

Ableism and Quality of Life During the Coronavirus Pandemic

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Michael Hickson was a 46-year-old with a severe acquired disability whose COVID-19 course involved multisystem organ failure, a court-appointed guardian, hospice care, discontinued fluids and tube feeds, and eventual death. While some details have been released by the hospital,¹ the recorded conversation between Mr. Hickson's wife and a treating physician has been shared widely in disability communities.

Physician: "Right now, his quality of life—he doesn't have much of one."

Spouse: "What do you mean? Because he's paralyzed with a brain injury, he doesn't have a quality of life?"

Physician: "Correct."

PHYSICIANS' PERCEPTIONS OF PERSONS WITH DISABILITIES

As physiatrists—physicians for patients with disabilities—we heard those words with heavy hearts and sunken stomachs. We can only imagine the anger, fear, and betrayal felt by our patients and other people with disabilities. Or perhaps they feel vindicated, that the quiet sentiments were finally said out loud. The recording expresses what people with disabilities long suspected: physicians don't always value the lives of persons with disabilities the way they value the nondisabled. Research confirms this.²⁻⁴ The privilege of the nondisabled is often expressed as "I would never want to live like that." People make personal judgments about how they would feel in somebody else's situation. The usually quiet sentiment, this time said aloud and recorded—"He doesn't have much [quality of life]"—showed how physicians' judgments and biases can have a grave impact on others, especially people with disabilities.

Stereotypes, assumptions, and biases about the quality of life of people with disabilities are pervasive throughout health care, resulting in the devaluation and disparate treatment of people with disabilities.⁵ Healthcare providers are not exempt from deficit-based perspectives about people with disabilities,⁶ and discrimination ensues when healthcare providers make critical decisions from these perspectives.⁵ Ableist biases are underrecognized among physicians, who often misper-

ceive quality of life for people with disabilities as poor, and fail to recognize that medical judgments can be biased accordingly.⁵ Consequently, necessary care can be withheld or withdrawn inappropriately.⁵ An estimated 25% of adults in the United States self-report disability; furthermore, disability is highly correlated with age as well as socioeconomic disadvantages.⁷ There is also extensive evidence that, as a population, people with disabilities experience healthcare disparities.⁸ Bias against people with disabilities serves to both restrict and reduce access to healthcare.⁹

The consequences of the pandemic have disproportionately affected the Black community, in terms of both economic and disease burden. Mr. Hickson, a Black man with disabilities who contracted COVID-19, personifies the intersection of race and disability and demands our concern and attention as physicians. We must appreciate the intrinsic worth of all people and populations, and seek to understand and respect their capacity to be active agents in their own lives, making their own decisions about their quality of life. The lives of Black people have value, but movements such as Black Lives Matter have been needed to highlight this truth, and there still needs to be meaningful action beyond rhetoric. The lives of people with disabilities have value. Healthcare systems and providers similarly need to acknowledge and act in a way that honors the intrinsic worth of people with disabilities.

People with disabilities face long-standing systemic barriers to equitable healthcare,¹⁰ as do Black people. During the pandemic, widespread alarm was raised about individual and structural racism in medicine, just as numerous disability rights organizations raised concerns that ableism would lead to undertreatment during the COVID-19 crisis, worsening existing healthcare inequities. In response, the US Department of Health and Human Services Office for Civil Rights in Action released a bulletin that stated, "In this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else."¹¹ Using the presence of disabilities to limit or deny a person's access to health care constitutes a clear violation of nondiscrimination law.¹² Hospitals and providers should not limit the care offered to people with disabilities because of their disabilities or utilize quality-of-life judgments when deciding whether or not to provide care.¹² While the hospital where Michael Hickson died released a statement

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claiming that they did not consider his disability status as part of their treatment decision-making, the recorded words of the physician suggest otherwise.

The impact of our words and actions, and not the underlying intent, most affects patients', families', and communities' trust in the institution of medicine, represented by individual providers. The hospital statement indicated "it was not medically possible to save [Mr. Hickson]."¹ The phrase "not medically possible" ties Mr. Hickson's case to one of futility; however, the recording was about quality of life, not futility. The National Council on Disability found that subjective quality-of-life assumptions influence medical futility decisions.⁵ While the intent of withdrawing care from Mr. Hickson may have been related to futility, the consequences of this decision are far-reaching as people with disabilities have reason to question whether someone else's judgment about the quality and worth of their life will lead to loss of their life.

Emphasizing perceived quality of life in making treatment decisions, as was implied for Mr. Hickson, is not a rare event and is one that is likely more common when health systems are stressed. Despite having policies and procedures to follow, biases creep into treatment decisions. In Oregon, for example, multiple cases of disability discrimination during the pandemic were brought to the attention of the state Senate by Disability Rights Oregon.^{13,14}

ADVOCATING FOR A DISABILITY INCLUSIVE COVID-19 RESPONSE

Physicians and healthcare leaders must consider the unique needs of the disability community through health equity efforts in the COVID-19 response. There must be universally accessible approaches when planning and implementing a COVID response to increase impact and ensure systems are reaching all underserved communities. For healthcare institutions and hospitals, disability equity must be emphasized in the development and implementation of COVID-19 policies. The exclusion of people with disabilities from decisions about people with disabilities is problematic. This systemic exclusion means that ableist beliefs and policies are often unchallenged.¹⁵ Including people with disabilities on committees creating crisis standards of care protocols or other policies that may purposefully or unintentionally discriminate against people with disabilities is an important step.¹⁶ Representation matters, and people with disabilities must be central in the development of all health equity strategies during a pandemic. Furthermore, when system-level decision algorithms exist that value the life of people with disabilities, clinician biases are minimized, leading to more equitable care.

Examples of strategies include accessible formats for essential COVID-19-related communications, such as American Sign Language, large print, or screen reading technology. We must acknowledge that necessary universal mask policies can generate communication barriers for people reading lips. Hospitals and clinics have rapidly expanded virtual care and telemedicine to improve access. This has enhanced access to care for many people with mobility disability, but can exacer-

bate disparities for those with vision, hearing, communication, or intellectual disability. To better manage this issue, tailored strategies, such as live closed captioning or digital patient navigators, can be implemented.

Additionally, a person with a disability has the legal right to be accompanied by a designated essential support person. Hospital visitor policies must become less restrictive or enable exceptions when a person with a disability requires their personal care attendant. When it comes to outcome data, it is important to highlight the need for better collection of disability data that can be used to identify inequities as well as monitor outcomes of treatment.

As previously acknowledged, people without disabilities tend to have negative attitudes (both implicit and explicit) toward people with disabilities. These attitudes are reinforced by societal-level institutions, policies, and structures that marginalize people with disabilities.¹⁷ We call on all physicians and those working in healthcare to question their biases. When you consider quality of life in your decision-making, ask yourself, "whose life?" Recognize and honor the personal, social, and cultural contexts that affect how an individual experiences "quality of life." Unless the answer to "whose life?" is your own or that of your incapacitated dependent, it is not your place to make "quality of life" judgments. You can and should describe potential outcomes at the physiological or activity level, but leave quality-of-life decisions where they belong—with the individual or their designated representative.

Social media activity in the disability community indicates that Mr. Hickson's story is perceived, regardless of the provider's and healthcare system's intentions, to be yet another breach of trust by the medical system. It is not the burden of the oppressed and betrayed to repair a broken relationship. It is our obligation, as individual physicians and the greater medical institution, to provide care that demonstrates the value and worth of people with disabilities. An imperative step toward equitable care for people with disabilities is to recognize and address our ableist biases.

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