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COVID-19: Advancing Empirical Bioethics Research

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Research is essential to advance knowledge of emerging and reemerging infectious diseases and to improve the effectiveness of therapies and the quality of care for all patients. Indeed, with more than 12 million individuals infected and nearly 560,000 deaths worldwide at the beginning of July 2020 (Johns Hopkins University Coronavirus Resource Center 2020), research is critical to identify and minimize the devastating effects of SARS-CoV-2 and COVID-19 in both the adult and pediatric populations. The morbidity and mortality statistics alone demand immediate attention. Research on a vaccine and on life-saving therapeutics, including antiviral regimens, is the highest priority currently. And, there is still much we need to learn about the pathogenicity of the virus and the variations in its severity and clinical course.

The COVID-19 pandemic has focused attention on the immeasurable human suffering throughout the globe and on the unique ethical issues that challenge healthcare systems, individual clinicians, researchers, patients and families, and diverse communities. As we find ourselves in unprecedented situations, the pandemic has elicited altruism and goodwill from so many (e.g., #stayhomesavelives, [1daysooner.org](https://www.1daysooner.org/)), but has also amplified the staunch individualism of others (e.g., protests at state-houses in Massachusetts, Michigan, Wisconsin, and other states). As bioethicists aim to contribute to conversations about what should be done to keep us all safe and healthy, ethical frameworks are applied to these novel circumstances to aid in ethical decision making, such as triage protocols, human challenge studies, and immunity passports (Persad and Emanuel 2020; Shah et al. 2020; White and Lo 2020).

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Importantly, empirical data are needed to support the development, implementation, refinement, or rejection of these approaches (Kon 2009). Empirical bioethics research on decision making during this pandemic can contribute to a body of evidence describing these unique ethical challenges, as well as the failures and successes of the decisions made to address and resolve them (Chuang et al. 2020). Here we aim to stimulate the collective imagination regarding the kinds of COVID-related empirical bioethics research we would like to see published in *AJOB Empirical Bioethics*.

Descriptive studies defining current practices, opinions, and policies can inform future research as well as the design of potential interventions aimed at improving care. An understanding of experiences and processes at the front lines of care can lead to better healthcare delivery systems for patients and for the clinicians who care for them. Such descriptive studies should include the full range of stakeholder perspectives. For example, we hear about frontline workers – not just in healthcare, but in a variety of essential industries – performing their jobs with inadequate personal protective equipment (PPE) and other workplace precautions. This includes workers in higher risk categories, such as those over age 65 or with diabetes or hypertension, as well as workers with at-risk family members at home. What do they see as the limits of their professional and ethical obligations? Do they believe they must perform their jobs in the face of significant risk? How do they define “appropriate risk” and how should it be defined? And what do they think are the ethical obligations of their employers? In defining the potential limits of professional duty and the duty to care, empirical research can help refine the issues, particularly as they affect healthcare and non-healthcare professionals.

Healthcare providers likely experience increased moral distress in a pandemic (Hartzband and Groopman 2020; Ulrich and Grady 2018). Every day the public reads stories about nurses, physicians, and others providing direct care to COVID-19 patients in ways that they were not taught, and even in ways that may go against what they learned and have always practiced. For example, the surge of COVID-19 patients in hospital emergency departments overwhelmed nurses and physicians, and in some instances they had to treat patients without the use of appropriate protective clothing and without access to other resources to support the quality of care that they had been taught to deliver. The “rightness or wrongness” of a decision may haunt a healthcare worker for years to come. In order to develop interventions to address the moral distress that is unique to working in a pandemic, we have to understand the sources and different types of constraints that lead to moral distress, as well as provider expectations, reactions, and coping mechanisms. What gives providers the moral strength to continue amid such traumatic circumstances (Ulrich and Grady 2019)? What types of resources—palliative care, ethics committees, moral distress consultation teams, pastoral support, grief counseling—can help to mitigate moral distress and other damaging emotional states? Longitudinal data are needed on the effects of COVID-19-related moral distress on healthcare providers’ physical and psychological outcomes over time, including their professional retention within healthcare systems.

