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FROM THE INSIDE

Ableism in the intensive care unit

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In the intensive care unit (ICU), healthcare providers are faced with complex ethical dilemmas on a daily basis [1]. These dilemmas require a thoughtful approach, which is driven by well-recognized ethical principles, such as the respect for autonomy (i.e., the patient has the right to make decisions about their own care and treatment, and healthcare providers should respect their wishes and choices, unless they are medically contraindicated), beneficence (i.e., healthcare providers have a moral obligation to act in the best interest of their patients and to do what is in their power to improve their health and well-being), non-maleficence (i.e., healthcare providers should not cause harm to their patients and should strive to avoid actions that may cause injury or harm) and justice (i.e., healthcare providers should provide care that is fair and equitable to all patients, regardless of their race, gender, ethnicity or socio-economic status) [2]. These principles serve as an ethical framework for decision-making in the ICU, helping healthcare providers navigate complex challenges and make decisions that are in the best interest of their patients.

However, the ICU community has also faced some disparities in the admission policies and the allocation of ICU resources to various subgroups of patients, such as older individuals, female and/or those from diverse racial backgrounds [3–5]. Moreover, despite the concerted efforts to prevent such discrimination to happen, patients with chronic neurological disabilities might also be denied intensive care because of their perceived diminished quality of life, this issue being even more exacerbated by the recent pandemic [6]; in one study, patients with an intellectual disability were less likely to be admitted to the ICU for coronavirus disease 2019 (COVID-19) and to receive some treatments, such as non-invasive respiratory support and endotracheal intubation, than non-disable patients, even after adjustment for different comorbidities [7]. Furthermore, on top of these well-known clinical conditions, other forms of disabilities, including autism and Down's syndrome, are becoming growingly prevalent in the modern society; as most of these children are increasingly surviving to adulthood, the probability that some of them would require hospital and/or ICU admission is very high [8]. However, there is also a consistent risk that these patients could suffer from stigma and discrimination, and that an adequate level of ICU care may not be provided to them.

Ableism, a form of discrimination that treats individuals with disabilities as lesser or less valuable than those without disabilities, is a pervasive issue that extends into the healthcare system [6]. In life-threatening conditions, where patients autism and Down's syndrome could require complex and life-saving treatments, the impact of ableism could be especially harmful and influence the interpretation of the ethical principles. One of the most pernicious forms of ableism in the ICU is the assumption that individuals with disabilities are not capable of making decisions about their own care (i.e., absence of autonomy). In many cases, family members or healthcare providers assume that they know what is best for a patient with a chronic disability; this not only disrespects the patient but also undermines the relationship of trust that should exist between the patient and their care team.

Another form of ableism in the ICU is a lack of accessibility to reasonable adjustments to aid communication for individuals with disabilities. In patients unable to communicate (for example, autism spectrum disorder), this could limit the patient–healthcare interaction and patient's ability to participate in any decision-making processes. Also, the absence of specialized equipment or communication aids can lead to misunderstandings, misdiagnosis and mistreatment, which can have serious consequences for the health and well-being of these patients (i.e., difficulty communicating his/her own needs and

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experiences could result in agitation and discomfort for the patient, which are often treated with sedatives and/or analgesics). The impact of such miscommunication is the improper use of the beneficence and non-maleficence principles, as patients may not receive the care they need, leading to further health problems and decreased quality of life.

Finally, the lack of knowledge and understanding of these disabilities among most ICU healthcare providers, who often receive little to no training on these conditions, is a concerning issue. This is particularly problematic as the presence of such conditions may be wrongly perceived as a "terminal illness" or a condition univariably associated with a "poor quality of life", and the ethical principle of justice (i.e., most treatments will result in "futile or unnecessary care" with prolonged suffering) may be employed to limit admission or more aggressive therapies in the ICU to these individuals. Unfortunately, there are several examples of such situations: first, some ICUs may have specific eligibility criteria for admission, such as a certain level of cognitive function or physical ability, which may exclude individuals with disabilities from receiving life-sustaining therapies. Second, some healthcare providers may hold biases toward individuals with disabilities, which may limit their admission to the ICU. Finally, financial considerations are also a concern. The costs of providing life-sustaining therapies in the ICU can be high, and some healthcare providers may limit access to these treatments that are considered "disproportionate" with regard to the presence of disabilities. These are clear cases of discrimination against disabled patients.

To address these issues and avoid ableism, it is essential that ICU healthcare providers receive comprehensive training and education on disabilities, including autistic disorders. This training should include not only the medical aspects of these conditions but also an understanding of the social and emotional experiences of individuals with disabilities. This approach should not lead to "overtreatment" of such patients; instead, it emphasizes the importance of properly assessing the influence of chronic disabilities on the patient's therapeutic requirements, challenges and likelihood of survival to tailor reasonable care. In addition, ICU physicians should try to create an inclusive and accessible environment for patients with disabilities, taking steps to accommodate their unique needs and ensuring that they receive appropriate care and support, to ensure loyalty and commitment in clinical management, professionalism, compassion, empathy, as for other ICU patients without disabilities. Standards for supporting communication need be set by the ICU healthcare professionals to facilitate interactions with patients affected by speech and/or hearing disorders, as in those with a tracheostomy. Some of these patients, alone or with the help of their families, may have advance directives that specify their wishes regarding life-sustaining therapies in the event of a medical emergency, which should be respected as for other patients, and according to national legal issues. A person-centered approach to care, considering patient's dignity and preferences should be upheld at all times. Ultimately, promoting access to healthcare professions for individuals with disabilities may contribute to a cultural shift and the potential development of tailored training approaches within our community.

As a father of a 11-years old boy with severe autism, I hope that a better understanding of patients with disabilities will not only help to break down barriers and promote equality but also help to address the importance of disability rights and advocacy in our society.

Declarations

Conflicts of interest
I have no financial conflict of interest.

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