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Deep brain stimulation for Parkinson's disease: A case for patient empowerment

Mark D. McAuley

Melbourne, Australia

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Dear Editor,

1. Case report

I am a 52-year-old right-handed man, diagnosed with Parkinson's disease aged 40 years. In early 2020, my levodopa equivalent daily dose (LEDD) of 1375 mg comprised levodopa/carbidopa/entacapone, pramipexole, amantadine and selegiline; daytime levodopa frequency was 2–3 hourly. Unfortunately, medication was no longer adequately controlling my symptoms, with breakthrough bradykinesia, gait disturbance, impaired verbal fluency and dyskinesia. My Unified Parkinson's Disease Rating Scale (UPDRS)-III scores were 40 (medication-off) and 8 (medication-on).

In May 2020, I underwent bilateral subthalamic nucleus deep brain stimulation (STN-DBS) surgery (Vercise Gevia™ with Cartesia™ directional leads; Boston Scientific, Valencia, CA). Medication was substantially reduced pre-operatively and DBS was activated the day after surgery. During the first month post-surgery, multiple DBS settings were explored: monopolar configurations utilizing different combinations of electrode contacts, with frequencies $\geq$100 Hz (primarily 130 Hz), pulse width 60 μs, and current $\leq$ 4 mA.

Although STN-DBS can be an effective treatment for Parkinson's disease motor symptoms, speech and gait difficulties may prove refractory [1,2]. These difficulties were evident post-operatively in my case, with right-sided freezing of gait (FoG) and dysarthria causing me severe difficulty relative to pre-DBS. For the first time, I required the use of a wheelchair to mobilize within my local hospital. Of even greater concern, my wife reported major deterioration in my speech. My speech was partially improved by ceasing levodopa, but family and friends indicated it was still much worse than pre-DBS.

To help identify a path forward, I commenced reading material on DBS programming. After reading Su et al. and Xie et al. [3,4], I wrote to my treating neurologist suggesting we try a DBS frequency of 60 Hz to address my difficulties with axial symptoms (McAuley MD, personal communication, June 1, 2020). One-month post-surgery, a 60 Hz-based program was implemented, utilizing the mid-tiers of both electrodes at current 5.5 mA and pulse width 60 μs. Within minutes, my wife noticed improvement in my speech clarity and breadth of vocabulary. My speech post-surgery was assessed by a speech pathologist (Dr. John E. Pierce, La Trobe University), who reported: "Speech recordings two weeks and three months post-surgery [at DBS frequencies >60 Hz] demonstrated mild to moderately-severe articulatory imprecision, as well as mild hypophonia with breathy voice quality; intelligibility was significantly affected. By contrast, speech recordings six months post-surgery [at a DBS frequency of 60 Hz] demonstrated no or mild articulatory imprecision with occasional, mild hypophonia and normal voice quality; intelligibility was significantly improved despite an increase in articulation rate (+0.7 syllables per second after pause removal during reading tasks). Overall, hypokinetic dysarthria had significantly improved, most notably in articulation and intelligibility."

This 60 Hz program supported my speech along with multiple other Parkinson's disease symptoms but did not address my debilitating FoG. In another letter to my treating neurologist (McAuley MD, personal communication, August 7, 2020), I queried whether use of the most ventral electrode contacts would address FoG, as reported by Koeglsperger et al. [5]. My neurologist activated the tip of the left-STN and we tried different combinations of frequency, pulse width and strength of current. Four months post-surgery, a dual-frequency program involving 60 Hz to the mid-tiers of each electrode and 179 Hz to the most ventral left-STN contact was implemented; this resulted in improved gait in addition to supporting my speech and other Parkinson's symptoms.

E-mail address: mdeclanmcauley@gmail.com.

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DBS program changes took several hours to fully impact my gait and speech. Between clinical reviews, I used the patient programmer to adjust the DBS current and recorded the impact on my movements and speech using a video camera, together with a smartwatch for step count. This approach enabled me to refine this dual-frequency program by adjusting the strength of current at the left-STN tip. The final program (Fig. 1) has remained unchanged since December 2020, when my UPDRS-III score was 2 with stimulation-on plus pramipexole, selegiline and amantadine (450 mg LEDD).

Twelve months post-surgery, FoG was still problematic. Levodopa was reintroduced, which improved gait but impaired my speech. Therefore, after 4 weeks, I requested to cease levodopa. My daily dose of pramipexole was then increased from 1.5 to 2.25 mg, which assisted my gait and did not cause speech problems. Fifteen months post-surgery, my UPDRS-III score was 3 with stimulation-on, combined with pramipexole and amantadine (425 mg LEDD).

