



The clinical and ethical practice of Deep Brain Stimulation: Results of an international survey of DBS experts and centers

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Problem Under Study

Deep brain stimulation (DBS) has become a standard therapy for some forms of movement disorders and is investigated for other neurological and psychiatric disorders, although many scientific, clinical and ethical issues are still open. In order to obtain an overview of the global practice on DBS, we have performed a survey among researchers, clinicians and DBS centers that addresses clinical and ethical problems currently discussed in the DBS literature, including:

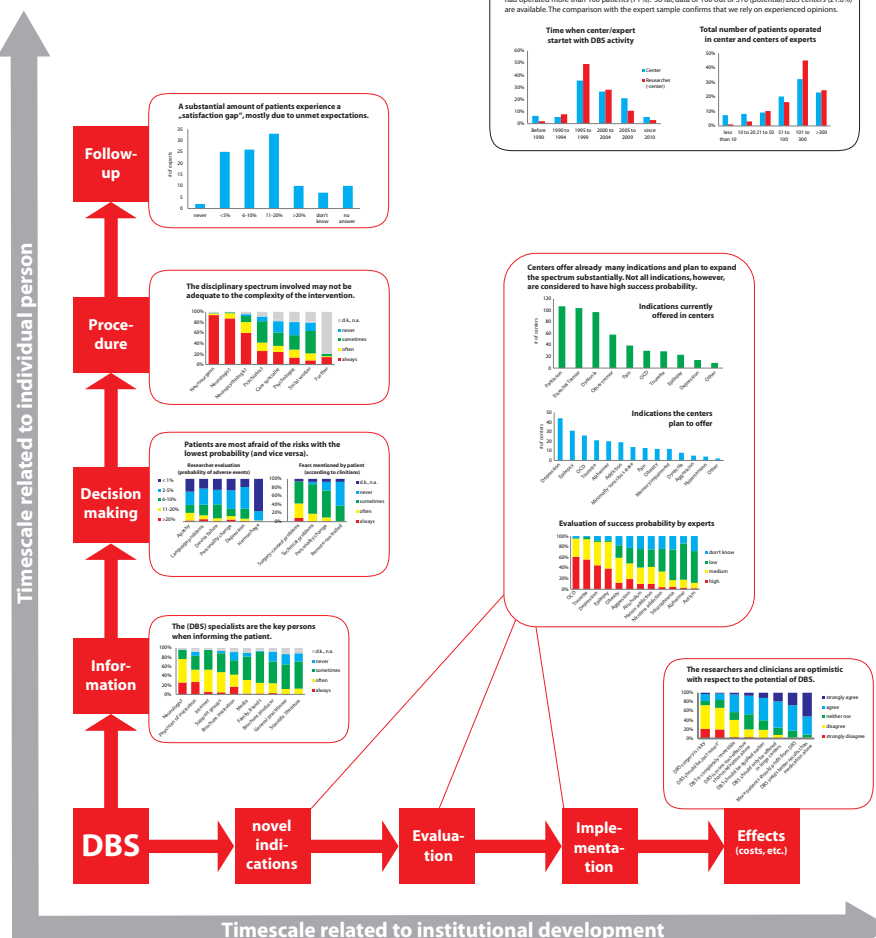
- The decision process of patients with respect to information sources, hopes and fears, etc.
- Disciplines involved in the procedure, their degree of expertise, target preferences, etc.
- Risk-evaluation, outcome-analysis, and the potential issue of a "satisfaction gap".
- Collecting data that allows assessing the referral practice, trends for novel indications, etc.
- Opinions with respect to controversial DBS claims.

Methodology

Researchers: The survey among DBS researchers and clinicians was performed in two waves between mid-2011 and mid-2012 each of them including two follow-ups. In the first wave, researchers identified in a large search performed by us [1] were addressed who published about DBS in Parkinson's disease since the early 1990s. The second wave addressed clinicians emerging from a global search of DBS centers. In total, 712 persons were approached. The survey questionnaire was developed based on our previous research in DBS [1-3] and has been cross-checked by a board of internationally renowned DBS researchers. The survey was anonymized.

Centers: The survey questionnaire for DBS centers has been pre-tested in a Delphi study including all Swiss centers [4]. Using bibliometry, we have identified 12 countries that ranked highest in global DBS research compared to the total research output in neurology and neuroscience: Australia, Canada, France, Germany, Italy, Japan, Netherlands, Spain, Sweden, Switzerland, UK, and USA. For these countries we have performed an extended, internet-based search to find clinics that offer DBS according to their website; 510 institutions have been identified. To those centers a short 2-page questionnaire has been sent by postal mail and two follow-ups were performed (the second follow-up is ongoing). The results of this survey are preliminary.

The "ethical landscape" of DBS & related survey results



Main Results

- 1) The spectrum of DBS indications grows fast; 73% of the centers plan to establish new DBS indications in the future; among them are indications (e.g., Alzheimer's disease) whose success probability are considered to be low.
- 2) Less disciplines than expected are involved in patient selection (mainly neurosurgery and neurology), in particular psychiatrists are routinely involved only in 26% of the cases.
- 3) The main fear of patients refers to surgery complications (42%), whereas "personality change" is less frequently mentioned as a frightening outcome (10%). On the contrary, the respondents consider apathy and personality changes as relatively common side effects (18/12% of the respondents believe that more than 10% of the patients may suffer from them), whereas surgical problems are considered to occur very rarely.
- 4) 38% of the respondents confirm the existence of a "satisfaction gap", i.e. report that in more than 10% of the cases the patients' expectations are not fulfilled.
- 5) A large majority of the respondents consider DBS to be a safe and successful intervention in movement disorders, superior to medication-based interventions, and claim that more patients should be able to profit from this intervention.
- 6) Specialists are the main information source for patients, although the internet is considered to be an important source, too.

Conclusions

Our survey expresses evaluations of experienced DBS experts that are optimistic with respect to the current use and potential of DBS. A mismatch of patient fears and risks as well as the satisfaction gap require closer investigation. The process of patient information and selection should be performed by more interdisciplinary teams which also include psychiatrists.

Ongoing Research & Outlook

We are currently finalizing our center survey and we will complement this research by bibliometric studies. Future research includes the investigation whether indications for a conservative assignment practice, which may disfavor suitable patients, are confirmed. Other issues are patient decision making process in assignment, and psychosocial effects of DBS.

References:

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