# **Fabricating Communication**

# The Case of the Belgian Coma Patient MAARTEN BOUDRY, ROELAND TERMOTE, AND WILLEM BETZ

ecent tests by the Belgian skeptical organization SKEPP have confirmed that the "facilitated communication" (FC) with Rom Houben, a Belgian man who was allegedly trapped in his paralyzed body for twenty-three years, was fictional (see "Miracle Coma Patient's Story Told via Facilitated Communication," SI, May-/June 2010). Neurologist Steven Laureys of the University of Liège and his team, who presented Houben's case to the international press in November

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2009, seem to have rushed to premature conclusions. Bearing in mind FC's deservedly bad reputation, they should have known better.

## The Miraculous Case of Rom Houben

In November 2009, the miracle story of Rom Houben, forty-six, made international headlines. In 1983 Houben was involved in a car accident, and his brain was deprived of oxygen for several minutes. Doctors had diagnosed Houben as being in a persistent vegetative state (PVS), a classification used for patients who are wakeful yet suffer from severe brain damage and show no signs of conscious awareness. However, on PET scans of Houben's brain taken three years ago, his treating neurologist Laureys claimed to have found signs of consciousness. Laureys, who has published research in the New England Journal of Medicine (NEJM) and BMC Neurology, is an acclaimed expert in coma and disorders of consciousness. In his latest study published in NEJM, Laureys and his colleagues (Monti et al. 2010) have shown that a small percentage of patients diagnosed as being in a persistent vegetative state still show forms of preserved cognition under the scanner.

Ever since the PET scans of Houben's

brain, Laureys's team has tried several methods to establish contact with him. At first, according to Laureys, Houben was able to answer simple yes or no questions by pushing buttons with his toes, which were not completely paralyzed. Due to his spastic paralysis, however, the method proved unreliable. Afterwards, still according to Laureys, Houben learned to type on a simple keyboard and was eventually able to fully express his thoughts and type elaborate sentences with the help of a so-called "facilitator." This is a trained assistant who guides the patient's hand along a keyboard, trying to feel and amplify his or her minute willful movements. All over the world video footage showed Houben and his facilitator jointly typing elaborate messages with one of Houben's fingers.

However, the method of FC has long been discredited. Controlled experiments have consistently demonstrated that not the patient but the facilitator is directing the "conversation" (Wheeler et al. 1993; Felce 1994; Twachtman-Cullen 1997). FC has in the past been used to tap into the minds of autistic or mentally retarded children, but this led to false allegations of abuse and other unfortunate complications. In 1994, the American Psychiatric Association issued a statement denying the scientific validity of FC, stating that "facilitated communication is a controversial and unproved communicative procedure with no scientifically demonstrated support for its efficacy."

#### **Skeptical Reactions**

On the basis of FC's dubious reputation, as well as the distributed video footage of Houben, skeptics and scientific authorities all over the world immediately expressed strong doubts about the case. For example, on his blog Neurologica, Yale neurologist Steven Novella noted that "it seems impossible that someone with his level of paralysis, and years of inactivity, would be able to type so quickly with just a little 'support." Moreover, Houben was hardly looking in the direction of the keyboard, and on some videos it is clear his eyes were completely closed. Not even a fully conscious person with no neurological damage can blindtype whole sentences with one finger. Experiments have shown that experts in blind-typing can orientate themselves on a keyboard only if they use at least two fingers. That is why keyboards have little nibs on some of the keys to give typists reference points. On the video footage of Houben's FC, however, his hand was in a brace, which leaves him with little or no sensory feedback.

In brief, the spectacular story was completely implausible on its face, even after a cursory examination of the basic facts and the available video footage. Moreover, a straightforward and simple experiment would have sufficed to check this out, as SKEPP and other critics immediately pointed out.

However, Laureys assured the international press that the method was reliable. For example, in *The Times* of London (November 25) Laureys claimed that while initially skeptical, he had convinced himself of FC's reliability by a series of controlled tests: "I showed

[Houben] objects when I was alone with him in the room and then, later, with his aide, he was able to give the right answers. . . . It is true." On the same day in *Der Spiegel*, Laureys commented that "naturally, I tested him to rule out the possibility that it's actually the speech therapist doing the writing." A few days later, when skeptics and scientific authorities all over the world had already questioned the case, Laureys backtracked somewhat, distancing himself from FC and telling the press that "further tests were required." By then, however, the

minute movements of the eyes or any other body part had failed.

