Clinical and ethical dimensions of an innovative approach for treating mental illness: A qualitative study of health care trainee perspectives on deep brain stimulation

Emily Bell, PhD, and Eric Racine, PhD

Les dimensions cliniques et éthiques d'une démarche innovatrice pour le traitement des maladies mentales : une étude qualitative sur la perspective de stagiaires dans le domaine des soins de santé sur la stimulation cérébrale profonde

Résumé

Contexte : *L'acquisition de connaissances et de pratique en rapport à la pensée critique est nécessaire pour aborder les dimensions cliniques et éthiques de nouvelles démarches ou de nouvelles technologies. Les stagiaires dans le domaine des soins de santé se servent en partie de leur formation pour gérer, raisonner et réfléchir sur les enjeux éthiques que posent certaines innovations ou technologies récentes. La stimulation cérébrale profonde (SCP) est une procédure neurochirurgicale qui comprend l'implantation d'électrodes intracérébrales, et à laquelle on a recours pour des cas de maladies de Parkinson et autres troubles moteurs. On commence à utiliser la procédure de SCP pour les cas de trouble obsessionnel-compulsif et de dépression réfractaires.*

Méthodes : *À partir d'entretiens, nous avons mené une étude qualitative afin de recueillir la perspective de stagiaires appartenant à diverses disciplines des soins de santé. Cette étude portait sur les préoccupations éthiques et cliniques liées à la SCP dans le cas de troubles psychiatriques.*

Résultats : *Les premières impressions sur l'utilisation de la SCP pour des cas de maladies mentales étaient mitigées. Nous avons identifié certains facteurs ayant influencé les impressions sur la SCP, ainsi que les informations manquantes ayant aggravé les doutes liés aux résultats à long terme et aux effets sur d'autres systèmes physiques et psychologiques. Les participants ont clairement commencé à explorer les préoccupations éthiques de la SCP. Ils ont notamment fait observer la nécessité pour les professionels de la santé de gérer les préoccupations d'ordre éthique, et ont favorisé l'autonomie des patients grâce aux choix de ces derniers, même dans le cas de démarches innovatrices.*

Discussion : *Nous discuterons des attentes des stagiaires à l'égard des preuves nécessaires au processus décisionnel, ainsi que le rôle d'une formation dans le domaine de l'éthique.*

Abstract

Background: *The acquisition of knowledge and application of critical thinking skills are required to tackle the clinical and ethical dimensions of new approaches and technologies. Health care trainees rely partly on their training to manage, reason and reflect on the ethical uncertainties of innovations and new technologies. Deep brain stimulation (DBS) is neurosurgery involving the implantation of electrodes into deep brain nuclei and is approved for Parkinson's disease and other motor disorders. Experimental uses of DBS are emerging in refractory obsessive compulsive disorder and depression.*

Methods: *We conducted a qualitative interview-based study to gather the perspectives of health care trainees from different disciplines on the clinical and ethical issues associated with DBS in psychiatric disorders.*

Results: *First impressions about the use of DBS in mental illness were mixed. We identified factors influencing impressions about DBS and information missing that compounded uncertainty about long-term outcomes and effects on other physical or psychological systems. Participants revealed nascent exploration of the ethical issues of DBS. They emphasized the obligations of health care providers to manage ethical problems and supported patient autonomy in guiding choice, even when choosing innovative approaches.*

Discussion: *We discuss trainee expectations about evidence in decision making and the role of ethics education.*

Introduction

The landscape of clinical practice and the degree to which health care professionals of different disciplines encounter ethical dilemmas are constantly evolving. Advances in clinical care require nurses and other health care professionals to acquire new knowledge and to apply their critical thinking skills in order to actively participate in scoping the clinical and ethical dimensions of new approaches and technologies. For trainees moving into the workforce, as discussed in the code of ethics of the Canadian Nurses Association, the ability to manage, reason and reflect on the ethical uncertainties of innovations and new technologies may be particularly important (Canadian Nurses Association, 2008, pp. 34–35). At the same time, both trainees and experienced clinicians need to be prepared to revisit the ethics of "established procedures". Indeed, evolving uses of common procedures may demand a re-evaluation of either the ethical judgments made about them or the best practices guiding their use.

Deep brain stimulation (DBS), brain surgery that involves the implantation of electrodes into deep brain nuclei, is one example of an established intervention (in Parkinson's disease and other motor disorders) that may call for close attention and re-evaluation. In Parkinson's disease, DBS has become a preferred strategy for disrupting the abnormal function of brain circuits. It has similar clinical effects (i.e., reducing tremor) to lesioning, but is both reversible and adjustable (Goodman & Alterman, 2012). Goodman and Alterman describe that the first published report of DBS for refractory obsessive compulsive disorder was in 1999 and for refractory depression was in 2005. Approximately 150 patients with refractory obsessive compulsive disorder or depression have since undergone DBS and the results of these studies suggest that, in some cases, DBS may lead to long-term improvement in symptoms (Goodman & Alterman, 2012). Different clinical centres engaging in experimental applications of DBS have described the implantation of DBS into different brain structures. However, its precise mechanism of action remains poorly understood.

