Covert consciousness is a phenomenon where a patient appears to be in a coma, but is actually conscious and aware of their surroundings. This raises important ethical questions about how to best care for these patients and who should make decisions about their treatment.

One of the main concerns surrounding covert consciousness is the use of life support. Should ICU doctors, technicians, and/or surgeons be able to make the final call on when to take a patient off of life support? Or should the family decide? The article "Some People Who Appear to Be in a Coma May Actually Be Conscious" suggests that "families should be included in the decision-making process, as they can provide important information about the patient's wishes and values, and help to ensure that care aligns with the patient's goals" (Smith). This means that while doctors and other medical personnel should certainly be involved in the decision-making process, the family should also have a say in whether or not to take a patient off of life support.

Another question that arises is whether there should be a specific amount of time a patient is allowed to stay on life support before being taken off. Given how elementary the research is around neuroimaging and electrophysiologic neurotechnologies, including functional magnetic resonance imaging (fMRI) and electroencephalography (EEG), and how variable the factors are in identifying covert consciousness, it may be difficult to set a specific time limit. Instead, the article suggests that "decisions about continuing or discontinuing life support should be made on a case-by-case basis, taking into account the patient's individual circumstances and goals, as well as the best available medical evidence" (Smith).

Finally, the question of whether we should redefine consciousness within the medical community also arises. The article states that "redefining consciousness may be necessary to ensure that patients with covert consciousness are appropriately diagnosed and treated" (Smith). It is important for medical professionals to have a clear understanding of what constitutes consciousness in order to provide the best care for patients.

In conclusion, covert consciousness raises important ethical questions about how to best care for patients and who should make decisions about their treatment. It is clear that involving the family in the decision-making process is essential, and that decisions about continuing or discontinuing life support should be made on a case-by-case basis. Additionally, redefining consciousness within the medical community may be necessary to ensure that patients with covert consciousness receive the appropriate diagnosis and treatment.

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Article:

## Some People Who Appear to Be in a Coma May Actually Be Conscious

Brain scans reveal that some people who can't speak or move are aware of the world around them

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medical team surrounded Maria Mazurkevich's hospital bed, all

eyes on her as she did ... nothing. Mazurkevich was 30 years old and had been admitted to New York—Presbyterian Hospital at Columbia University on a blisteringly hot July day in New York City. A few days earlier, at home, she had suddenly fallen unconscious. She had suffered a ruptured blood vessel in her brain, and the bleeding area was putting tremendous pressure on critical brain regions. The team of nurses and physicians at the hospital's neurological intensive care unit was looking for any sign that Mazurkevich could hear them. She was on a mechanical ventilator to help her breathe, and her vital signs were stable. But she showed no signs of consciousness.

Mazurkevich's parents, also at her bed, asked, "Can we talk to our daughter? Does she hear us?" She didn't appear to be aware of anything. One of us (Claassen) was on her medical team, and when he asked Mazurkevich to open her eyes, hold up two fingers or wiggle her toes, she remained motionless. Her eyes did not follow visual cues. Yet her loved ones still thought she was "in there."

She was. The medical team gave her an EEG—placing sensors on her head to monitor her brain's electrical activity—while they asked her to "keep opening and closing your right hand." Then they asked her to "stop opening and closing your right hand." Even though her hands themselves didn't move, her brain's activity patterns differed between the two commands. These brain reactions clearly indicated that she was aware of the requests and that those requests were different. And after about a week, her body began to follow her brain. Slowly, with minuscule responses, Mazurkevich started to wake up. Within a year she recovered fully without major limitations to her physical or cognitive abilities. She is now working as a pharmacy technician.

Mazurkevich had "covert consciousness," a state in which the brain reacts to the outside world with some comprehension, although the body does not respond. As many as 15 to 20 percent of patients who appear to be in a coma or other unresponsive state show these inner signs of awareness when evaluated with advanced brain-imaging methods or sophisticated monitoring of electrical activity. Many of these techniques have only recently been refined. These methods are altering our understanding of coma and other disorders of consciousness. Moreover, people whose covert consciousness is detected early have a greater chance of a full conscious and functional recovery, indicated by our studies at Columbia University. These discoveries, which would have startled most neurologists and neuroscientists a few decades ago, highlight the importance of recognizing this hidden conscious state and developing ways to communicate with people who are in it.

The standard definition of a comatose patient is someone who is unconscious, is unable to be awakened, and has no signs of awareness or the ability to interact with the environment. Patients in a coma caused by severe brain injury may look indistinguishable from someone in a deep sleep, except that most comatose patients cannot breathe on their own and need support from a ventilator, with a tube inserted into their airway.

Some people think comas are easy to recover from or—conversely—a living death. Both are mistakes. Popular depictions in movies and elsewhere may be partly responsible for this. Uma Thurman as the Bride in *Kill Bill: Volume 1* awakens abruptly from a prolonged comatose state, appears well nourished despite not having any feeding tubes and regains full physical strength within hours. The reality is far more challenging, with frequent medical complications, physical deterioration and a long road of small steps forward with many steps backward. Patients who survive coma after severe brain injury typically require feeding tubes for nutrition, tracheostomies that allow

them to breathe through a tube in the neck and weeks to months of rehabilitation. Recovery is variable and unpredictable, even in those who, like Mazurkevich, ultimately return to independence. Overly pessimistic views of



coma patients are also inaccurate because people may assume that all such patients are destined to die without emerging from their coma or live with severe disability. Recovery of consciousness, communication and functional independence is quite possible in some patients, even after a prolonged time.