Houben's habitual facilitator, Linda W., featured in the video footage in November, was not available for the test. Consequently, the director of a Flemish institute for "alternative communication" (Anne C.), who trained several facilitators working with Houben, acted as the facilitator ad interim. Interestingly, Laureys told the media afterwards that when he asked Houben (through Linda W.) whether he was willing to cooperate in a test, (s)he always gave the same reply: "I



Rom Houben hardly looks at the keyboard as he types with the "help" of his facilitator.

news of Houben's miraculous rebirth after twenty-three years had already circulated the globe.

#### **Controlled Tests with SKEPP**

At the request of the medical institution where Houben is cared for, on February 4, 2010, a SKEPP delegation (W. Betz and J. Torfs) was present to advise at a long overdue test of FC. We also conducted our own tests. We were surprised to learn from the institute's staff that over a period of two years all attempts to establish any form of communication with the patient by detecting and coding

don't trust you [scientists]." After looking for another facilitator for a year and a half (which raises the question of how Laureys performed tests in November 2009), Laureys and his team finally found Anne C. Through her "facilitation," Houben suddenly changed his mind and agreed to put FC to the test. If there had been any lack of reasons for skepticism, this observation alone would have sufficed to discredit the whole affair.

At the beginning and at the end of our trials, we tried to make normal conversation with Houben, and the FC seemed to work perfectly fine, producing intelligible and sometimes even elaborate sentences. In one test, we asked the facilitator to leave the room while we showed Houben a large printed word, which we read aloud to him several times. The facilitator was then allowed to return and assist Mr. Houben in giving the word back to us. Although a well-formed word, the resulting answer was completely wrong. We tried the same test with a large and simple drawing, which yielded identical results. In another test, we shielded the

Psychologists have found that the apparent communication by means of FC is an artifact of "action projection," in which the self-deceived facilitator is attributing his own unconscious movements to the patient. In a study into the psychological aspects of FC, Wegner, Sparrow, and Fuller (2003) subsume this effect under the phenomenon of "uncontrolled intelligence." This refers to the production of intelligent acts in the absence of any conscious intention to do so, or even contrary to one's own inten-

Facilitators typically express the strong conviction that the patient is the true author of communication in FC.

keyboard from the facilitator's view in the midst of an answer. Immediately, the typing changed into gibberish and soon halted completely. After the tests by SKEPP, a psychologist and assistant of Laureys gave Houben a set of headphones and asked him to type the words he alone could hear. The results were uniformly negative: the FC method was not tapping the thoughts of the patient at all but only the imagination and expectations of the facilitator.

### The Psychology of FC

Facilitators typically express the strong conviction that the patient is the true author of communication in FC. After the failed tests, Linda W. retained faith in the method, arguing that FC often produced information that she was unaware of and that Houben sometimes engaged in philosophical discussions with visiting friends that she could not even understand. It seems unlikely that facilitators like Linda W. are all lying, and there might be more subtle psychological mechanisms at work here.

tions. In one experiment, subjects who were instructed to answer a set of questions in an entirely random fashion still tended to give correct answers and afterward denied the influence of their knowledge.

According to Wegner et al., the mere fact that the facilitator's subtle movements coincide with possible movements of the patient suffices to significantly reduce the sense of personal authorship. In addition, the physical proximity to the patient further blurs the distinction between self and other. To be sure, facilitators still receive sensory feedback for their own finger movements, yet this is insufficient to compensate for the illusion that the patient is directing the communication. Researchers also found that an increased belief in the effectiveness of FC enhanced the projection of authorship to the communicator. They argue that, for facilitators, belief in FC provides a context for interpreting the effects of "uncontrolled intelligence."

In another experiment, Wegner et al. provided both facilitators and (healthy) communicators with headphones but asked questions only to the facilitators. Despite the fact that the communicators could not hear anything, communication performances still rose above the chance level. Moreover, easy questions were answered correctly more often than difficult questions, which is consistent with the hypothesis of (unconscious) intelligent action.

Facilitators often unconsciously draw from knowledge they have developed about their patients through their intimate relationships with them. Interestingly, many facilitators do admit that they sometimes intervene deliberately in the process of communication (Twachtman-Cullen 1997). Sometimes they start to type the first letters of a word to "get the patient going" or finish a sentence because they "get the gist already." By doing so, facilitators may eventually produce elaborate sentences while still retaining the conviction that none other than the patient is doing the communication.

