Ontario divides patients with cancer into three categories based on need and efficacy of treatment (Ontario Health 2020). Top priority is given to patients whose condition is unstable, imposes unbearable suffering, or immediately threatens life. Lowest priority goes to those patients for whom services can reasonably be discontinued until after the pandemic has passed. In the intermediate category are all others, whose condition allows services to be deferred or discontinued without undue risk during a single wave of the pandemic.

Overarching classification schemes can help to harmonize triage efforts by providers from multiple disciplines and increase fairness. Nevertheless, individual-level triage remains challenging, since services are rarely entirely elective. Physicians must consider who will be harmed least by delay, which may be impossible to predict with any certainty. The heterogeneity of cases and complexity of evidence pertaining to many medical and surgical services limit the ability to operationalize guidance into quantitative

scoring systems as has been attempted in critical care allocation processes.

How, then, should triage occur for non-critical care unrelated to COVID-19 during the pandemic? Even if quantitative criteria cannot be defined, criteria that are consistent, transparent, and objective should be determined by expert consensus, so that placing specific cases into general categories of priority is not left to the treating provider at the bedside. As in the critical care context, to minimize conflicts of interest, determinations should, wherever possible, be overseen by a triage team, a group of providers not directly involved in the patient’s care. Further, a process for appealing these triage decisions should be established. Finally, because the allocation of scarce resources for health care inherently involves difficult choices (Calabresi and Bobbitt 1978), providers must utilize best practices for communicating with patients in this context (University of Michigan Rogel Cancer Center 2020; VitalTalk “COVID Ready Communication Playbook” 2020).

Informed Consent

The COVID-19 pandemic, with its resource shortages, physical distancing, and urgency, is also posing profound questions in both clinical and research settings regarding whether current standards of informed consent remain applicable, or should be altered, and if so, how.

In clinical practice, patients and families might not understand or agree with decisions regarding triage; lack of cardiopulmonary resuscitation (CPR) for all patients, if futile; postponed treatment of patients with disorders other than COVID-19; patient access to investigational treatments, vaccines, and devices; or use of digital tracking technologies and the data that they generate. Treatment of COVID-19 often requires decisions to be made quickly, and some settings have been overwhelmed with patients needing urgent care, so there is less time for communication of information than usual. Patients may be unable to take consent forms home to read and discuss with families, and because hospitals commonly bar visitors, including surrogates, patients who lack capacity to consent for themselves face particular challenges.

As COVID-19 infection rates peak, it is possible that there will be more patients who need and want a ventilator than there are ventilators available. Moreover, patients and families may not agree to changes in code status. In such cases, wider public health benefits, the competing claims of other patients

to scarce resources, and avoiding excessive risk to healthcare providers (as in attempting resuscitation of a COVID-19 patient unlikely to benefit) may outweigh individual patients' or families' wishes and the obligation to obtain informed consent (Biddison et al. 2014; Dickert et al. 2017; Emanuel et al. 2020). Still, providers should communicate and inform patients and their families about these issues as fully as possible. It should be clear to patients, families, and the community when crisis standards of care have been triggered and how the situation has forced changes in customary practices. The conditions for overruling patient or surrogate preferences should be very specific (e.g., articulating when, for which reasons, and for which resource) and clearly stated in policy that has been developed with close attention to ethical issues.

The current pandemic presents enormous challenges to healthcare, but also important opportunities to consider and develop new models and approaches to informed consent under crisis standards of care, when life-saving resources are in short supply (Biddison et al. 2014). Consent serves several functions, including respecting autonomy, establishing trust, and facilitating communication (Dickert et al. 2017). But which of these functions is now most important, if not all are realistic? Serving the needs of the community becomes paramount in a pandemic crisis, but must be accomplished in a way that respects rights and preserves fairness. While current regulations allow waivers of consent in emergency situations, the pandemic suggests that we may need to elaborate more fully ethical standards for consent in the context of a public health crisis.

