

Jeffrey Wertheimer's presentation at the Neural Interface Conference, 2006

It is with great pleasure that I participate in this panel discussion entitled "The Patient Perspective on Deep Brain Stimulation." As we know, DBS therapy has truly enhanced our treatment of many disabling medical conditions, such as Parkinson's disease, and we have ongoing research endeavors ensuing in greater understanding about DBS. In light of the copious amounts of published articles, including those with rigorous methodology to those emphasizing theoretical conceptualizations, the denominator of our research and thought pieces is our patient, and in fact, the patient is the barometer of the success or failure of DBS therapy.

As such, the objectives of today's panel discussion are three-fold:

1. What do patients want engineers, scientists, and clinicians to know about DBS?
2. What do the patients hope the DBS clinicians are monitoring?
3. What do patients consider as must-have fixes and refinements relative to the surgical procedure and the technology?

I have the privilege to introduce two inspiring and dedicated individuals in the PD community who have bilateral DBS and who have a breadth of knowledge and experience to edify the clinicians and researchers in this room about their journeys post surgery. Dr. David Heydrick is a Neurologist practicing in Frederick, Maryland, and Mrs. Margaret Tuchman is the President of the Parkinson Alliance in Kingston, New Jersey.

Mrs. Margaret Tuchman's presentation: Please click on <http://www.dbs-stn.org/articlesdetails.asp?ID=22>

Dr. David Heydrick's presentation: Please click on <http://www.dbs-stn.org/articlesdetails.asp?ID=21>

Dr. Jeffrey Wertheimer's presentation: As many of you may know, the Parkinson Alliance is an advocacy group that conducts survey-based research to gain a greater understanding about the patient's perspective of PD and DBS.

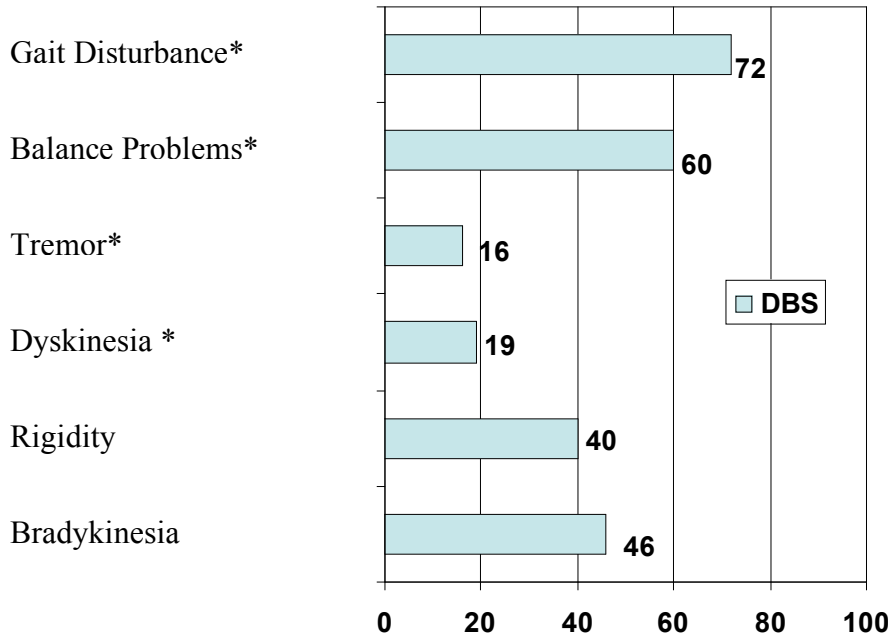
Although Mrs. Tuchman and Dr. Heydrick shared components of their individual experiences, many of their points can be generalized. I would like to take a moment to propagate some viewpoints from the DBS participants in our research.

I think it is important to convey to the audience that the vast majority of the patients do find the DBS therapy to be satisfactory. In our most recent survey of almost 100 participants who had undergone DBS, 94% found it to be quite satisfactory [with its effects over time].

Nevertheless, some interesting data was revealed in our research. First of all, as is known in the literature, not all motor symptoms are benefited from DBS. In fact, in one study

that The Parkinson Alliance conducted, there was a significant difference in severity of symptoms between Tremor and Dyskinesia and Gait and Balance.

