Interview

Qualitative research to determine social acceptability of neurosurgery for psychiatric disorders
— Interview with Professor Mark Bernstein* —

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Interview and translation :
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Abstract

This article is the record of an interview with Professor Mark Bernstein, a bioethicist-neurosurgeon from the University of Toronto, after he delivered a lecture during the International Satellite Symposium on neurosurgery for psychiatric disorders, held at the Tokyo International Exchange Center on May 27, 2013, endorsed by the World Society for Stereotactic and Functional Neurosurgery (WSSFN).

In his lecture and in this interview, Professor Bernstein introduced a number of qualitative research that he conducted on patients and surgeons to determine the acceptability of surgical interventions to treat psychiatric disorders. He believes that this kind of survey is necessary in order to develop a consensus on how to deal with ethically questionable medical procedures, especially psychosurgery.

He also expressed objections to the use of placebo in clinical studies. He equates placebo use to "deception" even if the patient was informed and has given permission to such use. In the Research Ethics Boards (REBs) that he attends in his university, he requests for scrutiny on placebo-controlled trials even if these trials are conducted by excellent researcher-surgeons. On the other hand, he acknowledged that the trend is now changing as more and more REBs are now accepting/approving placebo-controlled trials.

With regard to involuntarily commitment/treatment of persons suffering from psychiatric disorders, Professor Bernstein explained that the "Health Care Consent Act" of Ontario provide rules with respect to consent to treatment, participation in clinical research, and admission to a care facility of persons lacking the capacity to make decisions, including children, persons with psychiatric disorders, or adults who do not have mental capacity to make decisions. He explained that these rules define the hierarchy of supportive family members or public guardian who can make decisions on behalf of such persons.

We believe that a profound discussion of these perspectives, which have not been extensively discussed in Japan, may spur some meaningful evaluation, especially on the issue of ethical acceptability of experimental surgical intervention for psychiatric disorders.

Key words
psychosurgery, deep brain stimulation (DBS), qualitative research, psychiatric disorder, neuro-ethics

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1. Qualitative research concerning “psychosurgery” and enhancement

Interviewer　Thank you for your acceptance of this interview just after your lecture at the international satellite symposium titled “Surgical approach to Psychiatric Disorders: Revised What's going on in the world?”, held on May 27, 2013, at the Tokyo International Exchange Center, endorsed by World Society for Stereotactic and Functional Neurosurgery (WSSFN). This was held as the satellite symposium of the 16th WSSFN, and you also have additional lecture at the morning session of WSSFN on 30th. I think it is very meaningful to introduce your research results to Japanese audience as such kind of qualitative researches have not been often conducted in Japan. So at first could you please introduce your work briefly for the readers of this journal.

Bernstein　There is very little of discussion on the ethics of psychosurgery. And often, such discussions are generated by individuals. For example, I was on a CIHR grant (Canada Institute of Health Research) six years ago of which the principal investigator was Francoise Baylis. She's a famous Canadian bioethicist. The grant was to explore patients and communities' attitudes, society's attitudes, towards psychosurgery. And that's a little bit of what I presented yesterday. After that, we did some projects on qualitative research. I'm one of the few surgeons who does qualitative research. It's a wonderful way to assess things that cannot be assessed with quantitative.

We did four qualitative researches (interview and questionnaire survey) which I showed yesterday – one on patients in Toronto (Table 1) [1] ; one on surgeons in Toronto (Table 2) [2] ; one on surgeons in North America (Fig. 1, 3) [3] ; and one on surgeons in the world (Fig. 2, 3) [4]. The fourth one

Table 1　What do patients think of psychosurgery?

- We did a qualitative study with 27 patients undergoing brain surgery.
- Results: Surgery for depression and OCD is ethically acceptable.
- Results: Surgery with the explicit aim of altering normal or maladaptive traits is not ethically acceptable.

Source: Reference 1

Table 2　Results at one center

- Qualitative interview-based study.
- 47 neurosurgery staff, residents, fellows, and other neuro-clinicians.
- Case presentations:
  Case 5. A war veteran has PTSD caused by extreme experiences that occurred during military action. Ten years after these experiences, all available medical and psychiatric therapies attempted have been unsuccessful. Using fMR imaging and DBS, a team of neurosurgeons can successfully suppress the recall of the specific experiences that are causing this patient distress.
  a) Is it ethical to surgically eliminate memories in this situation?
  Why or why not?
- There is widespread support for neurosurgery for psychiatric disease given adequate informed consent and rigorous scientific methodology.
- There is general opposition towards use of neurosurgery for enhancement; alteration of nonpathological traits was generally found to be unacceptable.

