

More Education, Less Administration: Reflections of Neuroimagers' Attitudes to Ethics Through the Qualitative Looking Glass

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Abstract In follow-up to a large-scale ethics survey of neuroscientists whose research involves neuroimaging, brain stimulation and imaging genetics, we conducted focus groups and interviews to explore their sense of responsibility about integrating ethics into neuroimaging and readiness to adopt new ethics strategies as part of their research. Safety, trust and virtue were key motivators for incorporating ethics into neuroimaging research. Managing incidental findings emerged as a predominant daily challenge for faculty, while student reports focused on the malleability of neuroimaging data and scientific integrity. The most frequently cited barrier was time and administrative burden associated with the ethics review process. Lack of scholarly training in ethics also emerged as a major barrier. Participants constructively offered remedies to these challenges: development and dissemination of best practices and standardized ethics review for minimally invasive neuroimaging protocols. Students in particular, urged changes to curricula to include early, focused training in ethics.

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Introduction

As a tool at the service of science and medicine offering a window into the brain, neuroimaging is widely employed to address the neurobiological correlates of cognition and behaviour, and to gather biological data in aid of diagnosis and prediction of disease (Illes et al. 2003). As a technique, it combines powerful technology and a variety of support staff ranging from physicists, engineers, cognitive neuroscientists, psychologists, biostatisticians, radiologists and clinicians. Arguably, the concept of a successful neuroimaging study is one that optimally applies the technology to a research question to which the data provide a meaningful answer, in a way that ensures the ethical treatment of all persons involved in it. Hence, while Bayesian modeling of the haemodynamic response function in functional magnetic resonance imaging (fMRI) may offer a set of assumptions and language that is applied to the analysis of the blood oxygenation level dependent (BOLD) signal (Lindquist et al. 2009), research neuroethics serves the corresponding function concerning the treatment of persons whose selves and brains are at the origin of these data.

Neuroethics figures centrally in the global discourse of neuroimaging for several reasons. Studies of the brain with the use of neuroimaging carry special weight in the context of ethics, since they probe, or claim to, the physical underpinnings of mental and emotional responses. Moreover, the rapid expansion of neuroimaging with the development of new techniques that improve spatial and temporal resolution and enrich neuroimages with genetic data has raised challenges such as preserving the anonymity of subjects and confidentiality of forthcoming data, as well as handling evidence of pathology in presumed healthy subjects (known as incidental findings) (Illes et al. 2006). The response to this geometric increase in the generation of brain data from burgeoning neuroimaging studies with the involvement of human subjects, young and old, healthy and infirm, has been to overregulate at the science policy end. There is a growing sense that institutional review boards (IRB), whose original mission is to ensure the ethical conduct of neuro-research, may be acting as a barrier to science (Illes et al. 2010b) due to time delays, lack of expertise in protocol evaluation by these boards and inconsistent guidelines on the preparation of participant-intended documentation (Deslauriers et al. 2010). Conversely, it seems that neuroimagers are not adequately prepared by their training in ethics, and tend to associate it with administrative burden as revealed in a large-scale ethics survey of neuroscientists in the US and Canada (Lombera et al. 2010; Illes et al. 2010b).

The current study probed more deeply into the ethical issues and challenges that neuroimagers face, the barriers they come up against when engaging with ethics in the context of their work, what motivates them to consider ethics in the first place, and what tools and resources they envisage would facilitate this process. To this aim, we conducted focus groups with members of this scientific community and interviews with neuroscience students involved in neuroimaging as part of their

training. The overarching goal was to elaborate the significant findings highlighted by our earlier survey work related to the motivation and sense of responsibility to engage with ethics in the context of neuroimaging research and readiness to adopt new ethics strategies amongst these researchers.

Methods

Approval for this study was obtained from the Behavioral Research Ethics Board at the University of British Columbia. Participants provided written informed consent. All data were anonymized for transcription and analysis.

Data Collection

Participants for the focus groups and interviews were recruited from a large cohort of neuroimagers who self-identified for re-contact in a survey on ethical issues arising in neuroscience and neuroimaging (Illes et al. 2010b). They were affiliated with institutions in Canada and the United States and their research involved electrophysiology (e.g., electroencephalography [EEG]), magnetic resonance imaging (MRI and functional MRI), magnetoencephalography (MEG), positron and single photon emission tomography (PET and SPECT), optical imaging (NIR), deep brain stimulation (DBS), transcranial magnetic stimulation (TMS) or imaging genetics. Sixteen faculty members, eight post-doctoral fellows and eight students volunteered to participate in the time period between February and April 2009.

