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# Quality Improvement in Deep Brain Stimulation for Movement Disorders: Pandemic Impact on Specialized Elective Surgery

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## Abstract

**Background**: Deep brain stimulation (DBS) is an important treatment for Parkinson disease (PD), tremor, and dystonia in appropriately selected patients. The Canada Health Act emphasizes equity and “reasonable access to medically necessary hospital and physician services”. How to define “reasonable access” has not been well studied. We aimed to assess access to DBS implantation surgery, and to determine the time required from initial assessment through to surgery and which step(s) delay the implantation.

**Methods**: DBS implants from 2016 to 2023 at the University of Alberta were analyzed. The neurologists’ decision to proceed with DBS marks the start of the work-up. Time required to see neurosurgeon, psychiatrist, neuropsychologist, healthcare allies, and receiving DBS surgery were assessed. The impact of COVID-19 was studied.

**Results**: The total time from starting the work-up to DBS surgery was 387.76 ± 125.19 days prior to COVID-19, and marked delay occurred during and post-COVID-19 (840.15 ± 165.41

days and 839.78 ± 300.66 days, respectively). Most workups were done within 6 months pre-COVID-19, although a big range existed due to variable factors. The longest delay to surgery was from consent to DBS implantation, owing to lack of operative time. There has not been a recovery post pandemic.

**Conclusions**: Time to DBS implantation surgery from initial decision is lengthy and more than doubled over the course of the COVID-19 pandemic. The biggest delay was in the time from consent to implantation surgery, which has not improved despite the pandemic having ended.

**Highlights**

- Access to DBS should be timely and readily available.
- The time required from initial assessment through to surgery was assessed. The longest delay was from consent to DBS implantation, owing to lack of operative time.
- COVID-19 pandemic negatively impacted DBS workup and surgery. A full recovery is delayed post-pandemic.

## Introduction

Deep brain stimulation (DBS) is efficacious and safe in appropriately selected patients with Parkinson's Disease (PD), tremor and dystonia, and improves quality of life when medical treatment alone cannot achieve optimal symptom control [1-7]. Identifying this patient group requires careful and extensive workup by an experienced interdisciplinary team [8-10]. Whether certain aspects in the workup delay the time taken to proceed to DBS implantation surgery has not been well studied in Canada. This is important, because disease progression and aging can lead to missing the therapeutic window for DBS.

The Canadian healthcare system is governed by the Canada Health Act [11]. The Canada Health Act requires reasonable access to all medically necessary therapies. In the setting of DBS for movement disorders, how to define "reasonable access" to this necessary therapy needs to be studied. In a publicly funded system, one of the major barriers can be the time to access care. For example, in British Columbia, the wait time is up to 3-4 years [12]. Optimization of this process in order to overcome barriers to DBS access requires both a holistic and detailed understanding of

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the components of the timeline for patients from referral to a DBS clinic until implantation surgery.

The objectives of this current study are to identify possible delays and barriers in the process of DBS work-up and implantation at a large Canadian academic medical center, with a view to informing changes that can optimize current practice. The second objective is to analyze the impact of the COVID-19 pandemic on access to timely DBS surgery.

## Methods

*Study type, time frame, and patient characteristics*

In this retrospective, cross-sectional study, we analyzed the time for each step of the DBS workup process through to implantation for movement disorder patients from the interdisciplinary Parkinson and Movement Disorders Program (PMDP) receiving DBS surgery at the University of Alberta between May 2016 and December 2023. During this time frame, all patients followed the same process for evaluation and follow-up, and the same functional neurosurgeon performed all implantations.

Deidentified patient information was extracted from existing electronic medical records, including age, sex, diagnosis. Motor symptoms were assessed using the Unified Parkinson's Disease Rating Scale (UPDRS), Toronto Western Dystonia Rating Scale, Burke Fahn Marsden dystonia scale or Clinical Tremor Rating Scale as appropriate for the referred condition. Montreal Cognitive Assessment (MoCA) scores at initial consult, 4-8 weeks before DBS, when programming was optimized and at one-year post-DBS implantation were recorded. Motor scores were recorded with every visit, namely initial visit, before DBS implantation, at each programming session, as well as six months and one-year post-operation. Patients who had any aspect of their workup after March 15, 2020 and received DBS before May 2023, were labelled having received DBS during COVID-19. For those patients who had their workup during COVID-19, but received DBS implantation after May 4, 2023 (when the International Health Regulations Emergency Committee of the WHO downgraded the COVID-19 pandemic) were defined as post-COVID-19. If a patient underwent a staged procedure, the workup for a second procedure was considered independent from the first. The COVID-19 and the post-COVID were grouped together as "COVID-19" since there was no recovery for the process post-pandemic.

