

Speaking up to give voice to the severely disabled

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Marie-Christine Nizzi, research associate in cognitive science. Credit: Perry Smith

The question of who speaks for patients with traumatic brain injuries when considering medical decisions is the subject of a commentary in the *American Journal of Bioethics Neuroscience* by Marie-Christine Nizzi, a research associate in the Program in Cognitive Science.

"Patients with severe physical impairments often report good quality of life, but their opinions are routinely disregarded because of their conditions," Nizzi says.

The debate over [medical care](#) for the severely disabled focuses on whether [patients](#) are best positioned to report on their own quality of life, or whether doctors, policymakers, and the public are better qualified to speak for patients.

According to the paper—"Can We Trust Patient-Reported Outcomes?"—healthcare policies are determined, in part, from large opinion surveys of the able-bodied public or physicians, which tend to assume these patients do not have good lives.

"This is known as the disability paradox," Nizzi says. "Third parties underestimate the quality of life

experienced by patients. This paper advocates to include patients' voices to reduce bias in policies that directly affect the patients."

In the paper, Nizzi rebuts common arguments used to cast disabled patients as "less-than-credible witnesses." Such arguments claim that patients only report good quality of life because they fail to understand the severity of their condition or because a positive response might earn them additional resources.

According to Nizzi, the belief that other people know more about the life satisfaction of patients than the patients themselves is a misconception that dominates decision-making, particularly when it comes to expensive medical interventions.

"This one-sided view of what constitutes relevant expertise belongs to an outdated model of medicine," said Nizzi in the paper. "As we move towards precision medicine, disregarding the patient's expertise in their subjective experience perpetuates an ineffective one-sided view of expertise which has been found to damage patient satisfaction, trust, and adherence."

Much is at stake, according to Nizzi. The mistrust of patient self-reporting directly influences the attitudes of medical professionals, their clinical recommendations to patients' families, and their expert opinion when informing healthcare policies.

"These biases perpetuate the misconception that by combining one-sided expertise with third-person objectivity, one could altogether dispense with the patients' input," she says. "Specialists in the field already know that most patients with severe disability report good quality of life, but this knowledge has not penetrated the public opinion yet."

The article argues that the healthcare relationship between doctor and patient should move away from

being a "tutelage" toward being a partnership, where a physician's technical expertise is informed by the patient's report on their own thoughts, feelings, and sensations.

"When health care policies rely on prejudice, people die," says Nizzi.

The open peer commentary is in response to research previously published in *AJOB Neuroscience* on [ethical issues](#) in the allocation of novel, and costly, health care resources to patients with disorders of consciousness.

Nizzi, an expert in medical humanities, says she wrote the piece to stake out a moral position on how society should approach decisions on people's lives. "We need to listen and change policies accordingly. We can all be on the receiving end of a specialist who dismisses our subjective experience," she says.

Nizzi's other research is exploring the subjective experience of free will and agency in patients who recover from disorders of consciousness, but are left paralyzed and voiceless.

More information: Marie-Christine Nizzi. Should We Trust Patient-Reported Outcomes?, *AJOB Neuroscience* (2021). [DOI: 10.1080/21507740.2021.1904040](#)

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