Based on survey feedback about availability and attendance at professional meetings, five focus group discussions were held at the 2009 Organization for Human Brain Mapping (OHBM) meeting in San Francisco, California, and at the 2009 meeting of the Society for Neuroscience in Chicago, Illinois. Each focus group lasted approximately 120 min. In addition, interviews were offered via telephone and in person in the months following the focus groups to include student respondents who volunteered to participate but were unable to attend a focus group session. Individual telephone interviews with students were conducted from February to April 2009 and lasted approximately 45 min.

The semi-structured focus groups and interviews probed neuroimagers' perceptions of the ethical issues surrounding neuroimaging research outlined in the survey, the factors motivating neuroimagers to incorporate ethics into their work, the barriers or obstacles they face in doing so, and the tools they envisioned as helpful to surmount these barriers in the future. To structure the discussion, open-ended questions such as, "What are the ethical issues you face in your day to day practice as a neuroimager?" were used. Demographic information was probed first (e.g., respondent gender, age, imaging modality, research topic); subsequently ethics issues, motivators, barriers and tools were addressed in a naturalistic, free-flowing format. Respondents were encouraged to share their thoughts and suggestions as they occurred to them throughout the sessions without adhering rigidly to a prescribed structure. The focus group discussions and interviews, which yielded a

total of approximately 32 h of audio recorded data, were individually transcribed *in extenso* and *verbatim*.

Analysis

The output from each focus group and interview formed the basis for a rigorous and iterative process of qualitative analysis. The data from the focus groups and interviews were treated similarly, using a method of constant comparison. This involved segmenting the raw data (phrases, sentences, paragraphs), labeling and synthesizing the data, identifying categories and dimensions, and searching for patterns that could be associated and compared (Bradley et al. 2007). The goal was to identify a broad range of perspectives, not necessarily a consensus among participants, and to deliver a coherent conceptual description of the data that captures thematic patterns and characterizes phenomena of interest while accounting for the individual variations within them. As with all interpretive research processes, data collection and analysis inform one another iteratively, shape the direction of inquiry, permit consideration of new emerging themes, and allow for the flexibility to accommodate views that evolve over the course of data acquisition. This methodology enabled the examination of individual factors contextualized within the larger picture of the data collected.

In keeping with this approach, themes were identified both deductively by the discussion questions, and inductively through intense coding of the transcripts for themes emerging *in vivo*. A rich coding strategy allowed for the attribution of multiple codes to segments of data and identified the relationships that meaningfully described the data. Thus, descriptive and comparative analysis techniques were used to develop accounts leading to categorization and conceptualization of the data around the emergent themes. Categorizations were cross-verified by a third author (JI).

The data were analyzed using HyperRESEARCHTM Software for Qualitative Data Analysis (ResearchWare Inc., Version 2.81 for Mac). Data reduction was achieved by coding the dataset with 72 descriptive and analytic codes. This codebook was applied by KT to the focus group data and by AAK to the interview data.

Results

Demographics

Table 1 describes the professional characteristics of the study sample. All 32 participants reported involvement in human subjects research and confirmed the use of neuroimaging, which included fMRI, PET or MEG alone or in combination with neurophysiological methods such as EEG and stimulation techniques such as TMS and DBS.

Priority Ethics-Related Issues

Faculty and fellows frequently and consistently identified incidental findings (IFs) as a significant challenge in their daily research practice (see Fig. 1). This has

Table 1 Characteristics of the study sample

	Faculty	Post-doctoral fellows	Students
N	16	8	8
TMS	4	1	0
DBS	1	0	0
Genetics	3	1	0
Clinical populations	7	3	4
Children	5	2	0

All participants were involved in neuroimaging research; some also used stimulation techniques and/or worked with vulnerable populations such as patients and children