Healthcare Providers' Moral Distress

The process of triaging patients for scarce critical care resources relies on healthcare providers who are likely to experience a range of distressful emotions and thoughts (Khalid et al. 2016; Lee et al. 2005). Moral distress emerges when providers believe that the right course of action is not taken because of institutional or other factors (Jameton 1984). The very nature of triage-related decisions and processes can trigger moral distress because healthcare professionals may need to act contrary to what they see as core values and principles of their professions (e.g., value of each human life, informed consent, best interest of each patient) (Emanuel et al. 2020). Even if providers agree with a policy or a decision's intent and principles, they may experience symptoms of emotional and

psychological distress (e.g., fear, nervousness, anxiety, shame) (Biddison et al. 2014), especially when decisions involve patients for whom they are caring. While making and implementing triage decisions will be difficult, living with them may be even more so. Possible repercussions of pandemic care on healthcare providers include depression, sleep disruption, anxiety, and post-traumatic stress disorder (Khalid et al. 2016; Lee et al. 2005; Maunder et al. 2006).

Preparatory and follow-up practices implemented at different levels may help mitigate distress and empower healthcare providers. Acknowledging the strengths and significance of healthcare professionals can help ensure that self-efficacy and professionalism are preserved and nurtured (Ulrich and Grady 2019). Despite the importance of individual resilience for healthcare providers, they should never have to make triage decisions alone and unsupported, and it is recommended that such decisions be made by a triage officer or team, not the treating clinician (Biddison et al. 2014; Emanuel et al. 2020; Truog et al. 2020). Supportive resources are necessary for healthcare providers (e.g., palliative care, training discussion guides, clinical ethics support) so that they do not feel they are abandoning patients who do not receive or are removed from life support (Biddison et al. 2014). Institutions should clearly communicate the criteria and procedures established for triaging when needed, and should defend and support the workers implementing them. Healthcare professionals also need to be reassured that applying triage policy will not expose them to legal liability and that they have the public's trust (Emanuel et al. 2020). Finally, health authorities will need to facilitate post-pandemic support for trauma and compensation for injuries or death (Biddison et al. 2014; Khalid et al. 2016). Studying the experience of distress in this pandemic, and its meanings, is also important (Hodge 2015; Tigard 2019; Ulrich and Grady 2019).

Hospital Financial Vulnerability

Another ethical issue caused by the COVID-19 pandemic relates to health care organization (HCO) financial viability and vulnerability. HCOs in the United States are unique in that they generally function as businesses subject to the same economic impacts as other free-market retailers, but the services that they provide are considered essential. While HCOs have remained operational during the COVID-19 pandemic to meet the public's healthcare needs, the revenue they require to function at normal

operating levels has been significantly reduced in at least two ways. First, to help minimize the spread of COVID-19, HCOs have reduced the overall number of services they provide, thereby decreasing their revenue and operating budgets. HCOs, like other retailers, have begun to layoff or furlough staff in order to meet their operating costs (Gabler et al. 2020). Second, because most health insurance in the United States is employment-based and not provided to everyone by a government-sponsored plan, the abilities of persons to pay for medical care is negatively impacted when employers are forced to close and lay-off or furlough their staffs, which has been one of the most notable effects of the COVID-19 pandemic (Rushe and Sainato 2020). Even in cases during the COVID-19 pandemic where laid-off or furloughed workers still have their employer-sponsored health insurance, individuals may not be willing to seek medical care because of worries they may not be able to afford copays and deductibles.

Caring for patients with COVID-19 is financially draining on HCOs. New York, Seattle, and New Orleans have shown that successfully managing the pandemic requires a huge volume of costly resources. Yet, at a time when COVID-19 necessitates HCOs remain open to manage local outbreaks, some HCOs are at financial risk of having to shut down because of the pandemic. Just as important as identifying the most ethically supportable allocation plans for scarce resources, HCOs need to consider what they owe their employees and the communities in which they serve. Similarly, communities, states, and the federal government need to consider what they owe HCOs struggling to survive.

SOCIAL ISSUES

Community Engagement

Community engagement has long been integral to public health and specifically to planning for pandemics and addressing such controversial issues as allocating limited resources. Experience indicates that community engagement is potentially valuable across a range of functions, from setting achievable objectives for health-related initiatives to enhancing public awareness and understanding of complex matters and eliciting public concerns and priorities. If well-intended, designed, and executed, community engagement strategies can exemplify the principle of respect for persons in community and thereby engender and promote mutual trust and shared accountability between HCOs, their patients, and communities. In

the unprecedented crucible of today's COVID-19 pandemic, these goods, principles, duties, and values will be put to the ultimate test.