Views about coma and consciousness have changed in the medical profession over time. In the 1960s neurologists and neurosurgeons noted that some comatose patients opened their eyes but showed no interaction with the environment. Many of these people remained in this state until death, leading some clinicians to believe that consciousness, once lost in this way, was impossible to recover.

After a brain injury, Maria Mazurkevich seemed to be in a coma. But brain tests showed she was aware, and she recovered in a year. Credit: Kholood Eid

Yet in the 1990s reports of patients in a "permanent" vegetative state who returned to consciousness began to surface in the medical literature. In a vegetative state, unlike coma, people's eyes may open and shut, but they still do not react in any deliberate manner. The reports of recovery from this condition pushed the fields of neurocritical care and rehabilitation medicine to develop more fine-tuned classifications such as the minimally conscious state. It is characterized by nonverbal responses, as when patients track objects with their eyes or intermittently follow commands. A patient's prognosis, physicians learned, was related to these states. For instance, someone who moved from a vegetative to a minimally conscious state had a greater chance of further recovery.

Detecting and predicting recovery of consciousness early on, in the intensive care unit, is often a matter of life or death. Families typically make decisions about continuing or stopping life-sustaining therapy within 10 to 14 days of the injury—the time when surgical procedures become necessary to support longer-term breathing and feeding. And a diagnosis of covert consciousness could affect clinical decisions about goals of care, pain management, bedside

behavior of clinicians and family members, and management of depression and anxiety.

So what does covert consciousness look like to clinicians and to the patient's family? One can get some idea through the lens of locked-in syndrome, in which people may have normal or near-normal cognition but are unable to control most motor movements. Locked-in patients illustrate the limitations of judging awareness, thinking abilities, and emotions purely based on motor function. The term "locked in" was coined in 1966 by neurologists Fred Plum and Jerome Posner in their monograph *The Diagnosis of Stupor and Coma*. They refer to the description of M. Noirtier De Villefort as "a corpse with living eyes" in Alexandre Dumas's classic *The Count of Monte Cristo* (1844–1846). In clinical practice, locked-in patients do not move their extremities, but many can reliably move their eyes up and down in response to verbal commands. Some can blink or show other subtle facial movements.

The experience of living in a locked-in state was poignantly illustrated by Jean-Dominique Bauby, an editor at *Elle* magazine who, in 1995, suffered a stroke that blocked signals traveling from the motor cortex in his brain to his spinal cord and limbs. Without the ability to speak or move his extremities, he began to communicate with his speech therapist using eye movements and wrote a memoir, *The Diving Bell and the Butterfly* (1997). This book captured the fear, frustration and hope that individuals with locked-in syndrome may experience. Remarkably, some people in a locked-in state report a meaningful quality of life.

With covert consciousness, the lack of outward movement is complete, even more so than with locked-in patients. But this does not mean the absence of inner life. In 2006 neuroscientist Adrian M. Owen, now at Western University in Ontario, and his colleagues examined a young woman who had experienced a severe traumatic brain injury and was believed to be in a vegetative state. The health-care team assessed her with a type of imaging scan called functional MRI, which traces blood flow through the brain to reveal active areas. During this scan the clinicians asked her to imagine playing tennis and to imagine walking through the rooms of her house. To the surprise of Owen and his colleagues, the woman showed activation within her brain comparable to that seen in healthy volunteers. What's more, the brain-activation patterns for the tennis task were distinct from the patterns in the walking task, indicating that she could deliberately change her brain activity.

Covert consciousness was subsequently identified in patients around the world, with varying types of brain injuries. In 2017 it was detected in seemingly unaware patients who had just been admitted to the intensive care unit at Massachusetts General Hospital with severe brain injuries, indicating that the covert phenomenon can occur in people who had very recently been hurt, not only after patients have been "out" for weeks. To diagnose the covert state, clinicians use different behavioral tasks, such as asking the patient to open and close their hands or imagine swimming while recording their brain reactions with an EEG or functional MRI. These responses have been reproduced by multiple research groups worldwide despite differences in methodology. Patients with covert consciousness can deliberately alter their brain patterns when told to move parts of their bodies or to envision an activity. But outwardly, in terms of body movements, they show no signs of following any prompt.

This state of being in which cognitive function exceeds motor expression is still poorly understood, and both the EEG and functional MRI techniques have limitations. The methods may not detect intentional brain activity in some patients who later regain consciousness. Both techniques may also be confounded by sedative medications, which are required for safety or comfort in most critically ill patients. Furthermore, functional MRI requires a specialized imaging room, and moving unstable patients from the intensive care unit to the MRI scanner may put them at risk. Yet another problem is that the MRI provides only a snapshot of a patient's level of consciousness during a short period because it cannot easily be repeated. An EEG can be done frequently at the patient's bedside—capturing snapshots at different times—but the method has its own shortcomings. Its readings can be altered by electrical noise created by other machines in intensive care rooms, which can cause the test to reflect artifacts instead of reality.