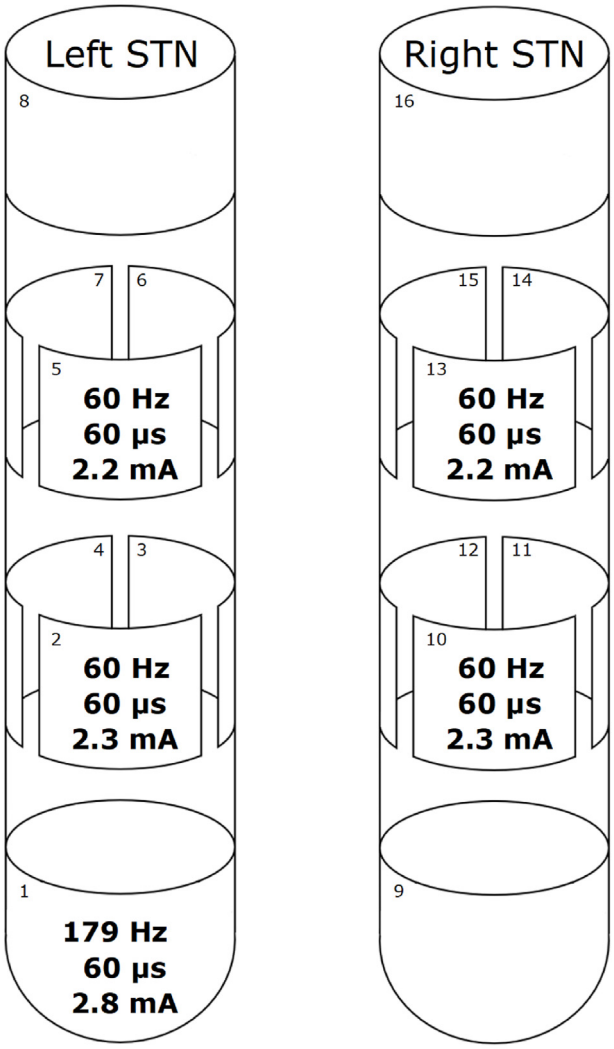

Fig. 1. Schematic representation of the dual-frequency DBS settings programmed at 6 months post-surgery. Left-STN: Electrode 1 (100% of current distribution) with current 2.8 mA, pulse width 60 µs, frequency 179 Hz; Electrode 2 (51% of current distribution) and Electrode 5 (49% of current distribution) with current 4.5 mA, pulse width 60 µs, frequency 60 Hz. Right-STN: Electrode 10 (51% of current distribution) and Electrode 13 (49% of current distribution) with current 4.5 mA, pulse width 60 µs, frequency 60 Hz. The impulse generator is set as the anode, and the electrode segments are set as the cathode. DBS, deep brain stimulation; STN, subthalamic nucleus.

Two-and-a-half years post-surgery, I can think and speak clearly, as measured by my ability to continue working in a high-level role; pre-DBS, I was preparing to retire due to ill health. FoG still causes me difficulty.

2. Observations relevant to clinicians and DBS manufacturers

An individual's ability to understand their clinician's management plan can help to attain a positive outcome. I feel this axiom is especially relevant to DBS, given the uncertainties associated with the choice of device settings [6]. I understand the therapeutic impact of DBS frequency is particularly poorly understood; however, advances in neuroimaging may guide optimization of frequency in clinical care [7]. The DBS system I received does not enable me to view the program settings that define the electrical pulses being sent to my brain; this design is intrinsically disempowering for patients and limits the ability of a patient to understand their DBS management plan. Manufacturers of DBS devices should ensure all their devices enable DBS recipients to read the current (or voltage), pulse width and frequency, per active electrode contact.

My personal experience indicates that speech difficulties appear to receive limited attention during DBS programming. Clear speech is incredibly important to me, and I needed to continually emphasize this priority to my treating clinicians. Clinicians should consider how effectively they address the impact of DBS programming on speech when it is a priority for their patient. This may include working in partnership with patients who seek to measure and report on the severity and impact of their Parkinson's symptoms in daily life.

3. Observations relevant to people with DBS

My experience with DBS motivated me to discuss DBS programming with others who have undergone DBS surgery. I also note Merner et al. report that patients' desire to control their own DBS programming declined over time in an observational study from pre-DBS to six months post-DBS surgery [8]. Personally, I relate to Merner and colleagues' theme of “shared control”; that is, I want to report my symptoms, make suggestions, and have an expert team adjust the DBS settings accordingly. Ultimately, clinicians have the challenge of identifying an adequately supportive combination of DBS settings and medication for each individual, often within tight time constraints. This can be particularly difficult given the uncertainty of how DBS pulses interact with the human brain. In that context, the following suggestions may help individuals with DBS implants to engage during DBS programming:

- At the commencement of a DBS programming session, ask the neurologist to explain the strategy they will employ that session to identify a DBS program with a greater therapeutic benefit.
- Between clinic reviews, record the impact of different DBS programs on your symptoms. For example, record videos of moving or speaking, or the time required to complete set tasks. Such records may assist in reporting to your neurologist the impact of DBS outside the clinic environment.
- Maintain a record of the settings for each DBS program prescribed. Just as one can discuss Parkinson's medication at a local support group, this enables discussion of DBS programs in a similar manner. Such information also provides a mechanism to check that the intended DBS settings have been programmed.
- DBS systems typically have a mechanism to allow the recipient to switch between programs pre-set by the neurologist. When leaving DBS clinic, ensure that the best program for you upon entering that clinic is still available. If the impact of new DBS

settings only becomes fully apparent after leaving the clinic, it may be helpful to revert to that previous program.

4. Conclusion

Empowering people with Parkinson's disease and DBS implants to engage during DBS programming may secure greater benefits from this remarkable technology.

Ethical compliance statement

Ethics clearance was not required for this letter to the editor. Patient consent is clearly implied as the author of this case report is the patient. I confirm that I have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

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CRediT authorship contribution statement

Mark D. McAuley: Conceptualization, Writing – original draft, execution and writing.

Declaration of competing interest

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