DBS has generated public and media interest because of its potential for improving the symptoms of some patients with severe mental illness (e.g., refractory major depression, obsessive compulsive disorder) (Racine & Bell, 2012). Consequently, health care professionals from different disciplines have reflected on the ethical and social challenges of DBS for these new indications (Bell, 2011/2012; Bell, Mathieu, & Racine, 2009; Fins et al., 2011; Glannon, 2010; Hildt, 2006; Lipsman, Bernstein, & Lozano, 2010; Lipsman, Giacobbe, Bernstein, & Lozano, 2012; Rabins et al., 2009; Schechtman, 2010; Synofzik & Schlaepfer, 2008). At the same time, a range of health care professionals (e.g., nurses, rehabilitative specialists) involved in the care of psychiatric patients have not yet been asked to offer their perspectives related to the use of—and ethical issues associated with—DBS in these populations.

Our study, therefore, attempted to better understand a range of health care trainees' perspectives (nurses, social workers and occupational therapists) on the clinical and ethical issues associated with innovative approaches to treat mental illness. Using qualitative semi-structured interviews and pre-assigned readings to expose participants to background information about DBS, we explored their clinical and ethical reasoning related to DBS and innovative therapies for psychiatric disorders, and their reactions to psychiatric DBS based on the readings.

Methods

Research ethics approvals were obtained prior to conducting this study (Institut de recherches cliniques de Montréal and McGill University). Informed consent was received from all participants prior to their participation. Health care trainees (baccalaureate and master's level) in the fields of nursing, occupational therapy and social work were recruited through posted advertisements at McGill University and also by describing the study in targeted courses (e.g., focused on mental health or ethics). We sought participants from these disciplines because they were identified as key professions involved in the broader care of individuals with mental illness from which perspectives on DBS and psychiatry were lacking in the literature.

Participants in the study completed a semi-structured interview with a member of the research team over the phone or in person. Participants were required to read three general scientific articles (Kluger, 2007; Kuehn, 2007; Miller, 2009) on the topic of DBS to familiarize themselves with the use of DBS in psychiatric disorders. One of us (ER) has found previously that advance readings (media articles) can be an effective way to encourage discussion about the opinions and perspectives of stakeholders on ethical issues, especially where they may vary in their knowledge about the topic (Forlini & Racine, 2009). Although participants were required to read the three articles prior to participating, and were asked in the interview to summarize briefly what the articles described, the articles themselves were not specifically referenced by the interview grid. We acknowledged that the perspectives offered by participants would be shaped to some degree by what they read. However, this approach allowed us to ensure consistent exposure to DBS and to prompt interest in discussion about ethical issues related to its use in psychiatry with which we could not assume participants would be familiar. It also simulated a plausible scenario where health care providers could be asked by patients or their colleagues their opinion about a novel technology. The interview questions focused on three general areas: 1) health care trainee impressions about refractory mental illness and reactions towards DBS as a therapy for psychiatric disorders; 2) health care trainee perspectives about ethical and social issues described in the broader literature on DBS (i.e., risk/benefit appraisals, patient expectations, informed consent, candidate selection, personality and social factors); and 3) health care trainee appreciation for information received about DBS from the articles (e.g., limitations of information given in the articles, benefits/knowledge gained by reading the articles). Consistent with principles of qualitative research, the individual questions posed were iteratively adjusted based on earlier interviews. This process led us to ask one additional question to health care trainees in both nursing and occupational therapy (recruited later in the study) about how they felt that their training prepared them for, or contributed to ethical reflection and the management of ethical issues.

We believe that using readings about a specific case (DBS) to set the stage for examining, through qualitative interviews, the clinical and ethical reasoning and formation of judgments by health care trainees is consistent with real world practice because it: 1) elicits first impressions and early critical reasoning about the ethical and social challenges of innovation; and 2) mimics the actions that health care professionals might take to access information about new advances in medicine (i.e., seeking short and readable general science review articles).