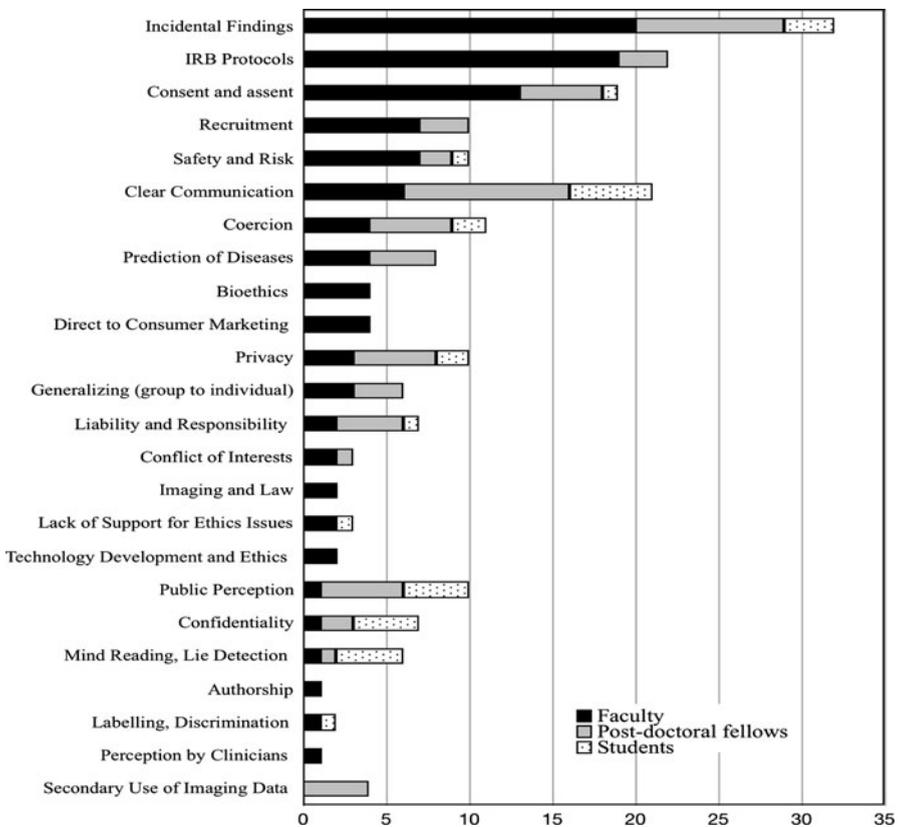


Fig. 1 Code frequencies concerning ethics-related issues and challenges discussed by faculty, post-doctoral fellows and students

important ethical implications not least because handling IFs may fall into the remit of a Principal Investigator (PI) who may not be adequately trained due to the lack of standard protocols or expertise. In the words of Participant 5, Faculty Group:

... the concept of the PI being responsible for ... identifying potential incidental findings, to me, is problematic because then it becomes the luck of the research participant about the ... competence of that PI to detect things ...

Moreover, replicating the quantitative survey findings, faculty as well as postdoctoral fellows, but none of the students, identified overregulation by IRBs as a significant issue. They voiced concerns that dealing with administrative hurdles at the earliest stages of the scientific process diverts the time and energy of neuroimagers away from their field of expertise:

... the biggest practical day to day problem ... over regulation by IRBs of our research ... certain aspects of the regulatory process have gotten a little out of, more than a little out of control and (...) it's very time consuming to obtain IRB applications... (Participant 3, Faculty Group 3)

All participants were also concerned about ethical issues surrounding informed consent, subject recruitment and confidentiality in data sharing. Particularly notable was the frequency with which student interviewees highlighted the issue of clear communication of neuroimaging findings and the need for transparency in reporting methods and analysis of neuroimaging data. These students at the earliest stages of their scientific careers appeared attuned to the malleability of this type of data, in line with controversy and debate surrounding neuroimaging analysis methods (Logothetis 2008; Vul et al. 2009):

I think there's particular potential for abuse in fMRI because the data are so complex and there are so many different ways you can analyze them. But if you're creative you can almost, you're guaranteed to find something somewhere in the data. And so if you're not careful you can probably skew those results pretty quickly ... (Student 5)

This issue dovetails neatly into that of communicating neuroimaging findings to the general public in a clear and accurate manner that leaves little room for misunderstanding, misinterpretation or manipulation, on the part of researchers (Lavazza and De Caro 2010) and the media:

I think science journalism is not always so great and people don't really, a lot of the articles I see, I feel like, they're written by people who don't really, haven't taken the trouble to familiarize themselves with the technology. And so they end up reporting it in a way that really doesn't convey where we are and what the technique actually does. (Student 5)

Issues such as mind reading and lie detection represent some of these controversial representative cases:

... there was a segment on 60 Minutes and it was essentially saying fMRI can read minds, and that's very problematic. (Student 8)

Student interviewees also frequently commented on the persuasive power of neuroimages, the public's trust in the technique as a diagnostic and predictive tool in

disease, as well as aspects of cognition and affect such as consumer preferences, beliefs or opinions:

Well a lot of people, I think, think that neuroimaging is a lot farther advanced than it is. So they think you'll be able to determine specific things about them from looking at their scans, which I can tell you that we're quite a ways off from that. (Student 2)

Motivators

One of the most frequently identified ethical motivator in neuroimaging research was "... people's safety and comfort in the scanner" (Participant 3, Faculty Group 2) (see Fig. 2). Researchers' own personal motivations for engaging in this work as well as their sense of personal responsibility also emerged as dominant motivating factors:

... one of my friends asked if we could put him in and see if he was going to develop Alzheimer's and that stopped us all dead in our tracks, and we thought, wow, we need to think about what we're doing a little bit, I guess because some of the research has larger implications than you know.... (Participant 3, Faculty Group 1),

... new researchers. ... they should be really thinking about what is their research? How critical is it? (Participant 2, Faculty Group 1)

Strikingly, virtue or morality were identified by all but one of the student interviewees as a prime motivator in considering ethics and conducting research in

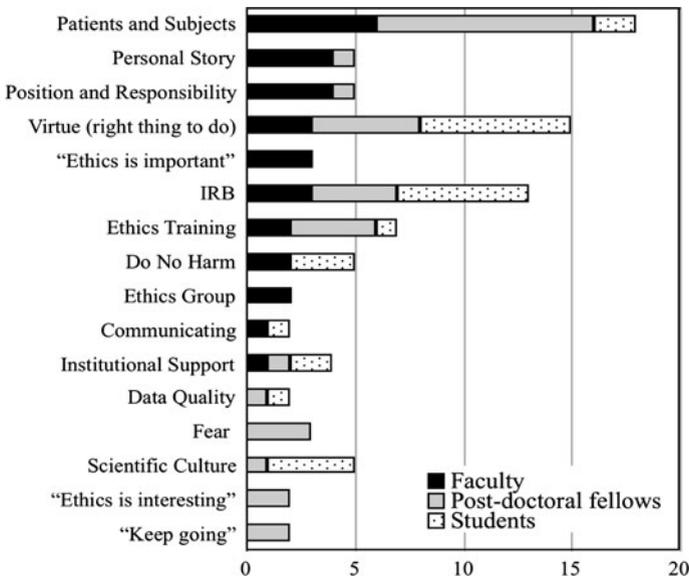


Fig. 2 Code frequencies on motivators to consider and incorporate ethics into neuroimaging research in faculty, post-doctoral fellows and students

an ethically robust manner. These themes emerged with respect to the science generally,

I mean why I think of it is, I mean I really do care, I really do think that, you know, the work that I'm doing, I really ...want it to have a positive impact (Student 3)

as well as specifically in interacting with human subjects in the context of research:

... you have a basic decency for people, you interact with them, you want to treat them ... the way you think they deserve to be treated. (Student 5)

Overall, satisfying the practical requirement of the IRB, ensuring continuing institutional support and avoiding potential adverse events also motivate this group of neuroimagers. Importantly, both internal, virtue-based motivation as well as the need to meet ethical regulations drives these researchers, as succinctly summarized by Participant 1, Postdoctoral Fellow Group 2:

I can think of two major motivations ...internal, my own ethical principles, and wanting to conduct my research in a morally justified way...

