



Deep brain stimulation in the media: over-optimistic portrayals call for a new strategy involving journalists and scientists in ethical debates

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Deep brain stimulation (DBS) is optimistically portrayed in contemporary media. This already happened with psychosurgery during the first half of the twentieth century. The tendency of popular media to hype the benefits of DBS therapies, without equally highlighting risks, fosters public expectations also due to the lack of ethical analysis in the scientific literature. Media are not expected (and often not prepared) to raise the ethical issues which remain unaddressed by the scientific community. To obtain a more objective portrayal of DBS in the media, a deeper collaboration between the science community and journalists, and particularly specialized ones, must be promoted. Access to databases and articles, directly or through science media centers, has also been proven effective in increasing the quality of reporting. This article has three main objectives. Firstly, to explore the past media coverage of leukotomy, and to examine its widespread acceptance and the neglect of ethical issues in its depiction. Secondly, to describe how current enthusiastic coverage of DBS causes excessive optimism and neglect of ethical issues in patients. Thirdly, to discuss communication models and strategies to enhance media and science responsibility.

Keywords: deep brain stimulation, science journalism, mass media, neurosurgery, neuroethics

INTRODUCTION

As a treatment for psychiatric disorders, neurosurgical interventions, such as prefrontal leukotomy, were performed in the mid-twentieth century on many tens of thousands of patients (Gostin, 1980, 1982; Mashour et al., 2005). This therapeutic approach, later called “psychosurgery,” was hailed by the media enthusiastically, despite a lack of scientific evidence of its effectiveness and without an evaluation of the ethical issues involved. Medical research is propelled, in part, by public needs and sometimes by public expectation. Researchers have an interest in promoting their research also in the popular press, and this can stimulate public interest in new therapies without adequate information. This is particularly troubling in the case of the new neuromedical discoveries with deep ethical implications.

The current experimental expansion of deep brain stimulation (DBS) applications, from the control of motor disorders to psychiatric conditions (Bell et al., 2009; Clausen, 2010; Schlaepfer and Fins, 2010) raises the legitimate worry that DBS treatments might also gain popularity in the media before a full evaluation of issues related to ethics and effectiveness is undertaken. This worry can, in part, be motivated by three factors. First, although distinct from classic psychosurgery (Synofzik and Schlaepfer, 2008; Schlaepfer et al., 2010), DBS is an invasive treatment that can generate several postoperative complications and side effects, such as cognitive, behavioral, psychiatric, and psychosocial impairments (Clausen, 2010). Second, the ethical discourse is often ignored in the scientific literature (Bell et al., 2010), which is characterized by a selection

bias favoring the publication of positive results (Schlaepfer and Fins, 2010). Finally, DBS in psychiatry raises additional ethical questions because its mechanism of action is not yet clear, even for movement disorders (Benabid et al., 2005; Kringsbach et al., 2007), the hypotheses being either synaptic inhibition or depolarization blockade (Dostrovsky et al., 2000; Perlmutter et al., 2002; Vitek, 2002).

In the first section this paper examines media coverage of surgical brain therapies for psychiatric disorders, in particular prefrontal leukotomy. In the second section, it explores current, enthusiastic media portrayals of DBS, and how these might encourage a false assumption that all ethical issues have been fully discussed. In the third section, it addresses the primary sources of DBS information used by science journalists and the roles of scientific experts, peer-reviewed journals and the media in evaluating and shaping ethical issues raised by the development and expansion of DBS. In particular it suggests embracing a novel strategy to produce ethical consensus about controversial issues such as DBS.

LESSONS FROM THE PAST

Deep brain stimulation is not the first surgical treatment for psychiatric disorders to be depicted in the popular media. Between 1935 and 1960, in Europe and the United States, prefrontal leukotomy (widely called “lobotomy” in journalistic accounts) was accepted uncritically by a large part of the scientific community. Consequently it was presented by the media as a “miracle cure” for

disruptive behaviors. In 1949, the Nobel Prize for Physiology or Medicine was awarded to the Portuguese neurologist Egas Moniz, “for his discovery of the therapeutic value of leukotomy in certain psychoses” (Nobel Foundation, 1949). This prestigious prize demonstrated the wide acceptance by the scientific community at the time, and most probably encouraged the public to see prefrontal leukotomy as a safe procedure.

