

Interview with Judy Illes

National Core for Neuroethics, Division of Neurology, Department of Medicine, University of British Columbia, 2211 Wesbrook Mall, Koerner S124, Vancouver, BC V6T 2B5, Canada (jilles@mail.ubc.ca)



*Dr Illes is Professor of Neurology and Canada Research Chair in Neuroethics at the University of British Columbia (UBC). She is Director of the National Core for Neuroethics at UBC, and faculty at the Brain Research Centre (UBC) and the Vancouver Coastal Health Research Institute. She also holds appointments in the School of Population and Public Health and the School of Journalism at UBC, in the Department of Computer Science and Engineering at the University of Washington in Seattle, WA, USA, and a Life Member of Clare Hall, Cambridge University, UK. Her research focuses on ethical, social, legal, and policy challenges at the intersection between the neurosciences and biomedical ethics. She is an internationally recognized author, lecturer, and mentor. She is a cofounder and Governing Board Member of the International Neuroethics Society, a former member of the Internal Advisory Board for the Institute of Neurosciences, Mental Health and Addiction of the Canada Institutes of Health Research (CIHR), and of the Forum on Neuroscience and Neurological Disorders of the Institute of Medicine (IoM). Her most recent books, *The Oxford Handbook of Neuroethics* (Oxford University Press) and *Addiction Neuroethics* (Elsevier), were published in 2011 and 2012, respectively.*

What (or who) inspired you to become a neuroscientist?

I have always had a fascination with the way that people behave and express themselves: the ways we speak, cluster, flock, attract, migrate, value, accept, and reject. I was a teenager when I boldly declared that I planned to be a psychology professor. My career path and endpoint have not been entirely linear toward that goal but, even so, in focusing on the science of the brain, and how it affects both individuals and societies, I really haven't strayed too far from it either. Much success and luck along the way are thanks to tremendous mentors: Jim Stellar, the late André Roch Lecours, Tom Raffin, David Magnus, Gary Glover, and Rémi Quirion. Interestingly, they are all men, but the path has been paved both by women and men who share my passion for neuroethics, as well as my deep commitment to mentoring other women neuroscientists.

How did you become interested in neuroethics?

Around the time I cofounded the Stanford Center for Brain Research, around 1995, the development of neurotechnology such as functional magnetic resonance imaging (fMRI) was speeding along. Although many neuroscientists were paying attention to the technology, hardly anyone was thinking about what far-reaching impact the new capabilities for imaging the function of the brain might

have. A few distinguished bioethicists and neuroscientists were starting to ask tough questions about the implications that emerging neuroscience capabilities would have for personhood and cognitive enhancement, for example, but no one dedicated fully to the task had a lens from inside the neurosciences. This was a career opportunity for me professionally, and a potential new funding niche for the Center.

Nevertheless, in reality the story is more complicated: I have always had a tendency to be in at least two places at once – this, by definition, makes me an outsider in at least one. I am formally trained in the hearing and speech sciences and neuropsychology. Neuroethics is similarly outside-inside neuroscience and is, at the same time, a younger sister to biomedical ethics. Neuroethics is a domain that not only allows scholars to embrace many parallel areas of inquiry, but indeed actively encourages the bringing together of different disciplines. For me, providing a place where I can nurture allcomers and their own burgeoning neuroethics interests is nothing short of privileged. In this regard, although my own passion still keeps my attention on neuroimaging, at UBC we have a broad range of neuroethics research programs that cover ethical, social, legal, and policy issues related to stem cells for spinal cord injury, dementia (with a particular focus in knowledge translation and the prediction of disease), neurodevelopmental disorders, neuroenhancement and determinism, addiction, and gene therapy. The disciplinary diversity and talent are phenomenal. What other field allows us to be both focused and so broad at the same time? I can't think of any other.

There are many important issues raised by new technological advancements in the neurosciences that require ethical considerations. Is there one particular issue that you are asked to comment about more frequently than others?

Hands-down, the answer to this question is incidental findings in research: unexpected anomalies in the brain discovered during a research study that are unrelated to the study and that may have clinical significance. A classic example is a vascular malformation in a presumably young and healthy college co-ed who volunteers to participate in an fMRI study. Even the US President's Commission on the Study of Bioethical Issues has been interested in this. What do we know? We know that these symptom-absent conditions are much less common in younger people than in older ones, that they require much more rapid medical attention in younger people than in older, and that most people regardless of age or gender would want to know if there is something in their brain that is noticeably

unusual, regardless of clinical significance. We also know that early guidance – that left plenty of room for flexible responsiveness on how to manage incidental findings – was the right approach at the time; today, however, investigators are asking for principled and consistent processes. We study and try to deliver on all aspects of this rich and complex problem.

You also have a strong interest in global health and cross-cultural neuroethics. What is one challenge that you have recently been involved in that relates to this?

