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Strategies to mitigate impacts of the COVID-19 pandemic on patients treated with deep brain stimulation

Dear Editor,

In the wake of the COVID-19 crisis, 160,000 patients worldwide who have undergone deep brain stimulation (DBS) are now experiencing critical treatment disruptions. These include patients treated for Parkinson's disease, dystonia, epilepsy and essential tremor as well as for psychiatric disorders, like treatment-resistant obsessive compulsive disorder and Tourette syndrome. With many hospitals overburdened [1] and the potential for community-based infection still high (and increasing), shifting to various forms of telemedicine DBS care has become part of a necessary "natural experiment" to mitigate risk for infection and continue care throughout the pandemic. However, the impacts of COVID-19 on patient outcomes and well-being remain unknown.

Some potential risks of and practical considerations for implementing remote DBS care were outlined by Gross et al. [2], who discussed whether and when to implant new patients with DBS, how to avoid and what to do in case of internal pulse generator (IPG) depletion, and how to address hardware infection or malfunction. Gross et al. provide effective recommendations for addressing potential neurosurgical risks during the pandemic; however, a gap remains in understanding how best to address potential *ethical* issues that can impact patient well-being in the context of remote DBS care. Our group of DBS clinicians and researchers – currently treating patients using conventional DBS and engaged in research on ethical issues arising in next-generation DBS care, respectively, highlight some of these ethical considerations here.

In the absence of remote programming technology for DBS systems, the shift to telemedicine for patients who wish to continue DBS treatment inevitably entails a greater level of involvement and participation from patients in managing their own care. Whereas before the pandemic, physicians and other healthcare professionals were able to conduct routine observations of motor function, assess changes in cognition, mood, behavior or quality of life, modify or titrate stimulation parameters and assess battery life in person, now most of these critical aspects of care are occurring remotely, resulting in greater patient control and autonomy over their treatment (particularly stimulation). Physicians may widen stimulation parameters within a safe margin to allow patients to "tweak" their stimulation and experiment with minimum thresholds on their own.

This key shift toward greater patient control over stimulation is part of a larger strategy to balance battery conservation with symptom management. Many patients without rechargeable batteries face the possibility of battery depletion during the course of the pandemic; thus, conserving battery life is of high priority. The expiration of DBS device battery can require hospitalization for emergency battery replacement to avoid negative impacts (e.g. "rebound effect") of abrupt cessations in stimulation [3] which may uncommonly rise to the level of a medical emergency. Impacts of depletion can be especially problematic for patients receiving DBS for neuropsychiatric disorders – including treatment-resistant depression, obsessive-compulsive disorder and Tourette Syndrome – who often run stimulation at higher currents and are more likely to experience battery depletion if they do not have rechargeable batteries. Patients may conserve battery life by titrating settings to minimum stimulation levels needed to manage their symptoms, and can even turn the device off completely in some circumstances (e.g., while sleeping).

A major ethical obligation when employing strategies that involve enhanced patient control over treatment parameters is to consider what level of control patients are comfortable assuming over their own stimulation. While many patients may welcome additional control over their settings as a source of comfort and even empowerment, others may not feel comfortable altering settings and may experience this responsibility as anxiety-provoking. Evidence from the literature on shared decision making suggests that patients' control preferences over treatment decisions vary widely and are not easily predicted [4]. We recommend that physicians actively explore – using available quantitative [5] or narrative tools [6,7] – whether their DBS patients are comfortable with taking on these new responsibilities before incorporating treatment strategies that entail enhanced patient control over stimulation. Remote care approaches should respect and align with patients' control preferences for treatment.

A second ethical concern related to patient control is the potential for unforeseen negative impacts resulting from untested or under-understood approaches. As with any untested intervention, outcomes are likely to be indeterminate. However, the uncertainty of integrating greater patient autonomy over treatment may be exacerbated by the already elevated baseline levels of uncertainty over DBS outcomes, given the high degree of variation in medical and psychosocial characteristics with the potential to influence DBS outcomes, even under highly controlled conditions. Understanding how patients will respond to changes in stimulation takes time, with most changes in movement, mood or cognition likely to happen naturalistically, that is, outside of the cross-sectional telemedicine visit. Indeed, even in a non-pandemic context, all in-person observations are cross-sectional representations of a continuum of symptom experiences. However, greater dangers to patient well-being may exist when physicians' insights are *exclusively* mediated by patient report and potentially further obscured by

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technological and logistical barriers [8]. In this context, patients must not only assume greater responsibility for observing and reliably reporting these changes, but physicians must also consider additional strategies and devices (e.g. employing flexible wearable devices that measure and remotely report on gait impairment, falls, muscle tone, tremors, sleep disturbances, or web-based calculators and smart phone applications that help to estimate device battery life) in order to facilitate remote patient monitoring to augment physicians' understandings about how best to manage patient-specific approaches to remote care.

A third ethical concern is whether remote care scenarios increase the potential for negative mental health symptoms to manifest or worsen among DBS patients, many of whom have primary or comorbid mental health needs. Limited access to in-person care for the treatment of psychiatric comorbidities (e.g., depression) before and after DBS surgery, as well as post-surgery psychosocial health needs (e.g., adjustment to the device; changes in identity and body image) may require special attention. Further, many DBS patients may be experiencing new distress due to the interaction of COVID19-related fears with preexisting psychiatric symptoms, potentially compounded by the social isolation imposed by pandemic conditions. These factors combine to put DBS patients with existing (and especially treatment-refractory) mental health treatment needs at significant risk for worsening of mental health symptoms and even suicide in the absence of effective and accessible care. Risks to mental health during the pandemic are critical and should receive equal consideration in relation to physiological and surgical risk concerns. As many researchers have argued [9,10], physicians (of all types) should be ready to address or offer referrals for patients with mental health needs that emerge or are exacerbated during this pandemic.

In sum, an ethically responsible approach to remote DBS care should entail explicit discussions between physicians about patients' control preferences for treatment, and about potential safety concerns in the context of patient-led experiments conducted "in the wild" (in the absence of consistent physician oversight). Further, physicians should identify and closely monitor patients who have the potential to experience emerging or worsening mental health symptoms during the pandemic.

Disclaimer

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Declaration of competing interest

The authors declare no competing interests.

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