In their paper on the portrayal of lobotomy in the American popular press, Diefenbach et al. (1999) concluded that the acceptance of lobotomy benefited from optimistic media coverage, especially in the 1930s and 1940s. It was proposed that unbalanced popular press coverage was an important factor in stimulating interest in lobotomy: “It was generally known that many patients were referred [] as a result of all the publicity” wrote Valenstein (1986) in his history of psychosurgery. Walter Freeman, an American physician who had strong relationships with journalists from widely read newspapers and magazines, played an important role in advertising the procedure (El-Hai, 2005). Diefenbach et al. (1999) described how competition between media professional to break dramatic stories combined with fame-seeking by representatives of the medical community (or with research interests in some fields) created a relationship which served both the media and the physicians, but not necessarily the public interest.

In a study on psychosurgery in Sweden between 1944 and 1958, Ogren noted that pioneering early experiments of prefrontal lobotomy, performed by neurosurgeons in collaboration with psychiatrists in Stockholm in 1944, were followed by a rapid implementation of the new surgical approach (Ogren et al., 2000). In 1946 and 1947, the two state mental hospitals, Umedalen and Sidsjön, introduced prefrontal lobotomy on a large scale. Prefrontal lobotomy was characterized, in certain city hospitals, by an initially high rate of postoperative mortality that reached more than 15%. Nonetheless, in a comparative media study Ogren found that most of the articles on lobotomy in the Swedish and American media were positive or neutral toward psychosurgery, whilst negative articles were less frequent. Neutral articles were more common in Swedish media (43%) whilst less common in American media (19%). Articles that were highly negative toward lobotomy were more often found in the American press (32%) than in the Swedish (14%). This difference was due to the lack, in the Swedish society of the time, of a small but strong opposition to this procedure that was present in the American scientific community. There was also a tradition of investigative journalism that pushed some American writers to examine patients’ postoperative outcomes (Ogren, 2007).

More balanced reports started to appear in American press in 1945, in parallel with the appearance of scientific studies that quantified dramatic side effects associated with the therapy. Following this more balanced reporting, the use of the procedure declined. This was also, in part, due to the introduction of chlorpromazine, the first drug for mental illness, which raised new hopes for psychiatric patients (Pressman, 1998).

Low-income patients with low-educational attainment were the first victims of media enthusiasm for lobotomy (Valenstein, 1986). Part of the explanation was the higher burden of psychiatric illness for patients and families in a poor social environment.

It is important to recognize that contemporary public perceptions of the efficacy of DBS in psychiatric disorders may parallel earlier enthusiasm for surgical interventions in psychiatry, since the media had already made a connection between psychosurgeries and DBS (Fins, 2003).

OVERLY OPTIMISTIC MEDIA PORTRAYAL AND NEGLECT OF ETHICS

Past and present DBS media reports, without or with only a passing attention to ethics, offer fertile ground for hype in both scientific journals and the popular press. For example, following the publication of “Memory Enhancement Induced by Hypothalamic/Fornix Deep Brain Stimulation” (Hamani et al., 2008), there was a wave of positive reporting concerning the use of DBS for memory enhancement, with a particular focus on Alzheimer’s patients, without scrutiny of either the vulnerable nature of these patients or the merely accidental or serendipitous nature of this discovery (initially the study was conducted to treat severe obesity). For instance, the scientifically respected and influential *Nature* announced the findings in an optimistic news article entitled “Brain electrodes can improve learning” (Abbott, 2008) and suggested the possible application for people with Alzheimer’s disease without any concern for the ethics related to this population of patients. This enthusiastic media shock wave was instantly replicated on an international scale. Indeed, *BBC News* popularized the same results by publishing an article positively entitled “Deep stimulation ‘boosts memory’” (Coombes, 2008), while articles appeared in *The Telegraph* and *The Independent* titled respectively “Discovery could make Alzheimer’s a memory” (Clout, 2008) and “Scientists discover way to reverse loss of memory” (Laurence, 2008). None of these articles discussed or mentioned the opportunity of using DBS for memory enhancement in a vulnerable population such as Alzheimer’s patients, although they all referred to this neurodegenerative disorder as a pathology potentially treatable with DBS.