Empirical bioethics research must also do more than describe. Empirical research should also assess the extent to which actual clinical practice reflects our purported ethical norms. For example, bioethicists have provided input regarding state and institutional ventilator

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triage policies, and many have expressed concern regarding whether these policies will discriminate against people with disabilities, people of color, and other marginalized groups (Schmidt 2020). We know that we cannot simply assume that our policies achieve our intended ideals. Fortunately, few institutions have had to implement these policies (yet); however, data on the demographics and outcomes of COVID-19 patients should be collected and analyzed to determine the effects of different triage policies. Data modeling and simulation have proven effective in forecasting the occurrence and progression of diseases, including the related demand for treatment resources and medical accommodations. The use of artificial intelligence (AI) and robots also has increased during the COVID-19 pandemic in both healthcare and non-healthcare settings. Data on the benefits and burdens of AI technology and the ethical challenges of using AI in a pandemic would be useful, and such data may help us understand how AI might change the nature and ethical norms of the provider-patient relationship.

Empirical bioethics research should also seek to develop and test interventions aimed at closing the gaps between our reality and our ethical ideals. Currently, although there is no approved, effective treatment for COVID-19, hundreds of clinical trials of potential treatments are being conducted at healthcare institutions across the country. How should patients with COVID-19 and their families be approached about research participation if they might be eligible for multiple—and possibly lifesaving—studies at the same institution? How do we best demonstrate respect for persons when treatment needs are urgent and personal contact must be limited? Empirical research can also inform if and when we need to revise our ethical ideals. One ethical norm currently being called into question is that research on human subjects should not cause known harm by directly exposing participants to disease. However, a grassroots movement of individuals who want to volunteer to participate in human challenge studies (1daysooner.org) has the bioethics community considering whether informed volunteers should be allowed to take on more risk than is normally allowed, and if so, with what precautions (Shah et al. 2020)? Indeed, how do we balance safety concerns in these situations? And what types of consent models might be appropriate for these types of studies?

A unique aspect of the COVID-19 pandemic is that it has drawn attention to the ethical responsibilities of citizens. If a vaccine becomes available without substantial safety data, what are the ethical obligations of citizens to become vaccinated? How should governments and private institutions regulate vaccination considering the need for herd immunity? If a vaccine is brought to market faster than ever before, what will be the effects on vaccine hesitancy, already widespread for pediatric vaccines? If a vaccine for COVID-19 results in significant complications for even a portion of the population, parents already hesitant to have their children immunized as directed may avoid immunization all together. An epidemic of vaccine hesitancy will lead to even further deaths from other vaccine-preventable illnesses worldwide (Santoli et al. 2020). And like other public health crises, the pandemic has highlighted the tensions between privacy and protecting the public. The central importance of contact tracing to reduce the spread of a highly communicable disease has encouraged use of cell phone data to track citizen's movements and who they come in contact with. However, this use of technology also raises the risk of governmental access to a citizen's whereabouts (de Jong et al. 2019). Will citizens fully understand what rights they

may have given away when signing up for a phone app which will allow them to return to work more freely?

These are just some ideas for empirical bioethics research related to issues raised by the COVID-19 pandemic. Our suggestions are not meant to be exhaustive but rather to stimulate discussion and collaboration. We recognize that there are many issues that warrant attention in addition to what we have outlined above, including but not limited to the ethics of misinformation and divisiveness, ethics preparedness for all citizens, immunity passports, stay-at-home orders and issues of liberty and autonomy, the safety of vulnerable populations and their transitions in care, global health ethics, and the overall public burden arising from the COVID-19 pandemic. Any empirical bioethics research undertaken should be meaningful—and should therefore meaningfully engage a broad range of institutional leaders, clinicians and researchers, and patients and citizens. Better understanding the experiences, views, values, and expectations of stakeholders across diverse communities can ensure that the bioethics community—along with policymakers, public health and healthcare systems, and research institutions—is better prepared during the months and years that lie ahead as we tackle the problems raised by COVID-19 and for future pandemics.

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