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*Ethical approval*

The study was approved by the Human Research Ethics Board of the University of Alberta (Pro00104715).

*Data analysis*

Each step in the patient timeline was assessed relative to the date of initial consult by the DBS neurologist, considered Day 0 (Figure 1). Every subsequent step of the workup including wait time for consults to neurosurgery, neuropsychology and neuropsychiatry, functional assessment with physical and occupational therapy, as well as time to MRI was assessed relative to that starting point. The steps of the DBS referral and evaluation process at the PMDP are described in Figure 1.

Statistical analysis and data visualization were performed in R Studio (Version 4.3.1). For comparisons between groups, we performed a Shapiro Wilk Test to test for data normality and Levene's Test for homogeneity of variance which informed our use of the Wilcoxon Rank Sum test as a non-parametric binary comparison test and the Kruskal-Wallis test for comparisons of greater than two groups. Chi-square was used to compare categorical data. Post-hoc pairwise comparisons were done using the Bonferroni test.

## Results

*Demographics*

There were 271 referrals to the PMDP over the study duration, with 78 proceeding to DBS surgery. There were 49 DBS implants before COVID-19 pandemic during the study period (PD 35, dystonia 10, and tremor 3 cases, respectively). Only 29 implants occurred during and after the pandemic (PD 19, dystonia 7, and tremor 3 cases). Among the candidates (Table 1), 69.23% were diagnosed with PD (n=54). In addition, seven patients elected to not continue with surgery despite being assessed as optimal candidates for DBS.

Among the DBS recipients, when compared with the referred cohort (male/female ratio = 1.12), male predominance was evident with a male/female ratio of 1.79 ($p<0.001$). There was no age difference between the pre-COVID group and post-COVID group ($p=0.69$).

*Time to Access Care*

Each stage of the interdisciplinary workup process was analyzed to determine its contribution to the total time to DBS implantation. The average total time from initial consult to DBS surgery was 564.6 ± 284.5 days for the entire study duration among the whole implanted DBS cohort (Figure 2A). The time to implantation was 387.8 ± 125.2 days (~12 months) pre-COVID-19 (Figure 2B). Most of the work up was completed within 200 days without holding up the DBS implantation. There was no significant cognitive decline as determined by MoCA and neuropsychological evaluation within this window causing patients to lose their DBS candidacy status (Figure 3).

*Impact of COVID-19 Pandemic*

During the pandemic, the overall wait times more than doubled. The time to DBS surgery increased to 840.15 ± 165.4 days during the pandemic and remained elevated at 839.8 ± 300.7 days post pandemic. Figure 2B and 2C compare each step in the workup before and during/post-COVID-19 pandemic.

The pandemic did not affect time to access to each stage of the DBS workup uniformly. Neuropsychiatry experienced an increase in average wait times (161.5 to 190.8 days, $p<0.05$), as did neuropsychology (144.7 to 330.7, $p<0.01$). Physical and occupational therapy also had a prolonged wait-time (152.9 to 195.9, $p<0.01$) (Figure 2B and 2C). Additionally, the average wait from initial consult to consenting to surgery has increased from 240.3 days to 519.9 days ($p<0.0001$), similarly, the wait time from consent to implantation also increased (149.2 to 313.9 days, $p<0.001$). In the whole process, the longest delay was from consent to surgery, which has not improved despite the pandemic having ended.

For those whose neuropsychology testing was longer than a year, our centre's practice is to repeat neuropsychological testing before final decision to proceed with DBS is made, given that cognitive function may deteriorate over time, increasing the cognitive risk of surgery. Due to the delay in the workup since the beginning of the pandemic, eight patients had their neuropsychological assessment repeated. The repeat assessment when indicated during or post-

COVID-19 did not reject any potential candidates. None of the DBS candidates became ineligible due to significant cognitive decline or developing other neuropsychiatric symptoms, such as hallucinations in the process.

