

Editorial

LIBERTY, JUSTICE, AND INTENSIVE CARE UNIT RECOVERY

By Aluko A. Hope, MD, MSCE, and Cindy L. Munro, PhD, RN, ANP



Crafting and sustaining a health care delivery system that can meet the needs of survivors of critical illness has been called the moral challenge for the 21st century.¹ Our health care systems are so good at providing highly technologic rescue in the intensive care units (ICUs) that we can now expect most critically ill adults to survive to hospital discharge.² These adult survivors have symptoms—such as fatigue, shortness of breath, and pain—that fluctuate and change over time; they struggle with high rates of new and persistent physical, cognitive, and/or mental health impairments; these symptoms and impairments challenge their ability to perform day-to-day activities, return to employment, sustain relationships, and reintegrate fully into society.^{3,4} If we are to meet the challenge of caring for ICU survivors, what principles should we use to guide our choices for designing the best health care delivery system? Perhaps we can turn to the bioethical principles of *beneficence*, *nonmaleficence*, *autonomy*, and *justice* as one rubric for envisioning such a system for ICU survivors.

Beneficence is the obligation of providers and the health care delivery system to maximize benefit to the patient and to rescue the patient from harm. Several

small clinical trials have examined the utility of specialized ICU follow-up clinics, in-person rehabilitation programs, case management, and psychoeducational programs for improving patient-reported outcomes after discharge from the ICU.⁵ These studies have primarily focused on improving outcomes such as long-term mortality; readmissions to the hospital; and improving functional status, aerobic capacity, and physical and mental health symptoms. Recently, the Improving Morbidity During Post-Acute Care Transitions for Sepsis trial evaluated the effectiveness of using a nurse navigator to optimize the delivery of a bundle of care practices that are associated with lower posthospital mortality and hospital readmissions in survivors of sepsis.⁶ The nurse navigator educated patients and families, helped patients with overcoming medical system barriers to care, discussed complex cases weekly with the lead physician, and communicated with patients either via the telephone or via the electronic health record. In that study, patients who received the complex intervention had lower 30-day readmission or mortality, an effect sustained at 12 months after hospital discharge when compared with the patients who were treated with usual care.^{6,7} The beneficence obligation in our ideal ICU recovery health care delivery system should invite future studies to test interventions geared toward improving patients' symptoms and impairments.

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“ Perhaps the principles of *beneficence*, *nonmaleficence*, *autonomy*, and *justice* can be used to guide our choices for designing the best health care delivery system. ”

Nonmaleficence is the obligation of the system to not harm patients. The nonmaleficence obligation in our ideal ICU recovery health system would invite studies of post-ICU services that include broad safety and harm-reduction outcomes. In addition, our ideal recovery health care system must be willing to contend with the notion that the health system can cause harm by overdiagnosis and overtreatment. Some survivors of critical illness will have symptoms and/or impairments that the medical system may never be able to eliminate. Survivors of critical illness have been known to adapt to their new circumstances and can report improvements in their well-being that are not tied to any change in their symptoms or degree of impairments.⁸ Survivors with unrealistic expectations of their health after hospital discharge may be more likely to feel unsatisfied with their health status. If our interventions in survivors focus only on improving symptoms or impairments in study populations where improvements are unlikely, our focus on rescue may make it harder for some of our patients to do the difficult psychological work to adapt to their impairments. The nonmaleficence obligation in our ideal ICU recovery health system would invite studies that will aim to help our survivors reassess their expectations for recovery, reflect on their values and priorities, and consider changes in their definitions of quality of life and well-being.