#### The Aftermath

When conducting our experiments in February, our intent was not to test Houben but to test FC. As anyone familiar with the reputation of FC expected, the results were completely negative. This is not to deny that Houben may have some limited consciousness. If so, it must have been very frustrating for him to hear all the bogus messages being produced in his name without being able to protest. After our test, SKEPP chairman Willem Betz had a long conversation with Laureys, who insisted that we needed to test more facilitators before jumping to conclusions. We declined and advised Laureys to clearly distance himself from the FC sham. Still, out of respect for the family and to allow the institution time to discuss the results with the dedicated staff, we agreed on a two-week embargo before making our results public. Ten days later, Laureys finally backtracked on the FC part of the story, claiming that new tests with Houben had failed to validate the method.

Of course, the failed test does not definitely rule out that Houben may be able to communicate somehow with the outside world. Understandably, Houben's mother still believes in FC because she thinks it has produced answers that the facilitator had "no way of knowing." She still hopes to establish a line of communication with her son some day.

Laureys's request for "more tests with more facilitators," at a time when the miraculous story was giving relatives of coma patients all over the world false hope, was clearly off the mark. More tests should have been conducted before launching the story in the international press in the first place. Why did Laureys need more than a year to debunk this spurious method when skeptics had pointed out to him that a controlled test could be performed in a matter of minutes?

Moreover, Laureys repeated to the media that "from the start, I did not prescribe this technique," which is somewhat disingenuous given his earlier statements in Der Spiegel and The Times. We wonder what world-shaking news there would have been to communicate if it had not been for the spectacular finding about the typing coma patient, validated by his treating neurologist, a renowned expert of consciousness disorders. Moreover, to this day Laureys maintains that FC proved successful with another patient of his, but he refuses to provide the details of the case, claiming that he will present them in due time in a proper scientific outlet. Consequently, he has refused to sign the resolution of the Behavior Analysis Association of Michigan (BAAM) on the scientific evidence against the validity of facilitated communication.

Naturally, this does not affect the fMRI research that Laureys and his colleagues published in *NEJM* (Monti et al. 2010), in which they showed that a small

percentage of patients initially classified as being in a PVS show signs of preserved cognition under the scanner. Still, to what extent these traces of meaningful cognitive activity indicate that there is still "someone in there" remains debatlicity boost, and the emotional impact on patient's families cannot be underestimated. The decision to present this story before the international media was premature to say the least, and Laureys has clearly overreached in this case. He



When his facilitator's eyes were shielded from the keyboard, Houben began typing gibberish.

able. In interviews Laureys claimed that his scans showed that up to 40 percent of patients previously diagnosed as being in a PVS were trapped in a paralyzed body and could be "released." But this is a premature conclusion. As neurologist Alan Ropper (2010) writes in an editorial for the *NEJM*, "cortical activity does not provide evidence of an internal 'stream of thought." The findings of Monti et al. suggest that there is a twilight zone between a vegetative state and a state of minimal consciousness, and we may want to recognize degrees of consciousness.

In any case, even if some of the patients under Laureys's scanner turn out to have a form of consciousness, FC is certainly the last method to recommend for establishing communication. The international news coverage of Houben's case has given the advocates of this sham method an undeserved pub-

would do the scientific community and the families of coma patients all over the world a great service if he would finally distance himself completely from the follies of FC.  $\square$ 

#### References

Felce, D. 1994. Facilitated communication: Results from a number of recently published evaluations. *British Journal of Learning Disabilities* 22(4): 122–126.

Monti, M.M., A. Vanhaudenhuyse, M.R. Coleman, et al. 2010. Willful modulation of brain activity in disorders of consciousness. *New England Journal of Medicine* 362(7): 579–589.Ropper, A.H. 2010. Cogito ergo sum by MRI. *New* 

England Journal of Medicine 362(7): 648–649.
Twachtman-Cullen, D. 1997. A Passion to Believe:
Autism and the Facilitated Communication
Phenomenon. Oxford: Westview Press.

Wegner, D.M., V.A. Fuller, and B. Sparrow. 2003. Clever hands: Uncontrolled intelligence in facilitated communication. *Journal of Personality and Social Psychology* 85(1): 5–19.

Wheeler, D.L., J.W. Jacobson, R.A. Paglieri, and A.A. Schwartz. 1993. An experimental assessment of facilitated communication. *Mental Retardation* 31(1): 49–59.