Source: Reference 2

Mark Bernstein BSc (Physics), MD, MHSc (Bioethics), FRCSC

Mark Bernstein is a neurosurgeon and former Head of Division, at Toronto Western Hospital, University Health Network, and Professor of Surgery, University of Toronto. His main area of clinical focus is surgical neuro-oncology. He is also a dedicated educator, having won numerous teaching awards. He is passionate about helping advance neurosurgery in the developing world where he has made about 20 visits to teach inside and outside the operating room. In 2011 he was awarded the Greg Wilkins-Barrick Chair in International Surgery to support this work. In 2003 he completed a Masters of Health Science in Bioethics. He explores various ethical issues and other aspects of patients' experience using qualitative research methodology. He has published over 300 scientific papers and book chapters, a Textbook of Neuro-Oncology, and about 150 non-medical stories, many of which attempt to bridge the gap between the surgeon's world and the public. He is married to Lee, a native Los Angelina, and has three grown daughters, and several canine children and grandchildren.

Fig. 1 Result of the survey of North American functional neurosuegeons

- Online survey distributed to 299 Functional Neurosurgeons in North America.
- 84/299 completed the survey (28% response rate).
- 50% of respondents are engaged in psychosurgery.
- Most common psychiatric indications
  - Depression (58%)
  - OCD (36%)
- 85% believed psychosurgery will increase globally in the future.

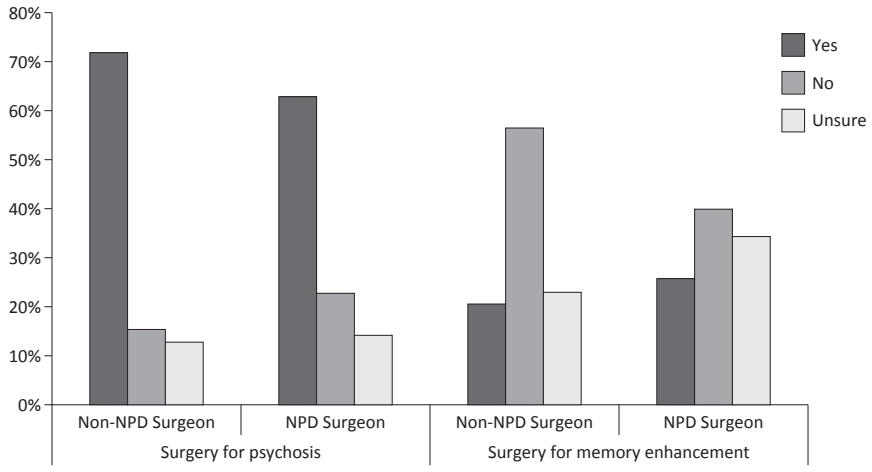

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Fig. 2　Survey of international functional neurosurgeons

Enhancement attitude

Do you foresee deep brain stimulation and other neuromodulation technologies being used within the next 50 years in non-pathological states for cognitive enhancement, such as for memory enhancement?

◯ Yes　◯ No　◯ Unsure

Suppose a safe and effective neurosurgery is available to enhance memory capacity in otherwise healthy individuals. Would it be ethical to offer this elective non-essential surgery to individuals who requested it?

◯ Yes　◯ No　◯ Unsure

If yes: Why is it ethical?

Please check all that apply.

☐ Individuals have a right to access any form of enhancement technology
☐ Cognitive enhancement is morally equivalent to cosmetic surgery
☐ Other (please specify)

Another sample case scenario

Suppose a safe and effective DBS surgery is available that can enhance personality, like making a selfish person less selfish or a greedy person less greedy. Would it be ethical to offer this non-essential surgery to individuals who request it?

- Online survey distributed to 831 Functional Neurosurgeons worldwide.
- 106/831 completed the survey (12.8%).
- 54% of respondents were engaged in psychosurgery.
- 95% believed the volume of psychosurgery cases will increase globally in the future.