We are working actively on a community-based participatory research project with a First Nations community in Canada whose members are at risk for early-onset familial Alzheimer disease (EOFAD). They have requested that we all maintain confidentiality about their identity. On the one hand, the risk of stigmatization is potentially so high that confidentiality is essential. On the other, although the Nation and its members have expressed a desire to be champions of the research and cross-cultural understandings of EOFAD, they are unable to fulfill this goal if their identities cannot be disclosed. Research collaborators from the community must publish under a pseudonym or anonymously; there is a risk to healthcare change and policy if policy-makers cannot know to whom to direct new policy; grant support for work with an unnamed entity is extraordinarily difficult to obtain. In this highly collaborative effort, we struggle with the challenges around confidentiality in this context and revisit them regularly.

Would you encourage all students and researchers to have at least some training in neuroethics?

Yes, absolutely. Much of our empirical work suggests that there is real receptivity to this idea, and the growing numbers of the neuroscience-based membership of the International Neuroethics Society further support these data. Clearly, the biggest obstacles are time and relevance. We are all overcommitted, and ethics curricula have historically been generic. Therefore, we must work to incorporate this new material seamlessly and meaningfully. We do this successfully with other new advances in neuroscience; there is no reason we cannot do it with neuroethics. Curriculum priorities we have identified so far through our work with neuroscientists at all academic levels are: (i) fundamental principles and contemporary writings in biomedical ethics focused on the CNS; (ii) applied societal implications of neuroscience, such as for the criminal justice system; (iii) translational considerations for clinical trials and other research that moves neuroscience innovation from the bench to the bedside, such as for better understanding of disordered states of consciousness; (iv) innovative approaches to disseminating neuroscience knowledge; and (v) ethical challenges and processes in commercialization. Case-based teaching and knowledge sharing will make neuroethics an even-easier fit for neuroscience than it is already.

What advice would you give to someone who is just starting his or her independent scientific career?

It's all about mentorship in the workplace and partnership at home. It is important to seek one or more professional

mentors to teach you how to strategize, cultivate those strategies, and to open doors through which opportunities to implement those strategies are realized. Great mentors are there for you through thick and thin. They have you at center focus and your success shines back on them. Great mentors are like good wines; they only get better over time.

A supportive partner at home is the best complement to good mentorship in the workplace. My husband, Machiel Van der Loos, is the ultimate. We started off as casual friends and became best friends. We share life's responsibilities 50–50%, capitalizing on our respective strengths, and deferring to each other where needed. We stumble clumsily, but together, when neither of us can take the lead toward an informed solution. Life is bumpy, busy, unpredictable, and academic life is especially replete with deadlines and moving targets. Being able to share this with someone who can be both an anchor and a back-up is essential.

As for neuroethics specifically, the leadership of the International Neuroethics Society has thought about this a lot. Our career advice at this time: follow a traditional neuroscience track and specialize in neuroethics. It's like having your cake and eating it too.

How important do you think it is that neuroscientists communicate their findings to the public?

It's not just important, it is vital. There are two reasons for this:

- (i) *Moral and professional duty.* As people entrusted with public funds to do our work, we have a responsibility to report back. Accountability is everything. Employees of any workplace have to account for what they do, so why would accounting to the public for what we do in neuroscience with tax dollars be any different? But I'm not the first to say this. I remember hearing Joe Palca of National Public Radio passionately promote the duty to communicate at the Society for Neuroscience meeting in New Orleans in 2003.
- (ii) *Broken telephone.* No one likes to be at the end of the line in the game of broken telephone. With the potential for a direct impact upon public policy or health care, why should the public feel any differently? At the magnificent Banff Centre in Alberta, to colleagues in journalism, neuroscience, and neuroethics and I proposed some concrete remedies to the challenges of communication in neuroscience. They are: the adoption of social media for direct bench-to-ear-side information flow; dynamic exchange with stakeholders that reflects reciprocity and mutual respect; identification of communication specialists; and an overhaul of how these activities are valued by our institutions. The implementation of any or all of these recommendations will go a long way.

What is the best piece of advice you've been given in your career?

The best general advice I received was to develop an area of expertise and become a leader in it: expertise measured by quality and quantity of publications that people care about; leadership measured by the fact that, when people are writing or speaking about an area of

research, they can hardly do so without mentioning you, work that you have conducted or seeded, or someone in your professional family. The specific advice I received was to focus on one thing for which I would always be known. I have done that, in some ways, but in others not. I've become well known for my work in neuroimaging and ethics, and for incidental findings in particular. But this business

about a single focus is not really for me. I really like growing a “garden of opportunity in neuroethics” as one of my Fellows calls it, where others can innovate and flourish. Through them I flourish too.

0166-2236/\$ – see front matter

<http://dx.doi.org/10.1016/j.tins.2012.06.006> Trends in Neurosciences xx (2012) 1–3