Barriers

There was a strong sense among discussants and interviewees that the IRB process is a top barrier (see Fig. 3). Due to overregulation and difficulty in communicating scientific and experimental particulars to the boards that review their applications, many neuroimagers expressed a sense of alienation that they ultimately felt undermines their work:

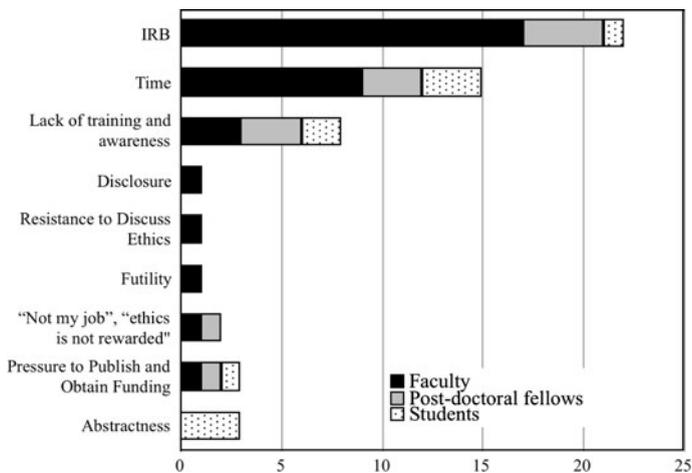


Fig. 3 Code frequencies concerning barriers in engaging with ethics in the context of neuroimaging research reported by faculty, post-doctoral fellows and students

... many of us already feel like even our own institutional review is not on our side. (Participant 6, Postdoctoral Fellow Group 1)

Time and administrative burden was identified as another significant ethics-related barrier faced by these researchers in relation to the IRB process:

The administrative burden is enormous ... writing IRB which takes several months ... this is just totally unacceptable ... the way the IRB is structured or one has to design ... I have to fill in the forms, I have tons of forms especially in the pediatric setting ... It's incredibly complicated. (Participant 2, Faculty Group 3)

A candid and self-reflexive insight into another major barrier in engaging with ethics emerged frequently in the student interviews: students noted insufficient scholarly training in ethics and lack of awareness, as seen in this statement by Student 4:

... I certainly don't feel like I'm necessarily informed about all of the ethical issues that exist. And so I really think it's more ignorance than apathy.

Tools

The need for a standardized approach to IRB protocols was clearly expressed in the context of tools and resources that would help neuroimagers address the administrative as well as basic ethical issues in the context of their interaction with IRBs (see Fig. 4). Participant 8 from Faculty Group 2 clearly stated:

I think on the very practical end might be these sort of a universal safety issues, consent issues, informed consent, protocol, if there was some consensus from large groups that do imaging. ... And that was some blessed set of documents that everyone could point to that would greatly simplify, and that was reviewed on like a six month basis, that we learned this and so we going to add that or ...

Ethics-liaison persons, case-based electronic review, online repositories, interactive pages, and reference libraries were also proposed as additional means of overcoming the administrative barriers associated with ethics review:

... an ombudsperson or some kind of a person who you can consult with in your department. (Participant 1, Postdoctoral Fellow Group 2)

Finally, the availability of advice and collaboration with ethicist colleagues was expressed as an important need for the short-term; change to regulatory policies, ethics education, and funding to support these changes were proposed as important future milestones:

... we need to think about the ethics problems that we're going to have tomorrow not just the ethics problems we have today. Otherwise we're going to always be a step behind and trying to catch up ... We need some way to