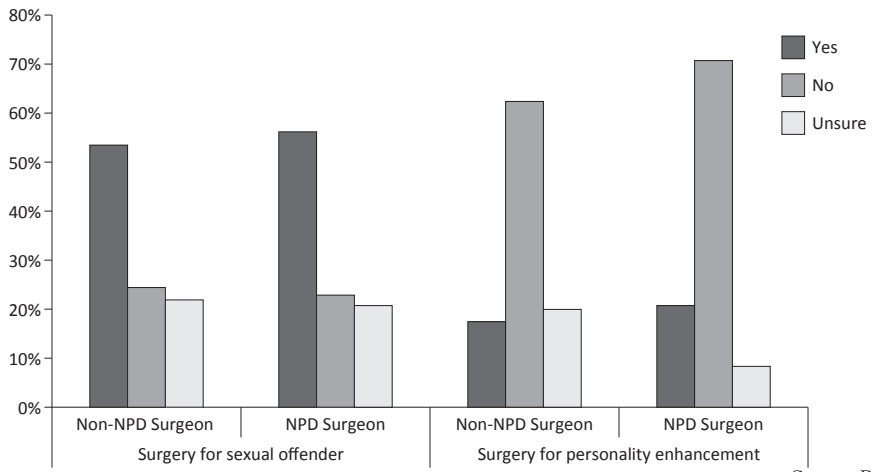

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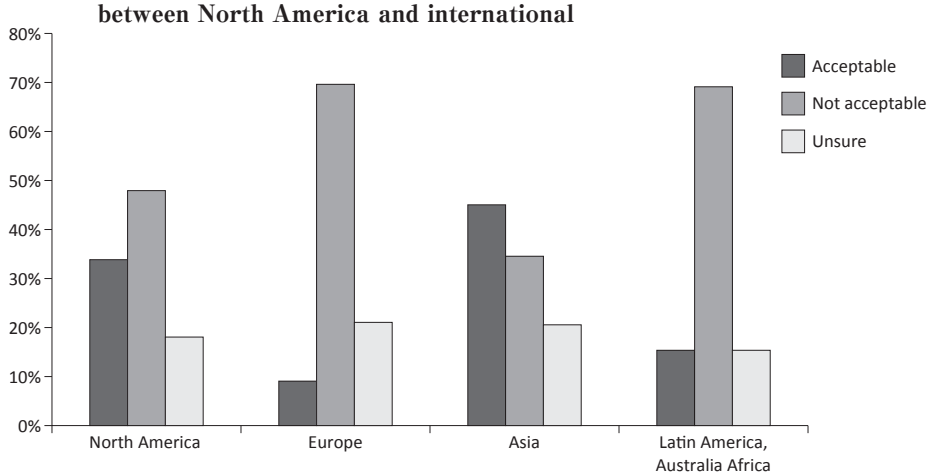
Fig. 3　Comparisons of acceptability of surgical enhancement of memory between North America and international



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included the Japanese. What better way to find out what people's attitudes are than asking them. That's all qualitative researches – Asking – so you sample patients and doctors and then ask them "Is psychosurgery for depression acceptable?" Of course with depression, they almost all said "Yes, it's acceptable", including those in Japan. Is psychosurgery acceptable for enhancement? Not so much. So with these studies, immediately, we have an idea whether there is an "ethical marketplace" out there.

We're working with the psychiatrists on this. So we've got three groups of patients. We've got patients with depression who have ECT (electroconvulsive therapy); patients with depression treated with drugs; and patients with depression treated with DBS (deep brain stimulation). We're doing qualitative interviews on those three groups on their acceptance of psychosurgery. That's a neat study because it incorporates the psychiatrists as well. Some of the yesterday's lectures, neurosurgeons said psychiatrists are not interested in surgery. But in Toronto we have a good working relationship with our psychiatrists. The Chief of Psychiatry at the university is one of the coauthors in Professor Andres Lozano's work (Lozano is one of the lecturers of the above mentioned symposium and interview with him was previously published in this journal [5]). But in general, people are right – general psychiatrists out there in the community are not very interested in this psychosurgery.

So I guess, for surgery, if this all comes from this past experience that Dr. Nudeshima spoke about (one of the lecturers of the above mentioned symposium, spoke about historical issue of "lobotomy" in Japan), that was such a stain of a culture of neurosurgery in psychiatry, and it looks like it's going to take another generation to clean that stain. For me it seems that the stain is already being cleaned. Surgery is being done for depression worldwide – certainly in North America and in some of Europe and in some of Asia – South Korea and China. To be perfectly honest, I think psychosurgery for depression to me it's a no-brainer. I mean, have you seen depressed people? It's a terrible life. It's worse than death. So if nothing works, surgery, sure why not? That's like appendicitis. Depression is a terminal disease. If you don't recover, you're going to die. Nobody would think of taking out a brain tumor as being experimental or taking out the appendix. Why not treating depression? That's just obvious. Even just having a debate about that is silly. It's the enhancement that is a debatable part.