Community engagement has been central to several noteworthy efforts to develop guidance and protocols responsive to the ethical challenges of allocating scarce resources. For example, in Maryland, from 2012 to 2014, community engagement forums were held across that state utilizing deliberative democracy methods to elicit informed responses to contending ethical principles for resource triage (Biddison et al. 2019; 2017). In 2009, as a core component of its pandemic ethics project, the Minnesota Department of Health used a variety of community engagement methods, from forums to small discussion groups, to explore public attitudes to a broad range of allocation issues (Vawter et al. 2010). Other community engagement projects around crisis standards of care have taken place across the country and in Canada, including in Seattle, Boston, Utah, Texas, New York, Colorado, Vancouver, Edmonton, and Montreal.

From these and related efforts, several lessons can be distilled. First, it is important to clarify the purpose and role of community engagement in addressing the ethical challenges spawned by pandemics: is it to solicit formative input for triage protocol development, to gauge community reactions to proposals and principles, or to educate and build awareness within the community in the interests of transparency and public adoption? Second, it is important to formulate community engagement plans within an informed context, grounded in knowledge of the community—its history, its demographic composition, and customs—and with heightened concern for disenfranchised and vulnerable populations. Finally, it is important to carefully consider, deploy, and assess engagement methods, taking into account the advantages and limitations of polls and surveys, focus groups, deliberative engagement forums, civil juries, interviews, and other methods.

Around the globe, government responses to the COVID-19 pandemic have been plagued by disinformation and poor planning. The result is a misinformed, distrustful public, which is already burdened by deficits in health literacy, especially around issues of dying and death (Finestone and Inderwies 2008). Although the cure for these acute as well as chronic social ills is multifaceted, there is evidence for the hope that community engagement can figure prominently in their treatment and, ultimately, prevention (Dannefer et al. 2020; Ozawa and Stack 2013; Willis et al. 2016). Even in the midst of the pandemic,

community engagement could be important to preparedness for communities not yet affected and in addressing ongoing controversies, from prioritizing healthcare workers in allocation schemes, as mentioned above, to navigating conflicts between individual autonomy and the greater good in the promotion of physical distancing and other non-pharmaceutical interventions.

Crisis Capacity in Rural and Remote Communities

Rural and remote communities rely on healthcare systems that are a part of their communities and their lives. These rural healthcare systems face unique challenges as they operate in communities where the roles of healthcare provider, neighbor, friend, and often family, overlap and intermingle, and where transfer of a presenting patient to a disinterested colleague is often not possible. Moreover, in rural North America, populations are more vulnerable to the economic and health impacts of a pandemic or other national crisis (“Status of State Medicaid Expansion Decisions: Interactive Map” 2020). Rural healthcare providers are not only fewer in number than their urban counterparts, they must work within the constraints of a system with fewer resources and more reliance on colleagues for day-to-day management of patient care.

Statewide pandemic planning should include rural and remote communities, who may otherwise fear that their health care facilities and providers will not get resources needed to provide pandemic care. They may also fear that the response to the COVID-19 crisis may involve shifting resources such as ventilators and providers to hard-hit urban areas, further eroding rural capacity.

Many rural facilities do not have access to bioethicists, and rural hospitals often lack or underutilize ethics committees (Cook and Hoas 2008). This may influence the ethical choices and deliberations of rural healthcare systems and providers. The lack of timely ethical guidance or expertise is compounded during a pandemic, as smaller systems are at greater risk of using all of their resources faster, without the financial or political means of larger institutions to replenish them. Regional coordination that allows rural healthcare facilities to work together and pool key resources may be essential.

The implications of the COVID-19 pandemic for rural healthcare systems include a need to reinforce the existing social relationships and, as is true in all health systems, to communicate clearly and early during a pandemic how and why certain decisions are

made (e.g., why family members may be disallowed at a loved one’s bedside, or how allocation decisions are made and the ethical rationale for chosen criteria). Given the lack of ethics expertise in some rural systems, sharing COVID-19 policies from urban or suburban healthcare systems is important. However, rural healthcare systems must create policies, guidelines, and resources that consider and address the rural populations’ circumstances and concerns specific to their community.