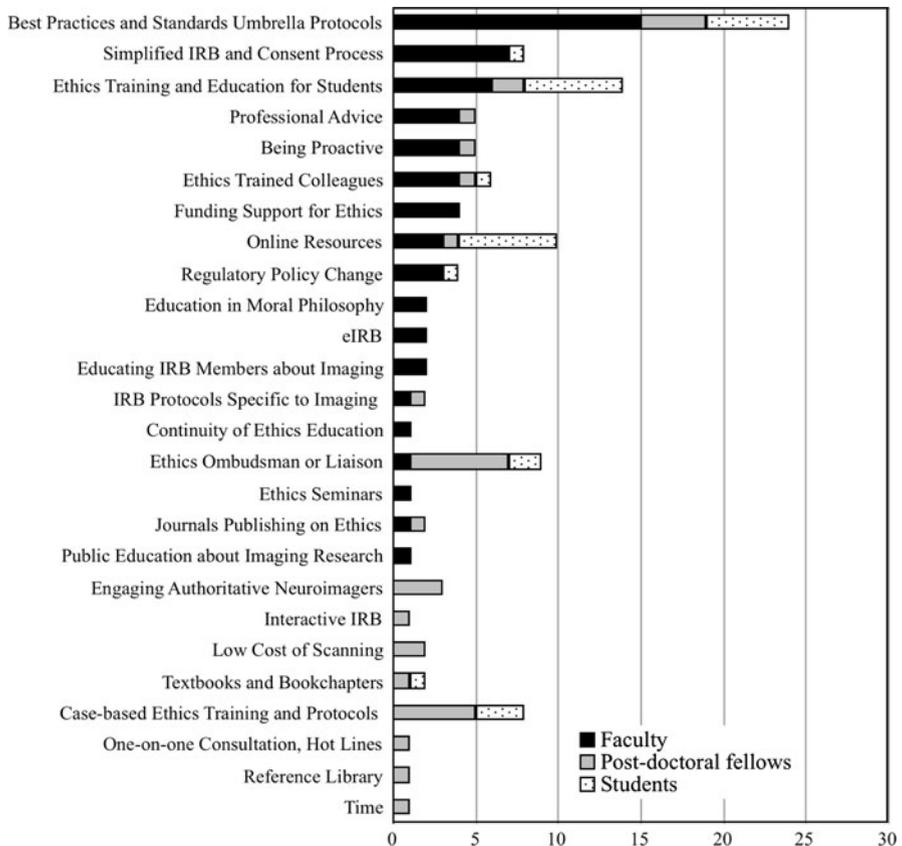


Fig. 4 Code frequencies concerning ethics tools and resources proposed by faculty, post-doctoral fellows and students

keep up with what the questions are or the questions are going to be before they become issues. (Participant 3, Faculty Group 1)

Notably, these student interviewees also advocated for the inclusion of ethics training into their PhD curricula:

I think it should be mandatory for every graduate program to have a course on ethics in neuroscience, or ethics in imaging. Like a specific course on it, and I think that should be the first course that you're required to take before you start up your studies. I think that would really help people to understand a bit more of why you have to do it, and make you think a bit harder while you're writing up the application. (Student 7)

This key issue highlights the importance of investing in ethics and incorporating it into neuroscience and neuroimaging training early, where it will have maximal impact, as seen in this insightful statement by Student 3:

I think that would be really helpful especially because ... we're kind of developing habits and learning the process.

Discussion

This qualitative study aimed to extend and enrich previous findings from a large survey of neuroimagers in the USA and Canada concerning the major ethical issues they face in the course of their research, the factors that motivate them to consider ethics and obstruct them in doing so to a greater extent, as well as the resources they require to support them in their engagement with the ethical dimensions and practical requirements of their scientific domain (Illes et al. 2010a). In follow-up to the original large-scale study, we probed these themes deeply during focus group discussions and interviews with neuroimagers across different strata of the academic hierarchy. The content and nature of discourse surrounding these issues are consistent with the survey findings and provide the added layer of depth we sought and specific solutions to the challenges raised. The time-consuming nature of dealing with cumbersome application documents and the absence of common language with IRB members represent a large administrative burden. This impacts more on senior faculty, who concentrated largely on this issue as a barrier in engaging with ethics and proposed the development of best practice procedures and standardized protocols as an effective remedy. Management of incidental findings and issues of consent and assent also figured prominently in the faculty and post-doctoral fellows' discourse.

The data collected from the student interviewees adds an intriguing new facet to previous findings. Perhaps commensurate with their relatively limited responsibility and executive freedom, as well as their natural unfamiliarity with IRB applications, student neuroimagers appeared to perceive ethics in a subtly different light. The ethically challenging issues they were mostly concerned with gravitate toward that of clear communication of neuroimaging data to the general public but also within the neuroimaging community. These students were concerned with a perceived malleability of neuroimaging data, ethically dubious scientific practice, and lack of transparency with respect to analysis methods and results reporting.

Consistent with this preoccupation concerning scientific integrity and the veracity of neuroimaging results, the overwhelming majority of the students interviewed in this study reported virtue and morality as the prime factors motivating their engagement with ethics. Faculty and post-doctoral fellows appeared to be motivated by more practical issues such as the protection of their subjects, which may also be a reflection of their position of responsibility with regard to these persons. We note that in a recent study in which participants were drawn from a Canadian pool of academics, internal motivators such as good citizenship appeared as the prime motivators for engaging with neuroethics, while regulatory pressures served as an additional motivator only for program directors but not grant-funded PIs (Lomber et al. 2010). These findings may reflect cultural and/or structural differences between Canada and the USA. Overall, it appears that the ethical preoccupations of

these students were deontological in nature while the attitudes of more senior researchers appeared to reflect a more consequentialist position.