Dr. Nudeshima's work is really historical expose which I'd love to read. But his presentation didn't include how people of these days think about it. Only documentation of the past won't help the future. What I'm trying to do with my work is to help the future. I'm a surgeon and a bioethicist, so I'm lucky I have my feet in both camps, and I can work with both groups.

There's a government-funded debate on this, like the CIHR grant. But while the government is supporting this, it's really generated by individuals. If I had not come up with this research project, I don't think anybody else would have done it. Even Professor Lozano, who's a world leader on this and he's my partner. But surgeon scientists are not interested in this kind of debates. Surgeon-nonscientists are of course not interested in. But in between, is the ethical discussion. Both extremes are not interested for different reasons. But in the middle, here's a guy like me, trying to raise this debate.

At the end of the meeting, your colleague had a slide of the need to get consensus, from talking to patients and doctors, which is exactly what I was talking about.

Professor Bernstein, giving lecture at the international satellite symposium "Surgical approach to Psychiatric Disorders: Revised What's going on in the worlds?" held by the World Society for Stereotactic and Functional Neurosurgery (WSSFN)

2. Hesitancy and openness in the debate toward consensus development

Remember the "killer robots", which appeared in my presentation. If the whole world says No to killer robots, then government should not put killer robots out. No to psychosurgery to increase memory, then we shouldn't do it. We surgeons should not be willing to do it if society says "No, it's not a good idea." So that's simply what my research is about. What you saw yesterday at the meeting may be indicative of what the surgeons feel about this (One surgeon raised objection to Professor Bernstein's presentation). Maybe they don't want to have this discussion. In general, I think surgeons are fairly reactionary people. We're fairly right-wing people.

Most of us in my profession are not very progressive-thinking, and some are frightened by even just having a conversation about it. What happened yesterday shows you how receptive or not receptive surgeons may be to having this kind of discussions because it's very threatening. If we find that the procedure does not have wide acceptance, it may alter how people have to practice. On the other hand, if Japanese neurosurgeons here said "Yes, psychosurgery for depression is okay" – maybe they will feel badly because they're not doing it.

They'll say "Oh, this guy has found out that patients are open to it and surgeons are open to it. I must be a bad guy because I'm not offering it to my patients." So it's very threatening when these kinds of discussions happen. It's very threatening to those on either side of the middle. That may have been representative of the way a lot of people think. As it turns out many people came up to me after meeting and said, "We really enjoyed your talk." So many people, actually mainly North Americans, we are very open; Europeans are not so much; and clearly, Japanese not so much. I think Koreans and Chinese, yes, they're very open. They're very interested in doing anything.

There is another good example of a controversial issue of vaccination. You know if there is a vote in the Japanese public, and it turned out the 87 percent were in favor of vaccination, and 13 percent were against it, that would help people make sensible decisions. So that's what we're trying to do. We're trying to find out what the majority of society would support or is ready to accept. Before the surgical operations for memory enhancement or even depression become widely available, doctors and patients need to know if it's ethically okay to do it, right?

Interviewer　I think there is a difference between compulsory vaccination and surgical oper-

ation for memory enhancement or for psychiatric diseases. In the case of surgery for memory enhancement or for psychiatric diseases, it is possible for the patient to choose whether they should have the surgery or not.

Bernstein So let's consider about the vaccination which is not compulsory. Even if it is not compulsory, it's sometimes controversial. Maybe all of these controversial issues should be made available for decision by individuals, accepting the situation of where we use utilitarian ethics where the public good is at stake.

If it's shown that a society is vulnerable; if everybody does not get vaccinated for polio, then the good of society is more important than your individual right and my individual right, and then we do it. That's why we all pay taxes, because the rights and the duties to society are more important than people's individual rights. I can't say I don't want to pay taxes because the good of society requires me to pay taxes. That's a utilitarian ethics. In DBS (deep brain stimulation) or in psychosurgery or in enhancement, it really is an individual decision. If there's no interest in it in society then don't waste time and money in trying to propose it.

