

Kopf Carrier #68

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# **Communicating Ethics and Neuroscience**

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## Introduction

Research into the human brain is not just incredibly demanding, but is also controversial. This is not the kidney, or the heart, but the organ in which we find our "selves." For that reason, any step toward understanding how the brain works has potential for controversy.

A man in Cleveland, who has been in a persistent vegetative state for ten years, makes a remarkable recovery after "deep-brain stimulation" and now feeds himself, brushes his hair, watches movies, laughs and cries and can say the first sixteen words of the Pledge of Allegiance. One of the attending doctors, Nicholas Schiff, argues that this amazing recovery challenges the standard practice of "treatment discontinuation."

But how significant is this one case? If this man could partially recover, what about Terry Schiavo, the woman in Florida whose family contested the doctors' decision to take her off life support? What would deep brain stimulation have been able to do for her?

If you believe the brain imaging, not much. Schiavo did have some brain activity, but patchy, with no evidence of enough connections among crucial areas. The man in Cleveland was quite different: his neural networks were "intact, but dormant"; they just needed some stimulation, and electrodes provided that. Judging from what appeared in the papers during the Schiavo case, things weren't that clear-cut to reporters or, presumably, the public. There was confusion everywhere, especially about the likelihood that she might one day have recovered. To some, withdrawing a food tube was murder.

How to communicate the differences between these two cases in a way that is fair to the science, but still captures the public's attention?

The science of limited consciousness, and who has a chance of recovery, is just one of a myriad of contentious issues arising from neuroscience. Can technologies like functional MRI be taken further and actually detect when someone is lying? Or reveal which company logo appeals to you more?

It's not just imaging. Drugs that are designed for use in attention deficit disorders and Alzheimer's disease are being used by students to help focus during exams – drugs that enhance both memory and attention. But we don't know their long-term effects. And even if they turn out to be benign, it is inevitable that they will be distributed unequally: some will be able to afford them, some won't. What can we do about them? Should we worry about the increasing use of drugs like Prozac by people who aren't depressed, but simply want to feel better?

There are many, many questions. Scientists and ethicists have thought about and discussed these problems. They have analyzed the media's reactions, and found that the communication of neuroscience in the media needs some expert attention.

#### **Current Research**

Experts in science and communication have played an important role in disseminating information resulting from many forms of research (Illes et al. 2008; Racine et al. 2006). Over the two past decades, for example, science reporting on genomics and the new era of genetic testing has been instrumental in creating a solid base of knowledge for informed discussion (Conrad and Gabe 1999; Cardinal et al. 2003; Condit 2001; Condit, Parrott, and O'Grady 2000; Racine 2003). Needless to say, stem-cell research has also been a hot topic in the media and public domain (Mulkay 1994; Williams et al. 2003). Until recently, however, significantly less attention has been paid to the communication of contemporary neuroscience.

This deficit must be redressed, because the communication needs are growing. In neuroimaging for example, there has been a steady increase of studies specifically with ethical, social and policy implications (Illes et al. 2003; Illes et al. 2005). Among these are studies of problem-solving, moral decisionmaking, emotion, motivation, racial attitudes, personality traits, religious experience, and even lying and deception. Results are reaching far beyond medicine, into the courts, classrooms, and the open marketplace.

Media coverage constitutes a central pathway of communication about the human challenges of the full range of new neurotechnologies, from monitoring the brain using imaging techniques to intervening with brain drugs or implants. That communication outside the academic literature is a vital source of information flow, but its value is heavily yoked to timeliness and accuracy, and to the trade-off of hope and hype. More often than not, these are delicate knowledge, thought and word balances managed independently by scholars at seemingly two ends of the communication continuum – the scientists on one end, and the science communicators on the other. The trend is counterproductive and the gap is one that needs to be filled.

### Addressing the Gap

There is still much uncertainty in the minds of the public about the science involved in neuroethics, not surprising given that communicating these topics requires bridging the substantial gap between institutional research and peoples' private lives. In a three-day science communications program in March 2009, we brought senior neuroscientists, ethicists and journalists together to identify strategies to improve communications. As a collective with substantial leadership and experience, we worked to clarify a path forward. We concluded our meeting with a call for a culture shift in neuroscience that fundamentally supports communication, the identification of communication specialists in neuroscience, and focussed new research for neuroscience to inform best practices, especially in response to the changing digital landscape of communication. We will look forward to sharing our progress with the readers of the Carrier and elsewhere in the coming months.

#### References

Conrad P., Gabe J. Introduction: Sociological perspectives on the new genetics: An overview. *Sociology of Health & Illness* 1999, 21(5): 505–16.

Cardinal, G., Deschênes, M., Knoppers, BM., Hudson, T., Labuda, D., Bouchard, G., Racine, E., Fecteau, C., Truong, S., Laberge, C. Statement of principles on the ethical conduct of human genetic research involving populations. 2003. www.rmga.qc.ca/doc/pop/ statement\_ANG\_.pdf Condit CM. What is "public opinion" about genetics? *Nature Reviews Genetics* 2001, 2: 811–15.