The audio-recorded interviews were transcribed verbatim and analyzed based on a conventional thematic qualitative content analysis approach (Hsieh & Shannon, 2005). A coding guide was first drafted where explicit definitions were generated for the major content areas (i.e., attitudes towards DBS and its use in severe psychiatric disorders, perspectives towards and ethical and clinical concerns identified towards DBS and its use in severe psychiatric disorders, appreciation of information

received about DBS from the articles and appraisal of the contribution of the trainee's discipline to the ethical debate) and sub-themes. The coding guide was then enriched with illustrative examples of included and excluded content for each code/sub-code, as well as any practical rules of thumb for the interpretation and application of the codes. To test the application of the guide, a sample of interviews was coded at the piloting stage (EB) and small changes to the coding guide were carried out after discussion between the two authors (EB, ER). Once the coding structure was agreed upon, qualitative data analysis software, NVivo 9 (Doncaster, Australia), was used to conduct axial coding of the full set of data where definitions and rules for the application of each code ensured exhaustive coding. During coding, additions and changes to the coding guide were allowed given the qualitative design of the study, leading to constant comparison with previous coding to ensure consistent

and rigorous analysis. The final coding was conducted by EB, reviewed by ER and any disagreements were discussed and consensus was sought.

Results of the coding were extracted code by code using NVivo to generate a summary of content in each subnode. These summaries were used to identify interrelated data. In this phase of data analysis, the following issues were considered: 1) the clinical reasoning demonstrated by health care trainees on the topic of DBS in psychiatric disorders, 2) basic points of tension identified by the ethical reasoning of health care trainees, and 3) perspectives of participants regarding their own contributions and the contributions of their disciplines to understanding or resolving ethical issues. We summarized the interview content to generate tables of these observations and used qualitative examples to illustrate salient or illustrative features of the interview data. Qualitative data have been edited for readability.

Table 1: Observations about the clinical reasoning of participants	
Characteristics of severe, refractory obsessive compulsive disorder or depression	• Are of a personal and individual nature and will be experienced differently by each person • Can be relentless and can negatively impact many areas of daily life and overall quality of life
Opinions and perspectives about DBS in psychiatry	• Mixed and qualified opinions and impressions about DBS being a potential cure or not in psychiatry.
DBS is a cure (qualified): *"It's a very appropriate word because it could be a cure for many psychiatric illnesses" (Participant S11)* *"Uh, um, I think eventually it could be a cure. Um, I mean I think there still needs to be more research done, and like they were saying, some a bit more long-term research done … ."* (Participant S8)	
DBS is not a cure (qualified): *"I would challenge it in the sense I don't think it's been around long enough to see the long-term effects that, yes, this person's lived their whole life without ever having this mental health issues again. I don't know if I would say cure per se? But it could be a form of treatment?"* (Participant S7) *"Um, I don't feel like that is a totally appropriate description of the therapy yet, just given, you know the, the variety of results of people are still getting in, that it's not a 100% guarantee, um… I would probably refer to it as another treatment option, maybe that shows promise, or something that's still experimental."* (Participant N5)	
Factors influencing the acceptability of DBS in psychiatry	• Severity of illness • Safety and efficacy • Trials of conventional treatments • Potential for improving quality of life • Need for new treatment options in severe, refractory patients

Factors creating uncertainty about DBS in psychiatry	• Limited information about long term success and relapse
	• General lack of understanding of effects on other body or psychological systems
	• Need for investigational research to further establish efficacy and safety
	• Missing information about study sample characteristics and mechanism of action of DBS*
	   [would appreciate more information about] "the mechanisms like how does it work and why does it work, you know? Because from what I can tell, they just, it's, it's just kind of trial and error for now." (Participant O6)
	
	• Missing information about stakeholder perspectives (patient anecdotes and patient perspectives)*
	   "Um, there were no personal anecdotes of patients. You know uh, I mean, I'm-, I'm-, I'm in nursing so I always want to know what the patient says." (Participant N5)

* Participants were not given primary sources of research. However, they sometimes described elements of uncertainty related to the use of DBS in psychiatry because of information they felt was missing in the advance readings to the interview. See methods for further methodological details.	

Results

Twenty health care trainees participated in the study from the disciplines of nursing, social work and occupational therapy. Eight participants were in nursing programs, six were in social work programs and six were in occupational therapy programs. Participants are identified with a letter that identifies their professional program (S= social work; N= nursing; O= occupational therapy) and a number that represents the order in which they were recruited to participate. All participants were female and the average age of participants was 27.5 years (range of 21–45).

A. Clinical reasoning of participants

Views on (severe and refractory) psychiatric illness
Participants highlighted the diverse experiences of individuals with severe and treatment-refractory psychiatric illness. They stressed how severe mental illness detrimentally impacts daily activities and long-term quality of life (see Table 1) as illustrated by the following examples:

"Well, um, for me what comes to mind is that they're not living, they're not living a normal life like you would be living 'cause they're constantly, if you're obsessive-compulsive, you're constantly, well, obsessed and you're always having to perform these rituals, so your life cannot be normal 'cause that always gets in the way of doing something. And then, if you're a depressed person, you know, you can't experience the joy of life, you can't laugh and you can't enjoy, you know, people or your friends and so, I feel like they're not living, they don't have a quality of life or a standard of life that we would have, well people, when I say 'we,' I mean people that don't have these uh disorders." (Participant S8)