There was no decline in cognition measured by MoCA one-year post-DBS in the whole group. The average MoCA score was 27.2 $\pm$ 2.2 at the initial visit, 27.2 $\pm$ 2.5 prior to DBS, and 27.0 $\pm$ 2.6 at the one-year follow-up (Figure 3). Although no patients were declined for surgery during the prolonged process, one underwent a staged bilateral procedure instead of their originally planned upfront bilateral implantation due to cognitive change.

The motor benefit of DBS was well maintained during the follow-up. We summarize in table 2 the change in UPDRS-III scores at 6- and 12-months after surgery in all PD patients as an example.

**Discussion**

This single-centre study analyzed the time required for each step of the DBS workup process. Our PMDP has been keen to provide timely care to those who need DBS therapy. Thus, DBS referrals were considered semi-urgent, and patients were usually seen by both the DBS neurologist and functional neurosurgeon within 70 days from receipt of referral, and these steps were without compromise during COVID-19 pandemic (72.24 days for the whole cohort). The time for subspecialty evaluation to initiate DBS is exceptionally speedy for Canada.

This data was collected as part of quality improvement to ensure that aspects of our workup did not unduly delay implantation. Such kind of study is lacking in a socialized health care system as in Canada. The time it takes to access services is an essential component of equitable and reasonable access to necessary medical care. Our analysis has shown that although we do many consultations and evaluations, none held up the DBS implantation.

Previous analyses of DBS access in Canada have taken the form of holistic reviews of the system without the necessary in-depth analysis of individual centre performance [9, 13]. "The Canada

Study" analyzed DBS access acrossed the country in 2015-2016 revealed that Alberta, which included the PMDP and the Movement Disorder Clinic (in Calgary), was performing 120% above the national average for the number of DBS surgeries [14]. Wait times for DBS surgery in Alberta were reportedly 6-12 months pre-pandemic [15]. This remains the case as in our study prior to 2020.

Disease progression can cause worsening function, independence, and quality of life and may result in the use of other therapies such as infusion of levodopa-carbidopa intestinal gel (duodopa) to maintain independent living. We did not examine the use of government funded in home care that has an indefinite duration in Canada compared to restricted access in the US. Additionally, prolonged wait times can result in patients developing worsening cognition leading to the reversal of their DBS candidacy.

Importantly, the COVID-19 pandemic has negatively impacted many aspects of patient care, and our work documents that people requiring DBS were significantly disadvantaged by COVID-19. Our data suggest that the effects of the pandemic were not uniformly affecting the DBS process. As such, overall delays in implantation were influenced by longer wait times in a subset of specific assessment in the workup. In total, the workup process from decision to consider DBS to actual DBS implantation increased from ~12 months pre-pandemic to ~28 months during and post COVID-19. Breaking down this analysis by individual components of the DBS workup pipeline helps identify where the potential system barriers are, thus can provide important data points in evaluating equity in access to DBS, understanding lags in the process, and identifying areas that need additional support and attention.

The most significant hold back was time to surgery from consent during and post COVID-19 pandemic. With operating room/time restrictions, priorities were given to emergency surgeries since DBS for movement disorders are still considered "elective procedures". For instance, during COVID-19, non-emergent surgeries were cancelled, and our neuropsychologist was seconded for hospital visitor screening. The widespread shortage in anesthetists added additional strain to the wait time. Further, limited, various care disruptions and prevailing staffing challenges were across the system during the pandemic and post pandemic. The delay in

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neuropsychologist is one example. The additional repeat neuropsychological testing due to the delay in the process has further prolonged the time to DBS implantation. Following COVID-19, Canada continues to experience a severe shortage of anesthetists and hospital crowding resulting in ongoing surgical cancellations. Delays in DBS implantation result in delays to the individual and family to improve quality of life and have the unintended consequence of increasing healthcare utilization, further straining the healthcare system [16].

Further, the pandemic period is characterized by not just longer delays in access to care but also greater variability in timelines. It should be noted that since categorization of a patient into the pre-COVID-19 and COVID-19 bins are done based on if any of their workup falls after March 15, 2020, there may be patients who were partially worked up before the shutdowns, and their procedure was delayed longer relative to their initial assessment compared to someone whose first assessment was during the pandemic. This can account for some but not all of the increased variability in patient wait-times when stratified by period.