Discrimination and Health Equity

Structural inequalities in both the United States and Canada put specific economic, racial, ethnic, geographic, and other marginalized groups at a disadvantage in accessing and using healthcare services, even in times of relative prosperity and calm (Institute of Medicine (US) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care 2003). Under the pressured conditions of a pandemic, health disparities can be increased. Disadvantaged communities can have delayed access to testing, problems with transportation to health facilities (especially in a time of physical distancing), lack of insurance, worry about immigration status, and higher existing chronic disease burdens (Quinn and Kumar 2014). These patients may also encounter provider bias, such as by having their pain undertreated or complaints minimized or misdiagnosed (Anderson et al. 2009; Hoffman et al. 2016). Structural racism partly explains why, for example, while black residents make up only about 23% of the residents of Cook County, Illinois, they account for about 70% of COVID-19 deaths as of this writing (Ramos and Zamudio 2020). Other ethnic and racial populations, such as Native Americans and Canadian Indigenous people, are also at particular risk (Artiga et al. 2020).

In addition, the social pressures of an economic depression, job loss, social isolation, and the closure of services has increased the risk of homelessness, hunger, and illness among the nation’s poorest populations. Members of low-income communities under quarantine, often suddenly without an income due to job loss, may find it difficult to buy food, sanitation supplies, and other needed resources in the pandemic, and may delay seeking health care due to financial strain or concern about losing employment due to absence. They may also need assistance with energy bills or rent. Immigrant and undocumented populations, with increased fear of deportation in the current

political climate, have also been delaying access to needed services for fear of discrimination or deportation (Parmet and Ryan 2018).

It has been widely reported that the institutionalized elderly are at particular risk in the COVID-19 pandemic. The non-institutionalized elderly may find themselves pressed into service to watch grandchildren in the wake of school closures, thus increasing their risk of exposure.

Concern has also been raised by disability rights advocates and their allies that the healthcare system, and proposed policies to guide allocation of resources, might discriminate against those with disabilities (American Association of People with Disabilities 2020; Department of Health and Human Services 2020; Disability Rights Washington 2020; Ne’eman 2020). Even in the best of times, navigating the barriers constructed by an ableist society can be challenging for the disabled. In a pandemic, mobility issues, the inability of health aides to come to work, the inability to obtain life-giving supplies, and even the loss of face-to-face contact for those with mental challenges can significantly exacerbate existing conditions.

The Americans with Disabilities Act, the Rehabilitation Act, and the Affordable Care Act all prohibit healthcare providers from discriminating against patients because of their disabilities, such as by excluding disabled patients as a category from treatments on the basis of their disabilities (Bagenstos 2020). Yet, many argue that this is precisely what some triage and allocation policies have done. A study by the Center for Public Integrity found policies in 25 states that it said would ration care in ways that disability advocates have denounced (Whyte 2020a).

A policy in Alabama (since repealed) read in part: “persons with severe mental retardation, advanced dementia or severe traumatic brain injury may be poor candidates for ventilator support” (Weixel 2020). Washington state recommends transferring patients with “loss of reserves in energy, physical ability, cognition and general health” out of hospitals and into outpatient care (Disability Rights Washington 2020; Washington State Department of Health “ashington State Department and Crisis Standards of Caree 2020). On March 28, 2020, the Office for Civil Rights (OCR) within the Department of Health and Human Services (HHS) issued a bulletin with guidelines aimed at ensuring that entities covered by civil rights laws keep in mind their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience and religion in HHS-funded programs

(HHS Office for Civil Rights in Action “Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)” 2020). On April 8, 2020, in the wake of protests from disability rights groups, the Utah Department of Health approved an update to its emergency plans to explicitly state that it does not discriminate against people with disabilities in allocating care (Jacobs 2020).

Facing a pandemic, the healthcare system cannot remedy the structural inequalities of the social system in the US, but it should not contribute to them. Disability advocates and experts should be active participants in the design of triage and allocation policies. Even in the face of the terrible burdens of an overstressed healthcare system, disability communities need special consideration to avoid inequities.