Autonomy refers to the expectation that our recovery health systems offer patients the possibility of making choices that reflect their own values. Thus our health system must be grounded in ensuring that our patients and families have the capacity to make choices without coercion or undue influence. Clinicians involved in providing such recovery care will need to have sufficient time to provide information, answer patients' questions, and address patients' worries or concerns. A recent qualitative study revealed

that clinicians' lack of experience in post-ICU care, discomfort with prognostic uncertainty, and lack of experience speaking with patients and families were some of the barriers to discussing postdischarge outcomes with patients and families.⁹ Autonomy also can be extended beyond mere agency to include the ideal of our patients being able to live authentically, in accordance with their own distinctive beliefs and values.¹⁰ Whereas agency focuses on the decisions made in one instance, authenticity invites the entire recovery trajectory to become a reflection of our patients' personality in the world. Often patients during recovery can struggle with bereavement challenges—feelings of guilt, stigma, or demoralization due to their symptoms or impairments that may contribute to them refusing a specific intervention in a specific moment. When survivors refuse treatment and that refusal seems inconsistent with the patient's own previously expressed values, an autonomy principle that acknowledges both agency and authenticity would invite clinicians to explore the reasoning and emotions behind the decision further, preferably in collaboration with the patient's family or friends. Similarly, in the face of tremendous suffering, some patients will express a willingness to take on high levels of risk for small chances of improvement. Sometimes patients will appear willing to ruin their finances for treatment approaches with a low likelihood of success. Clinicians need to be able to communicate openly with their patients about the costs and benefits of treatments. When clinicians can explore their patients' tolerance for risk and can be explicit about their own risk tolerance, they will be better equipped to help patients make choices consistent with their own values and preferences.

Justice refers to the nature of how we distribute fairly and equitably the health care services for ICU recovery across the members of a society; justice is also concerned with identifying what aspects of our patients' lives should be under the purview of the health care system. Different political ideologies will have different conceptions of justice. For example, a recovery health system designed within a libertarian political ideology might focus primarily on the individual patients and might aim to minimize the potential for government coercion into health care delivery.

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In the design of such a health care system, social factors such as poverty or low health literacy that may contribute to health outcomes will be conceived of as individual misfortunes that will either need to be medicalized and brought into the health care system or else left under the purview of social service organizations.

We would suggest that Sen's capabilities conceptualization of justice is the the most useful way to understand justice for ICU survivors.¹¹ Sen's conceptualization of justice suggests that we consider the social reality of the ICU survivor, that we understand well-being as their capacity to *be and do*, that we recognize the unique needs that arise from the diversity of human capabilities. A recovery health system designed with such an approach would acknowledge that different people have different needs depending on internal and external contextual factors. Internal factors include personal characteristics (eg, age or gender) and individuals' attitudes, beliefs, or coping strategies (eg, maintaining a sense of control or seeking social interaction with others). External factors include such things as availability of resources, social support, and stigma. This approach to justice invites interventions that embrace the importance of social support for overcoming some of the internal and external barriers to good recovery. Peer support, a system of giving and receiving support among people with similar experiences, is one such approach that has been studied as an intervention for ICU survivors that may have potential to address injustices for ICU survivors.¹² Multiple qualitative studies provide insights into how these programs potentially benefit patients and families by promoting resilience and increasing survivors' capacity to self-manage their health challenges through social, emotional, information, appraisal, and instrumental support.¹³⁻¹⁵

Alas, our justice obligation means that we cannot ignore the social context in which our research studies and our care are being conducted. Most of the research involving ICU survivors is being conducted in contexts where the participants are getting their basic health and social needs met. Research studies of ICU survivors will routinely exclude

participants who have social risk factors that may make it difficult for them to participate in follow-up (eg, houselessness, financial insecurity such that paying for transportation is difficult). So, for us to have a truly just recovery health system that can meet the needs of all our survivors, we must be willing to advocate for social, economic, and cultural changes that can affect the social determinants of health in our patients. With the internet and social media, ICU survivors are increasingly able to become more actively involved in consuming and producing knowledge about their health. Patients can no longer be seen as detached vessels for the care they receive; the era of patient engagement means that a just health care delivery system for ICU survivors will engage with the lived expertise of ICU survivors in any redesign or service improvement.¹⁶

Our capacity to rescue individuals from the ravages of critical illness obligates us to forge a health care delivery system of recovery in which all patients are seen as fully human and are given every opportunity to thrive.

The statements and opinions contained in this editorial are solely those of the coeditors in chief.

FINANCIAL DISCLOSURES

None reported.

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