By praising medical and scientific innovation without paying attention to ethical issues, the media risk to turn ethical neglect into de facto ethical approval, thereby promoting public acceptance of DBS. Other important questions raised by DBS applications (i.e., criteria for the selection of patients, acute, and chronic side effects, DBS use in pediatrics, benefits to patients, and quality of life) are absent in popular media, also due to the fact that they are not properly discussed in scientific literature (Clausen, 2010; Racine et al., 2010).

Regrettably, this type of optimistic coverage of DBS is not only limited to mass media. As Schlaepfer and Fins (2010) report, several DBS single-case studies have been published which highlight the secondary effects of research (such as memory enhancement) even when the primary goals (such as treating obesity) have not been achieved; as was the case in the Hamani et al. (2008) paper, referred to earlier. Even if selective publishing bias is not unique to research on DBS (Chien, 2004; *Nature Neurosci*, 2004; Lau et al., 2008; Schlaepfer and Fins, 2010), by focusing on the positive outcomes of DBS, both the scientific literature and the popular media neglect common ethical issues (risk–benefit ratio, informed consent, inclusion–exclusion, side effects, patient’s autonomy, etc.).

In a seminal study, Racine et al. (2007) reviewed 235 articles on neurostimulation techniques in the print news media in the U.K. and the U.S. They reported that 51% were optimistic depictions, whilst only 4% emphasized the risks. Among the articles reviewed, 29% contained a “personal twist,” including first person narratives and descriptions of “miracle stories of patients cured of Parkinson’s disease, dystonia, and Tourette’s syndrome” (Racine et al., 2010). Diem et al. (1996) and Schneiderman (2005) have pointed out that patients educate themselves and build their hopes from uncritical sources, such as television and the internet. In that sense, the media have an influential place in patient education, comprehension, and understanding of health issues.

From the point of view of the lay reader or potential psychiatric patient who goes through an informed consent process, the use of an easily optimistic depiction – both in the medical literature and in the popular media – can be far more influential than some of the austere and subtle explanations found in specialized ethics journals. Bell et al. (2009), in an insightful study using healthcare providers, report that enthusiastic media portrayals of DBS influence patients’ hopes and expectations. They concluded that healthcare providers view media portrayals of DBS as “playing a key role in establishing expectations for DBS patients and for the public in general.” Media portrayals of DBS can lead to a false assumption that ethical issues have been discussed which affects patients’ expectations.

Ford (2009) suggests that overly optimistic reports about new neurosurgical innovations generate an “educational vulnerability” for patients. He affirms that very often when patients consider neurosurgical techniques they have already been pre-conditioned by overly optimistic portrayals of novel brain interventions, and this compromises informed consent. This is similar to what Bell et al. (2009) report in their study of healthcare provider perspectives.

Even if DBS is both scientifically valid and reasonably safe, patients’ lack of appreciation of the risks and the potential consequences of the procedure raises significant ethical challenges. Moreover, whilst potential DBS patients may be legally competent, they may not be able to make meaningfully autonomous decisions regarding their participation in any proposed DBS treatment. This is not only because of the burden of their own illness, but also a consequence of the impression created by enthusiastic media accounts often coupled with the non-neutral attitude of the surgeon. Given the lack of common official ethical guidelines for patient selection in DBS trials amongst countries, it is difficult to prevent unethical applications of this technique on competent but fragile subjects.

Informed consent is an important mechanism for respecting patient autonomy, but in order to reach this ambitious goal, the effect of exposure to unbalanced media reports must also be considered. DBS providers have the responsibility of designing a process for obtaining a fully informed consent, while avoiding the exploitation of unrealistic hopes. Addressing the lack of awareness of the ethical and social challenges of DBS is a duty and a responsibility not only of the popular media. Most of the neurosurgical literature focuses mainly on technical details and only superficially addresses fundamental questions about patient selection and inclusion criteria, informed consent and resource allocation.