"Uh I would say, first word coming to my mind is uh isolation. Um, you know, necessarily because they're not, we're not able to, to find that therapeutic um balance where, you know, where they're gonna have some type of quality of life. Uh, so I I think these patients are very isolated … ." (Participant N1)

Views on DBS in (severe and refractory) psychiatric illness
Opinions and perspectives about DBS in psychiatry varied with a mixture of alarmed and surprised reaction:
"I think that um, my initial reaction was, you know, big shock and big apprehension." (Participant O3)

"Never heard about it, but, um, I wouldn't say it was surprising. I- I personally, I think I was like: 'Oh this is actually fantastic!'" (Participant S8)

"Um, I didn't like, it was the first time I really heard about it happening, but it wasn't, like it kind of made sense, like it didn't shock me, you know?" (Participant O4)

Overall, DBS was judged to have promising potential to treat severe obsessive compulsive disorder or depression and participants were interested and curious to learn more about it. However, most participants were unwilling to take a strong position relative to viewing DBS as a cure or not.
"… it would be nice to think that it's a possible cure, mmm, I guess it remains to be seen, uh, I don't know!" (Participant S5)

Instead, participants found it difficult to identify the conditions to be met for DBS to be considered a cure. Many participants also put aside the idea of cure for more meaningful descriptions of outcomes (e.g., improvement in quality of life). Analogies were drawn between DBS and electroconvulsive therapy (ECT), pacemakers and psychosurgery, the latter serving as a cautious reminder of a legacy of mistreatment of psychiatric patients. Key factors influencing the acceptability of DBS in psychiatric disorders were described (see Table 1) with strong confidence in the ability of evidence to resolve clinical uncertainty. Participants recognized that the goal of continued research is to enhance the available evidence and that future data will impact and inform opinions and perspectives about DBS and psychiatry in what they judged to be the "early days" of a novel intervention.

"… it seems like it's still uh, a w-, a work in progress, like I don't think I would necessarily feel comfortable recommending the use of the procedure at this point given the state of research 'cause it's still fairly new and it takes time to build up evidence and when you are using real people. Um, but uh, it seemed promising." (Participant N8)

Their clinical perspectives and opinions about DBS were informed by the advance reading material, especially since many claimed never to have heard about DBS or its use in psychiatric conditions (see Table 1).

B. Ethical reflections of participants

Embryonic/implicit state of ethics reflection
When asked about a range of potential ethical issues in the use of DBS in psychiatric conditions, often participants did not offer an explicit ethical analysis of the problem. They also rarely raised the potential for ethical concerns without being prompted. However, participants delivered an explicit set of ethical reflections where it related to the professional and ethical obligations of health care providers and to the importance of autonomy as a guiding principle for pursuing experimental therapies.

Emphasis placed on the obligations and duties of health care professionals
The professional and ethical obligations to be honest, form trusting patient-provider relationships and provide necessary information for patients to make free informed decisions were identified by participants as essential to managing potential ethical problems. This focus on health care provider obligations was conveyed when participants described tackling ethical challenges, such as the overly high expectations of patients or managing their potential influence on patients deciding on investigative approaches. In addition, participants offered their views about balancing the known and unknown effects of conventional and experimental therapies. They considered a wide range of potential effects (e.g., changes to personality, changes to relationships, undesirable side-effects) to inform these decisions, although patient autonomy and the patient's own evaluation of these effects were often prioritized over the judgments made by others. Although participants overwhelmingly wanted to support patient autonomy in guiding choice, their reflections on autonomy revealed a tension where they acknowledged the impact of factors that influence freedom of choice (e.g., desperation). They suggested the participation of others (i.e., friends, family, health care providers) to achieve a valid process of consent. The above is

a summary of major themes emerging in the reflections of health care trainees and in Table 2 we detail specific observations about the ethical reflections of health care trainees.

C. Perspectives on participants' own contributions and the contributions of their disciplines to understanding or resolving ethical issues

Participants explained that their training as health professionals (e.g., nurses, occupational therapists and social workers) reinforced specific strengths in the context of ethical dilemmas and ensuring good practice. Participants described different roles that health care providers in their disciplines played in the context of ethical challenges (Figure 1).

Acting as an advocate was described by a participant in nursing (Participant N7):

"Um, well I'm in nursing, right? And, it gets taught very early on that you're an advocate for your patients. And there are so many positions out there and so many treatments that get explained to the patient, in terms that they don't understand, and they get explained to the patients in terms of giving them hope…. So when I read something like this, my advocate flag went up …"

A participant in occupational therapy (Participant O2) stressed her role in considering the patient holistically:

"I think my profession really… are characterized by holism. So, we really, we are holistic, we really see the patient from all points of view, and we all make, we always you know, in my studies it is always "have you identified all the stakeholders? Have you identified, like, affective, emotional, whatever, physical component?" So, I think that we, we would be hav- having like a very good global picture of the patient, as well as like, its relation to like the DBS, and its suitability for DBS."