Interviewer So how do you think about the issue someone pointed out, a Chinese lecturer was questioned that Chinese government use psychosurgery for political reasons.

Bernstein It was an unfair question. But it was also a fair question, you know, but it was impossible for the lecturer to answer. As we all know, the Chinese government is a little different than some other countries. And there is potential for abuse. But that's another reason for us to have these public debates. If the public, the doctors and the patients are already talking about the ethics of DBS, it will be more difficult for the government to impose its will on the people, right?

So I don't think it's an issue anymore in Russia or in China. Certainly 10 or 15 or 20 years ago, it was probably an issue, but not now. China is opening up. They wouldn't do anything so foolish as to do mandatory treatment to prisoners and stuff. I'm an idealist, but I don't believe they would do that.

3. Ethical consideration on placebo

Interviewer On a different point. How about the discussion on placebo use or sham surgery?

Bernstein There's never been a good qualitative study on placebo, asking people if it's acceptable. I personally believe it's wrong because I think it's deception. Even if you tell your family doctor, "I give you my permission to deceive me," I still don't think it's right even if we give permission for deception. It would be like saying you give your husband permission to cheat on you. Even if you give permission, it's not right if he does that. So my view is that wrong is wrong.

Interviewer So in your opinion, even if the researcher explains to the research subject – "you may be part of the placebo group.", you don't agree to placebo use.

Bernstein I don't think it is right. I think it will be like explaining to your spouse – "I'm going to fool around. I'm going to cheat on you. Do I have your permission." "Oh yes, dear, you have my permission." "Okay, I'll cheat." So to me it's a deception, and it's wrong. But I'm in the minority on that. Most people do not feel strongly about placebos. I think placebos are fundamentally wrong.

Interviewer I can understand your opinion. In Japan also, there are some bioethicists who have similar opinion as yours. But how is the discussion at the ethics committee of your institute on that topic, because Professor Lozano already conducted the placebo trials?

Bernstein Yes, he has done a couple of placebo studies. We call them all Research Ethics Board, REB. In the United States they call them all IRB. Anyway, if the IRB or the REB feels that it's a powerful study, that it's a really good study, they will allow placebos. So there are many studies at my institution that have been allowed to use placebos. But they do question it. I've sat on the REB, and the placebo is strongly examined. But nowadays, most research ethics boards will pass placebos. It's become popular to have placebos. It's considered good science. And they may be right. But to me, deception does not justify good science. If we had to sacrifice good science, I would be willing to take that negative aspect of not doing good science to preserve people's dignity. I think that placebos really make a patient guinea pig.

4. Experimental surgeon on the involuntary admitted patient of psychiatric disorder

Interviewer Your opinion seems to be very precious for people to think about the implication of placebo use. So, different point. How do you think about DBS or surgical procedure for mentally diseased patients who are in compulsory hospitalization? Compulsory hospitalization mean that in some case psychiatric disease patients are hospitalized involuntarily, compulsorily, when there is high possibility or risk that the patient may harm others or oneself. In such case, the law permits some person, mostly a psychiatrist or sometimes public body decide to admit that patient without consent of this patient.

How do you think of getting this kind of patient of mental illnes subject to experimental surgical procedure or DBS?

Bernstein The basic tenet of consent is that if the person can't consent to an essential treatment, then their loved one can. First it's the spouse, then child. You know, there's a hierarchy, and then there's the public guardian at the bottom.

The law defines this hierarchy. And you can find it under the Consent Act of Ontario. Ontario is the province, the prefecture that Toronto is in. You would find it on the web – Health Care Consent Act. And then if the spouse said "Yes, you may do DBS on my husband because he cannot speak for himself," that is legal in the case of psychiatric. For appendicitis or for brain tumor, no discussion. For psychiatric cases, it usually goes to another level. There's usually a panel discussion. Yes, basically surrogate consent is available for the next of kin.

Interviewer So you mean that there are laws for the hospitalization of psychiatric patients, and in case of research acceptance, the same law can be applied.

Bernstein Yes. Health Care Consent Act applies not only to psychiatric patients. It applies to children as well. You know, a 4-year old child is considered incompetent to make a decision. So it applies to anybody who cannot make a decision – children, vulnerable children, adult who do not have mental capacity.

Interviewer Thank you so much for your opinion, and information of the situation of your country. At first the introduction of your qualitative research is very meaningful which we should learn for the preparation of ethical debate. Your idea would help more profound discussion among Japanese research ethics community.

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