ETHICAL DEBATE AND MEDIA CONSTRAINTS

When analyzing media coverage of DBS, it is important to examine the process of selection of what becomes “news,” and evaluate the primary sources of information on this topic: peer-reviewed publications and experts. This is confirmed by a study by Racine et al. (2010) which reports that 42% of the quotations about DBS published in articles in the popular press come from a scientist with a public sector affiliation and 14% come from physicians and other healthcare providers.

The role of science journalism, especially in covering ethical topics, has been discussed in depth in recent years. In a recent *Nature* editorial “Science Journalism, too close for comfort,” Boyce Rensberger, past director of the Knight Science Journalism Fellowship program at the Massachusetts Institute of Technology, argued that science journalists need to stay as close as possible to the researchers producing science, but still need to keep a healthy distance. Tracing a brief history of the evolution of science journalism in the Internet era – from the role of “cheerleaders” of scientists to the role of “watchdog” – he affirms that: “If science journalists are to regain relevance to society [] they must learn enough science to analyze and interpret the findings – including the motives of the funders. And, as if that were not enough, they must also anticipate the social impacts of potential new technologies while there is still time to make a difference” (Rensberger, 2009).

Anticipating the social impacts of promising new DBS therapies obviously requires a discussion about ethics. Such discussion is just starting in the scientific community, and with some reluctance: “Neuroscientists have reasons for their reluctance to wade into ethics. The questions raised are likely to be open-ended, and their arrival in the world outside the laboratory may be some way off” stated a *Nature* Editorial (2006) entitled “Neuroethics Needed,” which focused in particular on functional MRI. Now, how can science journalists identify and discuss, in a meaningful and satisfactory way, the ethical issues raised by a new DBS therapy when even the experts in the field and the scientific literature tend not to discuss them?

The answer is not easy, and lies at least in part in the search for new ways of cooperation, particularly between the scientific community and the media, which face these kinds of difficulties, not only when dealing with DBS and neuroscience, but throughout the whole spectrum of issues related to research and health. A recent statement published under the auspices of the International Society of Pharmacovigilance, for instance, highlighted the importance of such an approach: “New ways to cooperate with the media as professional equals must be explored to help the provision of balanced, comprehensible, trustworthy, and interesting safety information to the public on a regular basis, apart from specific announcements or reports of problems or crises” (Erice Statement, 2010).

Media are expected to play an informative and argumentative role – in particular, to conduct wide debate of social issues regarding DBS. In the current over-optimistic portrayal, media typically do not question the assumptions under which the medical literature reports DBS results. Ethics may be difficult to implement when dominant scientific news is based on DBS efficacy rather than safety. In addition, promises of a cure – with or without exaggeration, are useful to attract public attention in a news world in which every article needs to compete in order to be noticed. The issue, well

known inside the journalistic profession, is reflected in a recent headline in the *British Medical Journal*: “Health Journalism: two clicks away from Britney Spears?” (Coombes, 2009).

Although a variety of critiques have been leveled at mass media portrayals of DBS (Racine et al., 2007; Ford, 2009), it is very difficult to create a context in which such portrayals can be questioned by all parties – the media, science experts, and the public. Several experts in neuroethics have stressed the importance of a novel approach, capable of moving from the current widespread top-down approach – from the scientists to the general public through the “translation” by the media – to a multidirectional model of discussion that encourages open dialog and the mutual enrichment of all parties. In particular, Racine et al. (2009) argue that: “Such a scheme recognizes both that science is part of culture and that societies are increasingly multicultural. The distinction between expert and lay conceptions becomes a continuum, in which each interacts with the other. Given calls for increased public dialog, sustained relationships with the media and growing interdisciplinary dialog with colleagues in the humanities and social science are also needed. This scheme will also enable public advocacy for neuroscience [] and will firmly situate science communication within a robust framework.”

Public deliberation has already been used in several contexts related to health and ethics. It was adopted, for instance, to explore public concerns and desires about the development of biobanks (O’Doherty and Burgess, 2009) and the adoption of new health technologies (Milewa, 2006). Applying this logic to the communication of neuroscience research, Illes et al. (2010) focus on the need for scientists to listen to the public and the public’s interest in learning about science, in order to promote an approach capable of reflecting “the values of trust, reciprocity and transparency by engaging non-experts and acknowledging that they have a right to be involved in the conduct of science.” Illes et al. (2010) note, however, that this “calls for enhanced training of neuroscientists and a willingness to engage in less conventional approaches. Empirical research throughout the process of public engagement is an integral part of this training.”