Table 2: Observations about the ethical reflections of participants *

Identified important and meaningful contrasts between the use of experimental and conventional therapies
- Justified the use of DBS (experimental therapy) as a last-resort intervention despite its invasiveness and uncertain risks and benefits.
- Acknowledged that there may be room to consider experimental therapies in light of the undesirable or negative effects of other treatment options or the severity of illness.

  "Because it's still in the um testing phase, I would say, anyone who kind of has very severe side-effects, sometimes they've tried everything and nothing's working, for example, schizophrenia, someone who has major depression, a severe case of obsessive-compulsive disorder. Like I, someone who's really at the extreme end, and you know, they haven't, they've tried everything else and it's not working." (Participant S7)

- Identified that the availability of evidence about safety and risk, contrasted with current therapeutic approaches, should determine if DBS could be tried before conventional therapies
- Established that the best course of action for individual patients is determined by weighing the evidence.
- Supported patient autonomy in determining when and if it is appropriate to seek investigational therapies (although identified some boundaries [i.e., should not be first therapy tried, time should have passed, it should be last resort]) and very rarely alluded to an obligation of health care providers to grant or refuse access to experimental approaches.

  "So, somebody with obsessive compulsive, I guess for us, we don't see it as that big a deal like being, you know, controlled by our thoughts really and doing all the rituals but for them, they're seeking some kind of treatment that will like get rid of that, you know? So, something as invasive as deep brain stimulation would be, you know, something that they might want to try because everything else doesn't work." (Participant O5)

  "So, I don't see why, you know, someone really wants to try it after a few things? Why not?" (Participant O6)

  "… it's a very hard limit to put on someone to say you can't get this treatment until you've tried all these other ones." (Participant O1)

Supported autonomy as a guiding principle for individual choice under certain conditions
- Emphasised that the ultimate decision about whether to enrol in experimental trials should be that of the patient.

  "And, but I still feel like it's their choice, and we can provide the science and, you, you know, the best treatment we can, but they are the ones that need to make the educated um, choice, even though I might not agree with it or not." (Participant O4)

- Framed autonomy around a set of obligations of healthcare providers, including:
  - to assess the patient's ability to give consent;
  - to educate the patient about the intervention;
  - to disclose potential risks and benefits;
  - to support and uphold patient decisions;
  - to make patients aware of broad social and relational consequences;
  - to adopt an individualized approach and to provide counsel that is sensitive to a patient's situation.
- Identified that certain factors may constrain the choices patients see as available to them or limit their ability to make free informed decisions (desperation, family, difficulty assessing risk of the intervention, holding out hope).
- Suggested ways to improve the consent process such as making it an iterative process, increasing education, and involving those who have expertise and specific knowledge about the patient and their preferences (interdisciplinary teams, family, friends, case workers, social workers, patient advocates).

Identified that unrealistic patient expectations must be managed to ensure best clinical and ethical outcomes
- Expressed concerns about the potential effects of desperation, overly high or biased expectations and hope:
  - to impact patient's desire to pursue investigational therapies;
  - to shape satisfaction with clinical outcomes (i.e., meeting—or not meeting—expectations of DBS as a cure);
  - to influence the relationship with healthcare providers.

  "I think uh, there is definitely a possibility that someone could uh, you know, interpret this as their magic bullet or whatever you call it." (Participant N5)

  "...I think that can be um, like any other kind of treatment out there that's held out as the next great thing and um, especially people are um, frustrated by, by um, a condition that they're living with and they do want um, to not have that part of their lives um, I think it'd be very important to um, explain that this, this isn't necessarily um, you know whatever their expectations are there is no guarantee that it would turn out um, um perfectly according to their expectations I guess if there is a range of outcomes." (Participant N8)

- Suggested actions that may help to ensure realistic expectations and reduce the negative effects of desperation, including:
  - educating patients and communicating clearly;
  - being honest, transparent, and realistic about the potential clinical effects;
  - overly emphasizing the potential for outcomes that do not meet expectations;
  - drawing on information from empirical studies to substantiate the evidence and disclose all possible effects and outcomes;
  - adopting an individualized approach to the evaluation and management of patient expectations.
- Acknowledged that sometimes patient expectations can persist to be out of line with the information disclosed or discussed.