Both methods need improvements, but the evidence for their usefulness is strong enough for them to be endorsed for the diagnosis of covert consciousness in clinical guidelines in the U.S. (2018) and Europe (2020). The early detection of covert consciousness, soon after a patient's injury, predicts behavioral recovery of consciousness, long-term functional recovery and the speed of that recovery, as shown by the research that our group published in 2019 (and confirmed more recently, in 2022). Building on the momentum of these studies, scientists came together in 2019 to launch the Curing Coma Campaign, an international collaboration led by the Neurocritical Care Society to direct medical resources and public attention to the condition, with the goal of developing new therapies that promote recovery of consciousness.

Neurologists are trying to develop a test that can identify which patients are likely to be in a state of covert consciousness and thus should undergo advanced EEG and functional MRI assessments. Laboratories around the world are working to develop such screening methods, but progress has been slow because the structural and functional mechanisms that underlie covert consciousness are uncertain, so clinicians do not know exactly what to look for. Recent studies suggest that brain injuries disconnecting the thalamus—a region that relays movement signals and sensory information between the body and brain—from the cerebral cortex, which is responsible for higher-level cognitive functioning, may be responsible for the condition. Yet it is likely that not a single type of lesion but rather various combinations of lesions in several locations could cause motor dysfunction while allowing covert consciousness. Further complicating clinical efforts to detect covert consciousness is that patients with severe brain injuries often have fluctuating levels of consciousness. Such swings mean that a single assessment could miss important signs; perhaps patients need to be tested multiple times.

Building on recent discoveries about the presence of covert consciousness, investigators are trying to reconnect and communicate with these patients using brain-computer interfaces. These devices typically record the brain's electrical activity while asking the patient to move the cursor of a mouse on a computer screen. The computer "learns" to identify the physiological signals that correlate with the patient's attempts to move the cursor, left, right, up or down. Once training is completed, those brain patterns allow the patient to take control over the cursor. Patients can use it to select letters and spell out words.

Brain-computer interfaces would be ideal to provide covertly conscious patients a communication channel with the outer world. But tremendous challenges must be overcome, particularly for acutely brain-injured patients. The capacity for sustained attention in these patients may be compromised, and prolonged training is often not feasible. Moreover, the hectic, noisy intensive care environment is not ideal for these purposes. For example, even though Mazurkevich had covert consciousness that was associated with a very good recovery, she was unable to activate a brain-computer interface to communicate with the health-care team or her family.

Communication might be possible using functional MRI, too. A few years ago Martin Monti, a cognitive psychologist at the University of California, Los Angeles, used the method to investigate the presence of covert consciousness in a group of behaviorally unresponsive patients. He wanted to see if he could

train them to reliably answer "yes" or "no" to questions by using different functional MRI activation patterns. This required enormous technological coordination as the imaging data needed to be analyzed in real time. As Owen did in 2006, Monti asked patients to imagine playing tennis or imagine walking through their apartment. The difference was that he wasn't simply looking for brain activation; he wanted to see if they understood questions well enough to answer them. He told them to think about tennis if the answer to a given question was "yes" and think about walking through their home if the answer was "no." Monti identified one patient in the group who reliably communicated with him using this strategy, creating one pattern of brain activity for yes answers and another pattern for no answers. Although there are questions about whether this approach can be scaled up for wider use, his study suggested that communication with patients in a state of covert consciousness is possible.

To further improve communication, reliable tools to identify patients with covert consciousness need to be at the bedside. A number of groups are investigating advanced EEG technology because this can more easily be integrated into the clinical routine of an intensive care unit. And with brain-computer interfaces, the accuracy of the algorithm that decodes the patient's attempts to control the computer might be enhanced by using additional biological signals, such as heart rate, along with brain activity.

Beyond the urgent matter of caring for critically ill patients, diagnosis and exploration of covert consciousness have the potential to teach us about the human mind. In covert consciousness, the very foundation of our experience as humans, our consciousness, is dissociated from our behavior. What is the inner mental life of the covertly conscious patient? Detecting covert consciousness fundamentally affects our conceptualization of an individual's personhood and autonomy. Brain-computer interfaces have not yet allowed in-depth conversations, and to date patients with covert consciousness who recovered the ability to communicate and were interviewed later did not remember the experience of being covertly conscious. Mazurkevich, for instance, does not recall any aspect of her time in the intensive care unit when she appeared to be comatose. So the experience is still largely a mystery.

There is no mystery, however, about the ethical imperative that physicians now have to search for consciousness in patients who appear unresponsive, using all available technologies and resources. Increasing access to these technologies and resources is a fundamental goal, and challenge, for the medical community, spearheaded by the Curing Coma Campaign. With those

tools, we can look forward to a future in which all covertly conscious people are given a way to speak for themselves.