DISCUSSION

By presenting exclusively positive data, the media tend to describe and explain DBS outcomes without reference to ethical debates. Despite the immature state of DBS as a treatment for psychiatric conditions, patients rely on information about DBS from media portrayals. This may encourage the use of DBS as a treatment for more and more psychiatric conditions in which there are good theoretical grounds justifying the surgery but the evidence is still weak and preliminary. The ethical issues related to DBS are usually debated by scientists and experts only after specific concerns have been raised, as it happened in Canada after the discovery of the potential effects of DBS on memory (Hamani et al., 2008). What was presented as a possible treatment that could be offered to all patients has become the subject of a study by Laxton et al. (2010) on six Alzheimer’s patients which in phase 1 proved the safety of the procedure and is currently evaluating its long-term efficacy.

Unbalanced media reports can convey to the general public, and to potential patients, the idea that DBS represents a default option for the treatment of all refractory psychiatric diseases. As

noted in the first section, this happened in the past with other surgical treatments for behavioral disorders that have a heavy social impact. In the absence of public debate on the complex ethical aspects of the widespread use of DBS, enthusiastic media accounts might result in an unjustified promotion of these therapies (Schlaepfer and Fins, 2010). The need for more responsible reporting, both from popular media and from neuroscientists and neurosurgeons, calls not only for better research on this topic but also for the promotion of initiatives favoring a multidirectional model of discussion among all parties – science experts, the public and the media. This amounts to a “cultural” shift that openly acknowledges and rewards public outreach, whilst supporting the development of neuroscience communication experts, as well as empirical research into neuroscience communication (Racine et al., 2010).

In an environment in which the media are not expected (and often not prepared) to raise the ethical issues which remain unaddressed by the scientific community, the challenge is to rethink and reinvent communication strategies to improve the role of the media. This improved role requires the members of the press to act as watchdogs of science and to highlight the gap often existing between the goals of science and the needs of society. This goal could be achieved by promoting continuing education and training within the journalistic profession, with the help of the scientific community, which should start considering journalists as “professional equals” (Eric Statement, 2010). In order to achieve more effective communication by researchers, and to help journalists in their background research on ethical issues related to science, a number of approaches have proved effective. These include: free access for journalists to medical literature databases and official sources of information, peer review within the profession and science media centers designed to put scientists in touch with journalists in a context promoting cooperation and reciprocal trust (Schwitzer, 2008; Editorial Lancet, 2009; Kirby, 2011).

In a case-study published on *Science Communication*, Smith et al. (2010) evaluate the impact that a cancer media center had on the quality of cancer news in the United States. They conclude that in order to spread the use of good preventive practices, providing the community of journalists and the general audience with good informative materials about cancer prevention is not enough, and has to be coupled with the search for a “clear articulation of shared goals.”

The search for an alliance between all the stakeholders characterizes the experience of the British Science Media Centre (SMC). According to its director Fox (2009), combining the provision of good information materials with the organization of regular meetings and debates between the media and the science community improved the quality of reporting, especially on issues related to ethics. This goal was achieved by putting a great effort in helping specialized reporters: “[] The support we give to specialist correspondents has undoubtedly helped to strengthen their hand by ensuring that they get the best science stories in advance of non-specialists in the newsroom. The SMC has continued to champion specialist reporters both within the scientific community and in all our dealings with news editors. It is our strong view that they are the best allies of science in the media []” (p. 125).

The role of the media is crucial if a society wants to involve citizens in relevant decisions about their health. The partnership between science, research, and the media is needed if crucial health issues such as those related to the use of DBS are to be put on the public agenda appropriately. The public and furthermore the patients, need clear and accurate information. Until now, the provision of such clear and accurate information was mostly the responsibility of reporters and editors. The time has come for scientific publishers, scientists

and health care workers to contribute to this difficult task, especially in issues, like DBS, that have important ethical and social implications.

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