  "Yeah, they probably would think 'oh this will cure everything,' but I think that's why they would need to be, you know, told that: 'Look, this is, you know, we're still testing these things, and again it might not be a complete cure, but you should, you probably would feel better, which is better than not feeling better.' You know what I mean? So, I think they need to be fully warned of. We can't stop them from believing what's, you know, I mean they could be like: 'OK, you're telling me this, but I still believe I'm gonna be so, a hundred percent better ...'" (Participant S8)

Attributed distinctive meaning to personality or personal identity changes that may accompany brain-based interventions
- Recognized personality as an important feature of the person and gave mixed opinions about what they believed could be the effects of DBS on personality (e.g., from "extreme" changes (Participant S11) to more minor changes, "*don't think there is gonna be drastic personality changes*" [Participant N3]) and about the evaluation of these effects.
- Viewed changes to personality as being permissible.
- Suggested that the evaluation of personality effects should be done by the patient and/or those closest to the patient, but also that these can be given value by external observations (i.e., a change from an individual seeming negative to positive is seen as being good).
- Sometimes equated the concepts of mood and personality and at other times discussed these as being different but influenced by each other. Described differences between the concepts as residing in the internal versus external nature (e.g., mood as internal, personality as "how we are in the world") (Participant S4), or the opportunity for change (e.g., mood as more changeable than personality).

Emphasized the importance of understanding and gathering evidence of risk and safety
- Understood that risk and safety information is needed to inform the appropriateness of trials (e.g., to inform even the start of human trials), and for patients and health care providers to fully appreciate the balance of possible benefits and risks.

  "If you make a mistake, it can affect the person's life, it can change the life completely... you know, somebody would be willing to consent to do this and there might be some pretty bad side effects associated with it." (Participant O5)

- Viewed a wide range of potential relational effects of DBS (i.e., DBS as restorative for the patient and their relationships or DBS as creating new personal identity challenges and making things more difficult for self and for others) that must be considered in the broad effects of the intervention.

  "Um, yeah, I guess it's kind of like somebody who's, you know, a soldier and returns from the war, and obviously you're 'BANG,' how am I supposed to function uh in this society when I didn't, wasn't able to finish schooling, don't know how to relate to people too well, it's always just a bit about basic survival." (Participant S5)

  "And it's human life, right? And so perhaps this person will end up being really productive and they could turn out to be something great, whereas maybe they wouldn't have had that chance if they didn't have this." (Participant S8)

*Other, less salient reflections concerned resource allocation, follow-up in the community and the use of DBS for enhancement purposes. Regarding enhancement uses, participants questioned whether there would be an actual demand for such uses, especially given multiple existing barriers (e.g., regulation, cultural norms). Concerns about follow-up care clustered around possible challenges of a newly introduced technology for community care. Only a few comments concerned resource allocation and most indicated that resources should be attributed to psychiatric care and that stigma could impede this.

Figure 1: The roles described by health care trainees characterizing the contribution of their professions (nursing, social work, occupational therapy) to ethical reflection and the management of ethical issues

Discussion

Our study intended to better understand the perspectives of health care trainees on the ethical and clinical dimensions of an innovative approach for treating mental illness using the relevant example of deep brain stimulation, which has moved from neurological practice to trials in psychiatric conditions. Participants' first impressions about the use of DBS in mental illness were mixed. They identified factors increasing the acceptability of its use and missing information, which adds to the uncertainty about long-term outcomes, as well as effects on other physical or psychological systems. They were particularly sensitive to the overall impact of mental illness on patients, and they acknowledged the important role of using meaningful outcomes (i.e., improved quality of life) to establish treatment success. Participants revealed only fairly nascent exploration of many of the ethical issues that have been alluded to in the context of DBS (some of which may be common to other innovative approaches). They emphasized the obligations of health care providers to manage potential ethical problems and wanted to support patient autonomy in guiding choice, even when choosing innovative approaches. However, a range of factors could influence the freedom of this choice in DBS. Participants identified specific strengths they bring to understanding and solving ethical dilemmas they see as being in line with their own professions' role in caring for patients. Below, we discuss two key points of interest stemming from our data:

(1) expectations for evidence and information to guide clinical decision-making regarding innovative approaches, and (2) the role of ethics education in influencing the identification, prioritization and approach to handling ethical challenges.

Expectations for evidence and information to guide clinical decision-making regarding innovative approaches
One key observation in our data was that participants were very sensitive to anticipated gaps or the lack of information in evidence for DBS in mental illness, which resulted in uncertainties regarding its efficacy and risks. This lack of information or evidence also, perhaps understandably, prevented participants from taking a definitive position on the appropriateness of the clinical use of DBS. The clinical reasoning of health care trainees was, thus, based on the assumption that continuing research would generate new evidence, which would help resolve these uncertainties. At the same time, this evidence would also resolve questions about the most appropriate time for patients to be offered investigational or innovative options (as a last resort or even before standard approaches).