DBS is widely considered cost-effective due to the financial burden associated with PD progression resulting in Emergency Department visits and hospitalizations [17]. For PD, DBS treatment compared to best medical treatment (optimized on dopaminergic medications) added 1.69 quality-adjusted life-years, resulting in an incremental cost-effectiveness ratio of $23,404USD per quality-adjusted life-year [16]. Given our results demonstrated a delay to implantation of 8 months to as much as 796 days, continued restrictions in access to operating rooms and certain healthcare professionals (neuropsychology) continue to delay optimization of quality of life.

To improve timely access to DBS care, and to change the perception that "DBS is elective surgery", individual advocacy from physicians and health care teams will not be sufficient in improving patient wait times. Institutions, health regions and governments should be heavily involved in mitigating against the major burden on patients' health and wellbeing by developing recovery plans and implementing strategies to restore surgical activity safely and timely [18].
Other observations from the study included disparities in sex and low quality of the referrals. As a life-change treatment, access to DBS should be readily available and in a timely manner for

those in need. This study provided first-hand information and encouraged further study and consideration to optimize the access to DBS. In addition, these data may help policy makers to consider better implementation of important medical care.

**Author contributions**

Conceptualization: FB and JM. Methodology: KY, PT, JM and FB. Data collection: KY and PT. Writing – original draft preparation: KY, PT and FB. Writing – review and editing: FB, JM and TS.

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**Competing interests**

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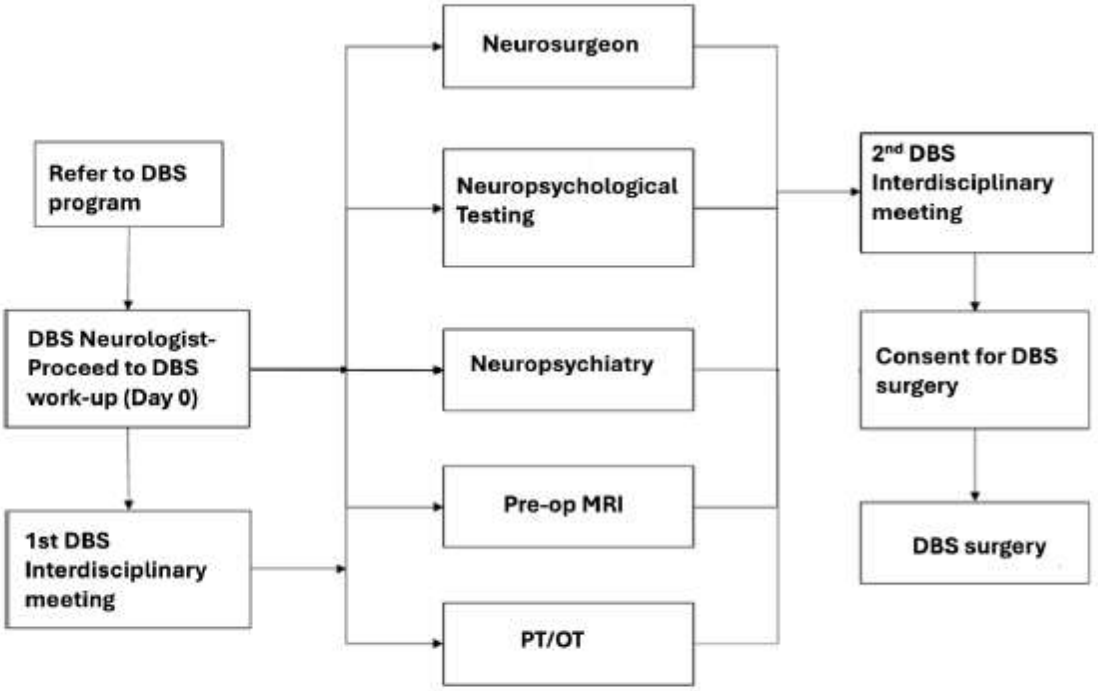


**Figure 1.** The DBS workup process at the PMDP of the University of Alberta.

The flowchart marks the process of DBS workup at the University of Alberta. DBS, deep brain stimulation; PMDP, Parkinson and Movement Disorders Program; PT, physical therapy; OT, occupational therapy.

