

The Ethical Dangers of Mind Reading Research

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As a psychology major and enthusiast, the power of the mind has always been something that has fascinated me both inside and outside of the classroom. Although I have never had quite the same passion for the hard sciences, when I noticed that a neuroscience course was being offered, and would fulfill one of my major requirements, I took a leap of faith and registered. The class was indeed challenging, but it was there that I learned and began to appreciate just how much the brain is capable of, even if I didn't fully understand all of the mechanisms behind its functioning. The topics covered in the course included the different regions of the brain and the processes they are responsible for, as well as the technology that is currently available to study brain activity, such as functional magnetic resonance imaging (fMRI). This type of brain imaging tracks blood flow in the brain to determine which region or regions are being activated. After lecturing about fMRIs, my professor briefly mentioned the extraordinary use of fMRI for communicating with individuals who are in vegetative states, as in the case of critically injured Scott Routley.

An article featured in *The Guardian* details the incredible story of Scott Routley, who suffered severe traumatic brain injury in a car accident and subsequently became completely unresponsive (Owen, 2017). His parents, however, were convinced that Scott was in fact able to hear and respond to them, despite being comatose. Neuroscientists Adrian Owen and Davinia Fernandez-Espejo sought to investigate Scott's family's claims, and did so through fMRI. They asked Scott to perform different mental tasks, such as imagining walking through his home, or playing a game of tennis. Amazingly, they found that the appropriate brain regions were activated for each task, indicating that Scott could not only hear them, but could also form and direct his thoughts. When they realized that they were effectively getting through to Scott, they

requested his parents' permission to move on to asking Scott questions. His parents agreed. They asked Scott whether he was in pain and told him to perform different mental tasks to represent either "yes" or "no." Again, Scott was able to direct his thoughts to answer the doctors' question, and responded that no, he was not in pain.

Although this was good news, and Dr. Owen did express that his interests shifted from initially wanting to progress science to trying to better Scott's quality of life and potentially help others like him, I couldn't help but question the ethics of conducting groundbreaking research on a person who cannot give informed consent, whose faculties are compromised, and whose situation very little is known about (Owen, 2017). Regardless of the good work Dr. Owen might have done, in working on behalf of Scott, while also trying to advance his own personal interests, he blurred the boundaries between the role of doctor and researcher. The difference in practice and research lies in their respective aims. Practice, whether it be medical or psychological, aims to improve an individual's life through treatment, while the purpose of research is to study a particular subject in a systematic way (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). At times, these goals may be conflicting. In Scott's case, treatment was not possible.

The duality of Dr. Owen's role is especially pronounced in his writing about the impact of his work with Scott, which seems to take a consequentialist approach. The consequentialist approach holds that an action is ethical if, in its outcome, the good outweighs the bad (Israel, 2015). Owen admits that his intentions were twofold: to help Scott and to gain more knowledge about different levels of consciousness. Dr. Owen writes that at least part of his work with Scott was, in fact, "less about Scott the person and more about helping us to dig deeper into the grey

zone”, and “understanding what situations were psychologically possible in this limbo.” Clearly Dr. Owen was under the impression that this work would have positive impacts beyond and greater than Scott’s case. Although this is true, and Scott and his family did benefit from this research, the extent to which Scott could truly be helped was limited. Scott could not communicate on his own terms, could not communicate answers more complex than just “yes” or “no,” and perhaps could not even decide whether or not he wanted to share his answers. I believe that it is also important to consider the sociohistorical perspective here, and to acknowledge that technology is constantly changing, and may possibly advance to reveal more personal information about the brain in the future. The concept of “sensitive” health information expands with the development of new technology.

Despite possible advancements to the field of neuroscience, I believe that proceeding to conduct research on Scott and his condition, as well as on others like him, constitutes a violation of the principle of respect for persons as outlined in the Belmont Report, and the general principle of respect for rights and dignity in the American Psychological Association’s Code of Ethics (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979; American Psychological Association, 2017). The Belmont Report’s principle of respect for persons, and the APA’s principle of respect for rights and dignity can both be described as respect for an individual’s sense of freedom, control, and ability to make conscious decisions about their own life and goals, all of which are implicated in the informed consent process.

As with any research, the informed consent process should include the weighing of costs versus benefits. fMRI is usually low-risk. However, according to the Mental Imagery and

Human-Computer Interaction Lab, fMRIs may not be safe for people who have experienced head trauma, or have neurological disorders such as traumatic brain injury (Mental Imagery and Human-Computer Interaction Lab). Additionally, it is not likely that Scott would've received any substantial benefits, with the exception of a few potential comforts, as this research was limited and could not be an effort to restore his functioning to what it once was. Most important, however, is the ethical issue of the lack of true informed consent and Scott's inability to weigh the costs and benefits himself. Although Dr. Owen did ask Scott's parents for permission before using the fMRI to communicate with Scott, a number of factors, such as the emotionally charged nature of the situation, and his parents' desperation and hopefulness for a chance at reconnection with their child, may have factored into their instantaneous granting of consent on Scott's behalf. Parts of Scott's brain were irreparably damaged, making him extremely vulnerable. In fact, Scott's condition rendered him arguably the most vulnerable of any population, as he was both physically and mentally debilitated, and thus in need of special protection. Dr. Owen himself even recognized Scott's vulnerability. He writes that he was never able to have a real conversation with Scott and that he was "so close to death it was sometimes hard to tell" (Owen, 2017). The lack of special protection for Scott and the duality of Dr. Owen's role as doctor and researcher is not consistent with the ethical guidelines put for in the Belmont Report, or the APA Code of Conduct.

## References

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