Legal Considerations

Many of the ethical issues discussed in this article are complicated by the uncertain legal implications of particular strategies and the heterogeneity of state laws. As a matter of procedural fairness and due process, all hospital systems that are implementing triage policies should have appeals mechanisms that patients and families can trigger to resolve disputes (White et al. 2009). However, appeals need to be adjudicated quickly so that appeals by patients who do not (or no longer) qualify for life-saving interventions do not delay the availability of those interventions to others by triggering in a drawn-out appeals process. Criteria upon which triage allocation decisions are made should be consistently applied and clearly communicated to patients and families. To ensure fairness, appeals should generally be heard by an objective third party (e.g., a Scarce Resource Allocation Committee) (Truog et al. 2020; White et al. 2009).

From an ethical perspective, triage policies should be applied consistently to all patients and should strive to avoid both overt and implicit bias. From a legal perspective, it is also important that triage policies and allocation decisions do not unlawfully discriminate against protected classes of individuals (e.g., on the basis of race, color, religion, sex, national origin, age, or disability) (Age Discrimination in Employment Act of 1967 1968; Americans with Disabilities Act of 1990 1990; Civil Rights Act of 1964 1964). As the OCR bulletin reminds healthcare providers and health systems facing difficult decisions about treatment allocation during this public health emergency: “persons with disabilities should not be denied medical care on the basis of stereotypes,

assessments of quality of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities or age." Instead, the Bulletin advocates for "individualized assessment of the patient based on best available objective evidence" ("Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)" 2020).

Yet, even when the most objective criteria are applied, healthcare providers will have to compare and prioritize individual patients on some basis, raising serious concerns about legal liability for these allocation decisions. To address this concern, states should create written crisis standards of care and all states should immediately pass legislation or issue an executive order granting immunity from civil and criminal liability if healthcare providers act in good faith in accordance with those standards during this public health emergency (Cohen et al. 2020; Maryland Public Safety Section 14-3A-06 2005; Michigan Legislature "Emergency Management Act – Act 390 of 1976 – Section 30.411" 2020; Whitmer 2020). Similarly, hospital systems should clearly inform their employees and associated healthcare providers of these legal protections, and that their actions during this difficult time will be indemnified. Without such protection and clear institutional support, front-line providers may be reluctant to take the agonizing but necessary actions that will save the most lives possible when not all lives can be saved.

CONCLUSION

Many other ethical challenges also complicate the current pandemic. News outlets have made much of visiting policies that have forced people to die alone, isolated from their loved ones and human contact (Lamas 2020; Leland 2020; Levitz and Berger 2020; Whyte 2020b). Maternity wards must struggle with COVID-positive women in labor and delivery, and some have barred partners from being present in delivery rooms, although this has been challenged. The shortage of ventilators has led some systems to split ventilators, that is, to use one ventilator on multiple patients, which is challenging clinically and ethically. Planning has scarcely begun for post-pandemic reentry and release of vulnerable populations from confinement, and comes with its own set of challenges. The questions of how to reopen the economy, and which economic needs will be prioritized, will require complex ethical judgments for political and business communities to negotiate. Post-pandemic medical needs for mental health care, for the backlog

of less serious conditions now needing care, and for an exhausted and disheartened medical community will need attention. And the lessons of COVID-19 will compel society to support the responsibilities of public health authorities to plan better for the next pandemic.

There are important lessons for the bioethics community as well. Despite all the efforts to write policies that are fair and equitable, many of the policies that have been put in place can be critiqued for their lack of sensitivity to some of the needs of the disabled and disenfranchised. Front-line physicians report that triage and allocation decisions happen every day and in ways not recognized by even the best-intended policies, showing a common gap between institutional policy and the real day-to-day work of healthcare professionals. Some of the ethical decisions that most impact the lives of patients are not the ones that bioethicists have traditionally put at the center of their concern.

The COVID-19 pandemic is still in a relatively early stage, and will continue to evolve for many months, at least, from the time of this writing. Experience, changing circumstances, patterns of illness, and other factors will continue to shape ethical policy and may force a reevaluation of some of the ethical principles and assumptions that currently guide treatment decisions. Bioethicists, along with other healthcare professionals, must learn the lessons of COVID-19, rapidly put them into practice, and be better prepared for the next pandemic that is surely to come.

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