The current study cannot contrast directly reports from faculty and post-doctoral fellows against those of students. The qualitative nature of the data represent a snapshot of a small group of individuals bound to a particular culture and time. Furthermore, the two coders analyzed the data from their own interpretive lenses. Comparison is also problematized by the different methods employed across these two groups. One might argue, for example, that face to face in-depth interviewing may have offered the student participants a safer context in which to air their ethical preoccupations concerning data malleability and science communication, which are sensitive topics that the interview method is more suited to highlighting (e.g., Mack et al. 2005). In contrast, the group setting in which the faculty and post-doctoral fellows responded may have inhibited the degree to which they were prepared to be forthcoming about such issues. However, all respondents volunteered to participate in this follow-up study, rendering the whole group a self-selecting one. Thus, self-selection may represent another potential limitation of this study. That said, self-selection may have mitigated the potential effects of the methodological difference: we deem it unlikely that a respondent who comes forward of their own accord under conditions of anonymity might choose to withhold information from their peers in a focus group interview, but not from the researcher conducting an interview. These caveats notwithstanding, our observations may represent an intuitive continuing point from which to address the roles of experience, expertise and administrative load on attitudes to ethics and concepts of ethical behavior within academia and science.

All participants constructively offered remedies to the challenges they experience in engaging with ethics. Irrespective of academic qualification or seniority, participants called for the development and dissemination of best practices in neuroimaging, consensus in lieu of variability, standardized ethics review for neuroimaging protocols that are minimally invasive, and simplified consent processes to bridge the perceived distance between investigators and experimental participants. In addition to streamlining the ethics review process, participants urged immediate changes to neuroscience curricula to include early and more focused training in ethics. Student interviewees in particular clearly identified their limited awareness of ethics issues and in some cases lack of clear grasp of what ethics constitutes in the context of neuroimaging research. These students emphasized the imperative for the incorporation and enhancement of ethics training in existing neuroscience curricula, and recognized that this can only be accomplished through top-down changes in educational policy:

I think some of that just does need to come from strong leadership within the community to just say, 'Look, you need these workshops, you need these courses, you need to really spend some time doing real discussion about the ethics of these things.' And take it, and try ... I think it's just needed to be taken seriously from an education standpoint. I mean, earning a Ph.D. should include taking an ethics course on these things. (Student 4)

There were similar urgings by faculty:

... getting it into the educational process early, probably the half credit ethics course should be bumped up to a higher level of prominence in the curriculum especially for graduate programs that emphasize career trajectories that are going to take you into human subjects research like neuroscience of biomedical engineering, so I don't know what the ethics curriculum looks like in most graduate programs right now, ours is also pretty minimal. Faculty Group 1, Participant 1

The current study brings forward the North American call for the inclusion of neuroethics training in neuroscience curricula, from its youngest to its most senior academic stakeholders, and adds to the growing voice of the international community (Conti and Corbellini 2008; Sahakian and Morein-Zamir 2009). Proposals on the form and content of learning tools and educational initiatives in a manner that accommodates the time pressures and constraints imposed by loaded curricula for students and the academic duties of post-doctoral fellows and faculty have been put forward (Lomber et al. 2010). These include a theoretical component on fundamental principles of ethics, bioethics and neuroethics, but focus primarily on applied themes of societal implications of neuroscience, translational challenges with respect to clinical populations, commercialization issues and knowledge dissemination.

Neuroimagers occupy a position of power because of the knowledge gap between themselves, the participants in their experimental procedures, and the lay public in general. Research participants are particularly vulnerable because they volunteer in confidence private information ranging from their medical history to unique metabolic readings of their brain and thoughts. With this power comes responsibility to the persons who participate in their experiments and to society at large, not least because of the persuasive power of images of the brain (Beaulieu 2002) and their potential for abuse in the creation of neuromyths (Illes et al. 2010a). Neuroethics training will furnish them with the capacity to carry out this work as aware and empowered moral agents. Neuroimagers are entitled to this training and they are calling for it now.

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