Condit, CM., Parrott, RL., O'Grady, B. Principles and practices of communication processes for genetics in public health. In Genetics and public health in the 21st century: Using genetic information to improve health and prevent disease. Koury, MJ., Burke, W. and Thomson, EJ., editors. Oxford, UK: Oxford University Press, 2000.

Illes J, Kirschen MP, Gabrieli JD. From neuroimaging to neuroethics. *Nature Neuroscience* 2003, 6(3): 205.

Illes, J; Racine, E; Kirschen, M. A picture is worth 1000 words, but which 1000? In Neuroethics: Defining the issues in theory, practice and policy. Illes, J., editor. Oxford, UK: Oxford University Press, 2005.

Illes, J, Lau, PW, Giacino, JT. Viewpoint: Neuroimaging, Impaired states of consciousness, and public outreach. *Nature Clinical Practice Neurology* 2008, 4(10): 542-3.

Mulkay M. Embryos in the news. *Public Understanding of Science* 1994, 3(1): 33–51. [PubMed: 11659866]

Racine, E, Bar-Ilan, O, Illes, J. A decade of brain imaging coverage in the print media. *Science Communication* 2006, 28(1): 122-143.

Williams C, Kitzinger J, Henderson L. Envisaging the embryo in stem cell research: Rhetorical strategies and media reporting of the ethical debates. *Sociology of Health & Illness* 2003, 25(7): 793–814.



# Editor's Column

How fast time goes by! Here it is almost time for the 39th Annual Meeting of the Society for Neuroscience. I wonder how many of

you realize that the meeting this year in Chicago is a unique event. Never in the 38 previous years has the SFN meeting been held in Chicago. As I recall, the original schedule for 2009 was to have the meeting in New Orleans, but that had to be changed after Katrina and the possibility that New Orleans would not be ready for such a huge convention by this year. Fortunately, New Orleans has come a long way back and I for one, hope we can meet there again soon. We can only hope that nothing like that happens again to New Orleans or any other city.

As usual, David Kopf Instruments will be a major exhibitor at the meeting. We will be in Booth 843. I do hope that many of you will come by to say hello and to look at the wonderful array of stereotaxic instruments and associated equipment that will be on display. As you know, David Kopf Instruments is the oldest and highest quality full line of stereotaxic instruments and related equipment in the world. There will be a new catalog available and as usual, representatives who will be able to help you with all your stereotaxic needs. Besides supporting individual researchers with their equipment needs, Kopf was one of the very first major supporters of the Society for Neuroscience and has helped several related organizations in the neuroscience community over the years.

In 2005, in memory of David Kopf, who founded the David Kopf Instrument Company and who passed away in 2004, Carol Kopf and the company decided to sponsor the David Kopf lecture on Neuroethics at the Society for Neuroscience annual meeting. Over the past four years, the Society for Neuroscience has picked outstanding lecturers to present various aspects of the very important topics in neuroethics. This is obviously a topic that is of increasing importance in our field, as we gain increasing knowledge of how the brain and nervous system functions and how behavior is produced. We must be constantly vigilant that the knowledge that we generate is used in only the most ethical and humane ways. David Kopf was very concerned about this topic; thus it is entirely appropriate to honor him with this lectureship. The company is very pleased to be able to sponsor this lecture each year. This year, the David Kopf Lecture on Neuroethics will be presented by Steven Laureys, MD, PhD from the University of Liege, Belgium. His topic will be "Eyes Wide Open, Brain Wide Shut: (Un)Consciousness in the Vegetative State". This topic is obviously one of great interest to not only our neuroscience community but to the general public. Perhaps no brain related topic has recently generated as much controversy as that of the status of people in persistent vegetative or minimally conscious states. All of us must become more aware of what our science is able to say to this issue and be able to help inform the often emotional dialog associated with it. We look forward to seeing you at the lecture on Monday, October 19 at 10 am.

This issue of the *Carrier*, number 68, was written by Judy Illes, PhD, who presented the David Kopf Lecture on Neuroethics two years ago. Judy has long been active in the area of neuroethics and serves as editor of the American Journal of Bioethics (AJOB) – Neuroscience. She has long been a strong advocate

for increased communication within the scientific community on neuroethical issues and for creating better avenues for informing the public of the scientific advances that relate to the use of that information in the public domain. Her article here bears directly on the talk that will be given at the meeting in October by Dr. Laureys; how can the neuroscience community make clear the current knowledge about various vegetative or minimally conscious states. Dr. Illes recently held a conference of scientists, journalists and ethicists to examine the issue. Hopefully, she may present some of the conclusions of that meeting in another Carrier article. I think you will find the present article very timely and interesting.

It is the early part of hurricane season here in Florida. We have not yet had any sort of storm activity yet and none appears on the horizon at this point. We hope it stays that way. By the time we go to Chicago, we will probably have had at least a couple storms develop somewhere; but hopefully not here.

We look forward to seeing you in Chicago. Please stop by the booth to say hi. If you would like to submit an article for the *Carrier* please contact me or send a message to David Kopf Instruments. All back issues of the *Carrier* are available for download on the company website (kopfinstruments.com) so you can look at what has been published in the past. The company supplies a \$500 honorarium for each article published. We would be pleased to send you the instructions for the *Carrier* or to help you formulate ideas you might have for an article.

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