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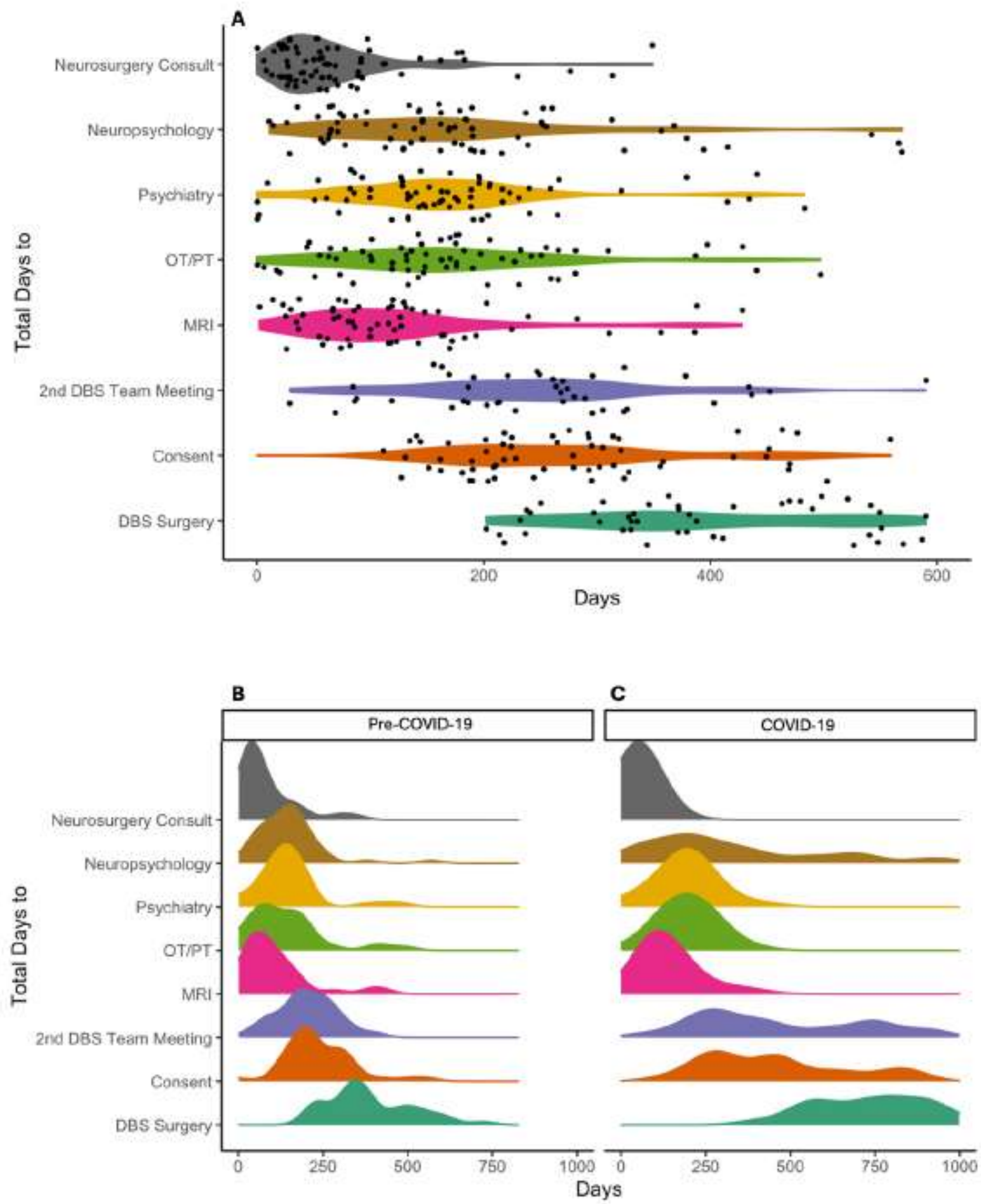


**Figure 2:** Time to access DBS surgery.

The panels mark days needed to complete each step of the DBS work-up. Day 0 is when a patient was first deemed to be a DBS candidate. Panel A is the summary of all patients through the study period; panel B was the baseline practice before the COVID-19 pandemic, and panel C marked the status during/post the pandemic.