Percent reporting Moderate to Severe symptoms (Mean Age: 62 (9.4); Duration: 15.6 years (5.4); Time since DBS: 3.5 years (2.56))

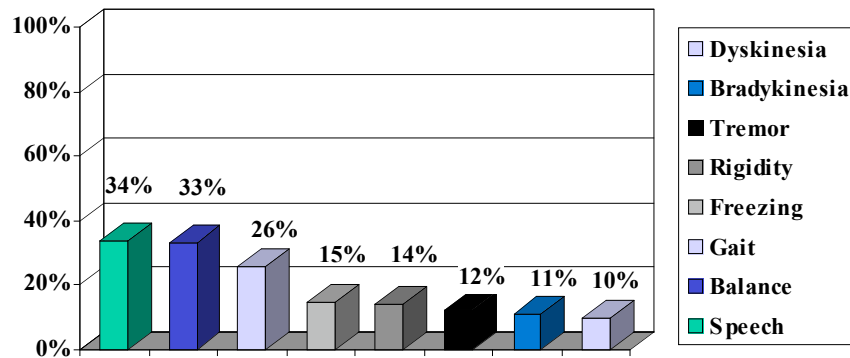


(Wertheimer, et al., 2006)

N=94

Second, as we know non-motor symptoms are very prevalent in the PD community, and non-motor symptoms can be some of the most debilitating for the patient and his/her carers, which can include symptoms such as speech disturbance and emotional disturbance to name a couple.

Most Common Troubling Symptoms Reported (Age= 62 years (9.6); PD Duration= 15 years; Time Since DBS: 3 years (1.47))



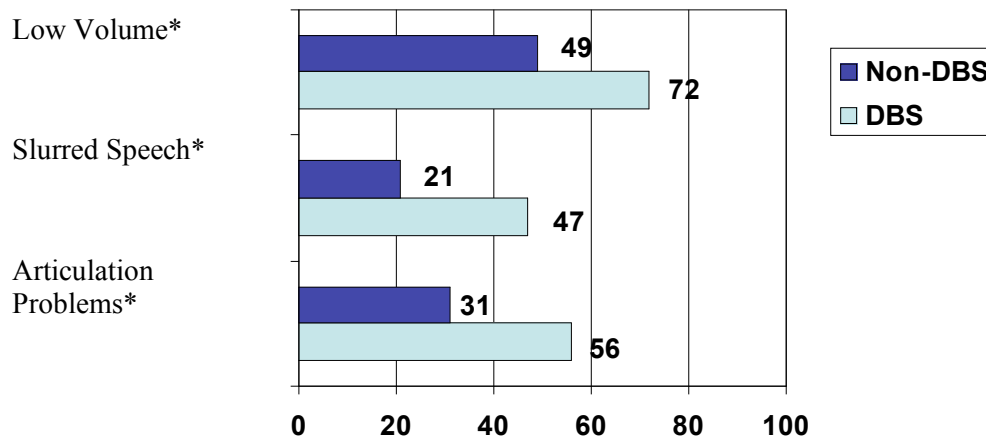
(Tuchman, et al. 2004)

N=108

Speech: There is ongoing evidence that speech is adversely affected by DBS. Although we know that speech is often impacted by PD patients in general, we found that a significantly greater proportion of PD patients with DBS reported speech problems, of moderate to severe degree, than PD patients without DBS.

DBS: N=94; Mean Age 62 (9.4); PD Duration: 15.6 years (5.7); Time Since DBS: 3.5 years (2.56)

Non-DBS: N= 86; Mean Age: 62.6 (10.8); PD Duration: 8.2 years (5.6)



* p >.01

Emotional well-being: I am not stating anything new by informing you that emotional distress is also prevalent in this population and clearly disabling in some instances in its own right. The PD patients with DBS express some strong opinions about the importance of monitoring appropriately neuropsychiatric symptoms, and the implications from our research point to the benefits of a “teamwork” approach - the use of additional team members in the monitoring of the PD patients’ well-being is warranted – e.g., psychology and psychiatry, rather than GPs or neurologists alone.

Programming:

Standardized Programming: Training for programming is not a standardized practice at this point in time and is not easily accessible – from the eyes of the participants in our study. We found that 43 percent of the participants in our study were dissatisfied with the access they had to DBS programming. Clearly it would be nice to change this perspective.

- Margaret makes an excellent point when she indicated that more and more people are having the surgery, while a shortage of skilled post-operative professionals to handle programming exists.
- Will the future bring direct training of programming into residency programs or fellowships so neurologists in general are competent in DBS management?
- How can we invoke the perspective in PD patients with DBS that they are in direct view rather than in the periphery – when it pertains to this issue?

Summary:

The take home message "from the patients' perspective:"

1. We need improvement in communication between doctors and patients – more explicit expectations of the DBS effects on both motor and non-motor symptoms.
2. Improved marketing and understanding of the top-notch DBS multi-disciplinary treatment teams.
3. Monitor non-motor symptoms closely (e.g., neuropsychiatric or neurobehavioral), as these are known to have a big impact on quality of life.
4. Improvement is needed in the following symptoms: balance, gait
5. Improvement in understanding and intervention as it relates to difficulties in speech.
6. Improved programming and increased access to programming
7. Better preparation surrounding the battery change and subsequent adjustments.
8. Improvement in the apparatus itself (e.g., even via the materials utilized).
9. A greater understanding of the somatotopic anatomy of a DBS target to tailor electrode placement and/or possibly designer field generation capability.
10. Develop a closed loop system where the programming changes in real-time based on external stimuli.