Resolving uncertainty in medical decision making related to innovative approaches
Unfortunately, what may seem like a somewhat simple paradigm ("*evidence needed to inform future use*") is surely more complex and is practically complicated by other challenges. For instance, it assumes that access to the most up-to-date information in the literature regarding experimental or innovative uses will resolve

some of the uncertainties that affect medical decision making. However, considerations regarding the small size of surgical trials, variations in sample characteristics and the impact of case studies in the published literature may also influence the quality and usefulness of evidence, especially since these are marked traits in literature on surgical trials (McCulloch, Cook, Altman, Heneghan, & Diener, 2013). Schlaepfer and Fins (2010) have highlighted the particular challenges brought by the publishing of individual case reports in DBS literature. Selective publishing encourages the "excessive reliance on a single-patient case report" and can lead to overly optimistic expectations, or dismissals of risks (Schlaepfer & Fins, 2010). Another important factor for resolving uncertainty, valued by participants in our study, related to deliberation about important endpoints or outcomes to measure in investigative trials. In Parkinson's disease, an approved indication for DBS, the literature presents some evidence of psychosocial and relational challenges faced by patients and their partners despite measured improvements in motor symptoms of the disorder (Agid et al., 2006; Schupbach et al., 2006). What both of these examples put in perspective is that charting the research needed or published that is most useful to resolving uncertainty is complicated and requires a realistic appraisal of the value of different kinds of available evidence.

Incorporating patient values and preferences in decision making
When faced with conditions of uncertainty in decision making, other important practical and theoretical issues surround the role of the patient and the consideration of their values and expectations in making decisions about innovative or experimental approaches. Participants stressed the active role that patients with severe mental health problems can play, signalling a clear deepening of respect for this patient population, with recent DBS literature giving credence to this view. Research suggests that depressed patients should not be presumed to lack decisional capacity (Dunn et al., 2011). In fact, depressed patients may have reasonable motivations for entering DBS clinical trials despite the fact that they may have some therapeutic misconception (i.e., over-estimation of benefits, under-estimation of risks, or conflation of the goals of research with those of care) (Christopher et al., 2011; Leykin et al., 2011). Of course, making decisions or recommendations about the use of innovative approaches relies on the ability of practitioners to help patients balance benefits and risks (maximize beneficence and minimize nonmaleficence), often under conditions of uncertainty and where evidence about efficacy and risk is lacking. In our study, participants placed a great deal of value on the role of patient autonomy in guiding decisions about innovative therapies. It is possible that the presence of clinical and scientific uncertainty augmented the importance of patient preferences and values in contributing to clinical decisions. Of course, if patient autonomy is to be given priority, then it becomes imperative that patients are well informed and not acting under the influence of strong bias about the potential effects of DBS, a concern generated by overly optimistic portrayals of DBS in the media (Racine & Bell, 2012; Racine, Van der Loos, & Illes, 2007). Future research could explore whether—under conditions of uncertain evidence of risk and safety—health care professionals view that there is more room for respecting patient autonomy over other principles (beneficence, nonmaleficence).

The role of ethics education in influencing the identification, prioritization and approach to handling ethical challenges

Health care trainees in our study rarely offered unprompted descriptions of specific ethical concerns or conflicts in the case of DBS in psychiatry. Formal frameworks applied to ethical reasoning were not identified, yet health care trainees clearly had intuitions about ethical challenges and were able to identify potential solutions to mitigate these, especially in cases where health care provider obligations figured prominently. Below, we discuss two factors that we hypothesize may intersect with these observations and that have important ramifications for understanding how health care professionals identify and manage ethical challenges in their practice.

Challenges implementing professional ethics education
An early reaction might be to question if these findings are indicative of a failure of ethics education in some disciplines. However, professional societies have committed to ethics education in training (Weber, 1992) and there is evidence that demonstrates that ethics education (and in some cases education alone) may, in fact, improve the moral development of students in health care disciplines such as nursing (Auvinen, Suominen, Leino-Kilpi, & Helkama, 2004; Dierckx de Casterlé, Janssen, & Grypdonck, 1996; Duckett et al., 1997). At the same time, there is acknowledged variability in the form and content of formal ethics education (Burkemper, DuBois, Lavin, Meyer, & McSweeney, 2007) and some disagreement about whether particular curricula lead to improved moral development (Auvinen et al., 2004). This is overlaid on the challenge of carving out ample time for ethics education. In Canada, a recent review of ethics content in the online curricula of occupational and physiotherapy programs has demonstrated that a mean of only approximately 5.9% to 6.5% of the total proportion of credits contain any ethics training (this includes credits for courses where ethics was only a portion of the described course) (Hudon et al., 2013). This is despite the fact that health care trainees in our study, communicated that the discussions about ethical issues surrounding DBS and mental illness were interesting and valuable.

