Brain-activity device could give a voice to 'locked-in' patients

Paralysed able to reply yes or no to doctors' questions Four patients in trial said they were 'happy' with life

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Doctors have used a brain-reading device to hold simple conversations with "locked-in" patients in a procedure that promises to transform the lives of people who are too disabled to communicate.

The technology allows the paralysed patients – who have not been able to speak for years – to answer "yes" or "no" to questions through the detection of telltale patterns in their brain activity.

Three women and one man, aged 24 to 76, were trained to use the system more than a year after being diagnosed with complete locked-in syndrome (CLIS). The condition was brought on by amyotrophic lateral sclerosis (ALS), a progressive neurodegenerative disease that leaves people paralysed but aware and able to think.

"It's the first sign that completely locked-in syndrome may be abolished forever, because with all of these patients, we can now ask them the most critical questions in life," said Niels Birbaumer, the neuroscientist who led the research at Tübingen University.

"This is the first time we've been able to establish reliable communication with these patients and I think that is important for them and their families," he added.

"I can say that after 30 years of trying to achieve this, it was one of the most satisfying moments of my life when it worked."

All of the patients, who are fed through tubes and kept alive on ventilators, are cared for at home by family members. To train the patients on the system, doctors asked them to think "yes" or "no" in response to a series of simple questions, such as "Your husband's name is Joachim" and "Berlin is the capital of France".

During the sessions, the patients wore a cap that uses infrared light to spot variations in blood flow in different regions of the brain. As they answered the questions, a computer hooked up to the cap learned to distinguish the blood-flow patterns for "yes" and "no" in each patient.

When the patients scored at least 70% on the training questions, the questions became more personal, including quality of life. Perhaps unexpectedly, all four indicated they were "happy" with life, suggesting that locked-in syndrome may not be the living hell many presume it to be.

But while the renewed ability to communicate with the world was a boon for the patients and their carers, not all of the answers went down well. One patient was a 61-year-old man whose 26-year-old daughter asked whether she should marry her boyfriend, “Mario”. Her father said “no” nine times out of 10. “She went ahead anyway,” Birbaumer said. He did not ask if she regretted posing the question.

The findings, reported in the journal PLOS Biology, do not mean that all lockedin patients are content with life. The four patients studied had all chosen to be kept alive on a ventilator after their breathing failed, a decision that suggested they did not wish to die. Only a small percentage of CLIS patients who are moved on to ventilators survive the transition. “We have never had a patient who survived outside family care,” Birbaumer said.

But patients with locked-in syndrome have reported a good quality of life before, even matching that of healthy people of the same age. Birbaumer said the reasons were unclear, but he wondered if patients become focused on the good social interactions around them, and even experience something akin to a state of meditation. “We find that they see life in a more positive way,” he said.

For his next project, Birbaumer wants to build a system that lets patients communicate more proactively. In the 1990s, the French journalist Jean-Dominique Bauby, who became locked-in after a stroke, dictated his bestselling memoir, The Diving Bell and the Butterfly, by blinking his left eye to select letters from the alphabet. Birbaumer believes a system that reads brain activity could achieve the same ends for completely locked-in patients who cannot even move their eyelids.

Adrian Owen, a neuroscientist at the University of Western Ontario in Canada, has been exploring whether the same technology, known as functional nearinfrared spectroscopy, or fNIRS, can be used to communicate with other kinds of brain-injured patients, including those presumed to be in a vegetative state.

“The results of this study suggest we are on the right track,” he said. “Finding a portable, cost-effective and reliable means for communicating with patients who are entirely physically non-responsive is the holy grail for those of us working in this field. If these findings can be replicated in a larger group of patients they suggest that fNIRS may be the answer.

“One of the most surprising outcomes of this study is that these patients reported being ‘happy’ despite being physically locked-in and incapable of expressing themselves on a day-to-day basis, suggesting that our preconceived notions about what we might think if the worst was to happen are false. Indeed, previous research has shown that most locked-in patients are actually reasonably satisfied with their quality of life.”