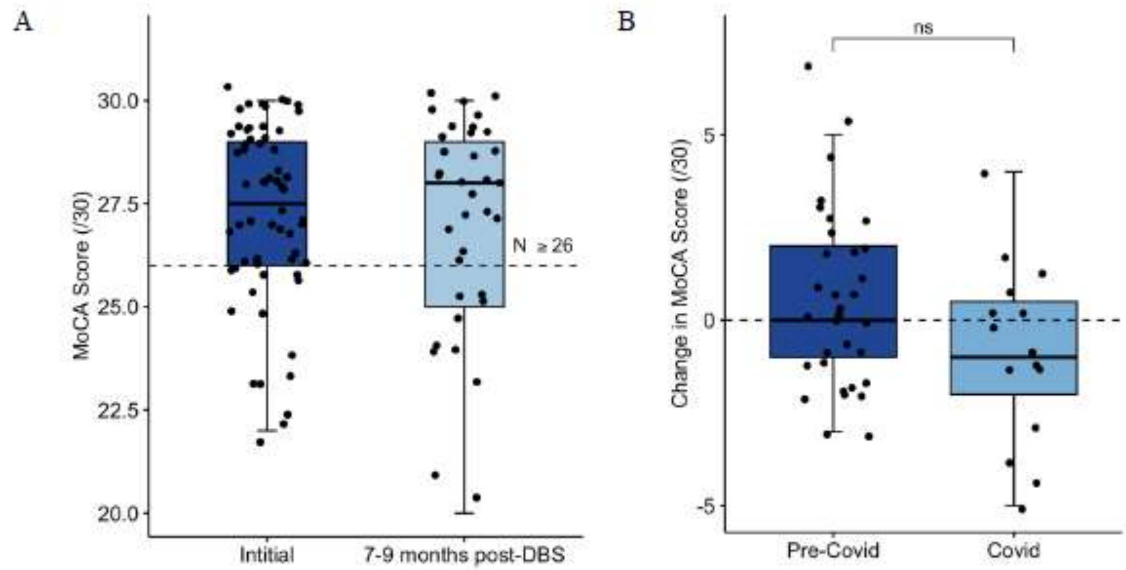


**Figure 3.** Assessment of MoCA before and after DBS.

The repeat MoCA score did not demonstrate decline at 7-9 months post-DBS when programming was optimized (Figure 3A). Compared with the pre-COVID-19 group, there was no significant decrease in MoCA in the COVID-19 group (p=0.21). MoCA, Montreal Cognitive Assessment.

**Table 1:** Comparing demographics for people received DBS before and during/post COVID-19. Demographics results of the patients who received DBS, comparing those who received DBS surgery pre-COVID-19 pandemic and those were operated during and post-pandemic.

PD, Parkinson's disease; SD, standard deviation.

| | **Total** | **Dystonia** | **Tremor** | **PD** |
|---|---|---|---|---|
| **Total cases** | 78 | | | |
| **Male, n (%)** | 50 (64.10) | | | |
| **Average age at DBS surgery, year (SD)** | 57.73 (11.4) | | | |
| **Pre-COVID-19** | 49 | 10 | 4 | 35 |
| **Male, n (%)** | 31 (72.1) | 3 (30) | 3 (75) | 25 (71.4) |
| **Average age at DBS surgery, year (SD)** | 59.9 (7.8) | 61.6 (5.9) | 63.0 (5.2) | 59.21 (8.5) |
| **Post-COVID-19** | | | | |
| **No. of Cases** | 29 | 7 | 3 | 19 |
| **Male, n (%)** | 16 (57.1) | 3 (42.9) | (0) | 13 (68.4) |
| **Average age at DBS surgery, year (SD)** | 54.6 (14.8) | 34.80 (18.7) | 62.67 (11.6) | 58.47 (9.5) |

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**Table 2:** UPDRS-III pre-DBS and post-DBS at 6 and 12 months for PD patients. Using Parkinson's disease as an example, the motor benefit of DBS is shown as percentage of improvement from the pre-DBS states, respectively.

| UPDRS-III | Pre-op | 6 months post-op ON DBS | 12 months post-op ON DBS |
|---|---|---|---|
| OFF medication | 33.1±9.5 | 20.2±8.3 | 20.3±8.8 |
| (% improvement from pre-op OFF state) | | 39.0±22.1 | 38.7±12.1 |
| ON medication | 14.9±6.3 | 12.5±7.2 | 13.6±6.8 |
| (% improvement from pre-op OFF state) | 54.1±16.9 | | |
| (% improvement from pre-op ON state) | | 16.1±12.5 | 8.7±7.9 |

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