A lack of common interdisciplinary understanding about ethics
In fact, differences could exist, and may be encouraged through education and professionalization, in the way that disciplines conceptualize ethics and interface with the language of ethics. In our study, for example, health care trainees seemed more sensitive to ethical challenges in situations where health care provider obligations were central, where there was an emphasis on issues related to preserving autonomy and where solutions were characterized by health care teams' actions. It may not be surprising then, when examining both the different philosophies prescribed in education and in these disciplines at large, that these issues, over others (i.e., resource allocation), were highlighted by the trainees in our study. For instance, weight has been placed on education and practice of an ethic of care in nursing (Lemonidou, Papathanassoglou, Giannakopoulou, Patiraki, & Papadatou, 2004) and values related to increasing patient participation and autonomy are central within the professional ideals of rehabilitation training programs (Canadian Association of Occupational Therapists, 2007). This is not to

say that other ethical principles are not emphasized in the codes of conduct of these professions (Canadian Nurses Association, 2008). Other important conceptualizations of ethics might see: 1) ethics as a form of advocacy to protect patients and their rights, 2) ethics as a negotiation of professional values and professional identity relative others in the team, and 3) ethics as a form of moral agency where health care professionals identify their own moral positions (Delany, Spriggs, Fry, & Gillam, 2010). Similarly, Larouche and Flaherty (2000a, 2000b) propose an analysis of the contribution of different disciplines to ethical analysis/deliberation and emphasize, for example, the potential actions of social workers as advocates and as "moral creator, emphasizing shared responsibility and broad inclusion", and of nurses as "moral reproducer", "moral interpreter" and "moral creator" (Larouche & Flaherty, 2000a, 2000b). Unfortunately, the lack of a common application or meaning of ethics across disciplines may seem like different members of a health care team are speaking different languages of ethics, influencing their identification and prioritization of, as well as their approach to ethical issues. As Kaldjian and colleagues (2013) state, "a shared language of ethical terms should improve communication, which not only carries immediate practical benefits, but also respects the moral imperative of explaining and justifying actions that affect the lives of other persons ..." (Kaldjian et al., 2013). This does not decrease the potential importance of having a specialized ethics attached to different disciplines, but hazards caution in understanding the relative content of different ethical reasons drawn from different training or professional contexts. Table 3 contains suggestions to explore and develop interdisciplinary approaches to ethics.

Table 3: Recommended actions for improving interdisciplinary ethics

- Engagement of professional societies and peer groups/networks in identifying particular discourses about ethics
- Increased awareness of how health care professionals' own training shapes ethical reflection
- Identification of common elements to be taught and adopted in ethics (practically and philosophically) among allied health care professionals
- Examination of the ways that ethics learning is incorporated into individuals' identity as professionals and into their practice
- Identification of ways that multidisciplinary teams impact the ethical philosophies of their individual members
- Measuring the impact of discipline-specific ethics training programs

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Limitations of this study include small sample size and context-dependency built into the recruitment strategy. Participants in the sample had a range of experience working as health care professionals and in the trainee setting (some mature students had already completed some years of professional work) and we do not know the extent of ethics training/education, if any, received by any health care trainee at the time of the interview. Unfortunately, our recruitment strategy did not enable us to determine how many of the individuals ultimately invited to participate declined and only female students volunteered for

the study. We must also acknowledge that participants' perspectives were likely shaped to some degree by the advance readings, although it is impossible to know by how much or with what impact. In addition, the advance readings themselves contained some very minimal information about ethical concerns associated with DBS and this could have also impacted the issues emphasized by participants. We acknowledge common limitations of qualitative research such as unknown generalizability, as well as the possibility of subjective input of researchers into study designs, questions and data analysis.

Implications for nursing

There is a need to better explore the meaning of ethics in the context of the nursing profession and the core features that signal the identification of ethical challenges from the perspective of nurses. Training programs should seek to incorporate perspectives of nursing that are coherent across the discipline and highlight where differences in discourse may exist with other professions. Ultimately, the recognition of diverse discourses about ethics will inform the management of ethical challenges within multidisciplinary care teams. Nurses could play a leading role in the development of interdisciplinary health ethics.

Conclusions

New technologies and health interventions are creating a dynamic clinical environment where the ethical responses they generate may need to be revisited periodically. The recent development of trials for DBS in psychiatric disorders—beyond approved neurological conditions—creates such a situation. We explored the case of DBS and found that trainees from nursing and other disciplines struggled with both the uncertainty surrounding such new applications of technology and how to factor their own disciplinary backgrounds into a broader ethical analysis. Specific actions for enriching our understanding of ethics discourses could include engagement of professional societies in understanding the relationship between professional training and attitudes towards ethical dilemmas.

About the authors

Emily Bell, PhD, Associate Researcher, Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM), Montréal, QC

Eric Racine, PhD, Director, Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM), Montréal, QC

Address correspondence to: *Emily Bell, PhD, Associate Researcher, Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM), 110 avenue des Pins Ouest, Montréal, QC H2W lR7*

*Tel: (514) 987-5500 ext. 3327; Fax: (514) 987-5763; Email : **emily.bell@ircm.qc.ca***

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