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ORIGINAL PAPER

Deep Brain Stimulation for Parkinson's Disease: Why Earlier Use Makes Shared Decision Making Important

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Abstract
Introduction As deep brain stimulation (DBS) has shifted to being used earlier during Parkinson's disease (PD), data is lacking regarding patient specific attitudes, preferences, and factors which may influence the timing of and decision to proceed with DBS in the United States. This study aims to identify and compare attitudes and preferences regarding the earlier use of DBS in Parkinson's patients who have and have not undergone DBS.
Methods We developed an online survey concerning attitudes about DBS and its timing in PD. The survey was distributed nationally in the United States via the Michael J. Fox Foundation Trial Finder, the American Parkinson Disease Association flyers, and as a link on the Parkinson Alliance website. Differences in responses between PD DBS and non-DBS patients were assessed.
Results A total of 445 patients with PD met eligibility criteria for the survey of which 160 self-identified as having undergone DBS. Fifty-five percent (n = 124) of non-DBS patients believed that DBS for PD should only be considered after all medication options have been tried. Patients favoring early DBS had fewer concerns regarding the surgery than those favoring later DBS.
Conclusion Our findings highlight a variety of important considerations and concerns patients have regarding DBS and its timing. These viewpoints are important aspects of shared decision-making, as they help to identify patients' preferences, values, and goals, which should enable providers to better navigate, with their patients, the decision path for therapeutic options to consider.

Keywords Deep brain stimulation · Parkinson's disease · Shared decision-making

Introduction

Deep brain stimulation (DBS) is an effective therapy for the management of Parkinson's disease (PD) motor symptoms. DBS is generally reserved for

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advanced motor symptoms, such as fluctuations and/or dyskinesia, which are not effectively managed by medications. There has been a shift for its use *earlier* in the development of motor complications even when medication management is a viable option [1], with recent evidence suggesting that DBS may have a role in the management of *early* stage PD [2]. Given the variety and complexity of treatment options for the management of PD, including the timing of when in the disease progression neurosurgical modalities like DBS should be considered, it becomes key to engage patients in determining the optimal treatment strategy. Shared decision-making (SDM) is a process in which physicians and patients arrive at a treatment plan together after considering patients' individual values, preferences, and goals. It is a form of patient-centered care that involves the patient directly in determining the best course of action. Studies examining SDM in PD across several countries have identified patients' desire to engage in decision making; however, barriers were identified [3–5]. Some of these barriers included: lack of expertise regarding specific treatments amongst physicians; a perception amongst some patients that there is no choice regarding their treatment; and a lack of information for patients directly comparing different options. Although many foundations, including the Parkinson's Foundation, the American Parkinson Disease Association, and the Parkinson Alliance, include patient-centered general information about DBS, little is known about PD patient attitudes and preferences that may influence decision making about timing of DBS. In response to this knowledge gap and the updated Food and Drug Administration (FDA) indication for DBS in PD which allows for earlier use, we conducted a national survey to compare different attitudes and preferences between PD DBS and non-DBS patients and to identify factors that may influence the timing of DBS in the United States. The results of this study advance understanding of patient's attitudes and perceptions of DBS and can help shared decision-making in clinical encounters for those considering the surgery. Moreover, the preliminary data established here is the foundation for future development of patient decision aids, a tool which facilitates SDM and may help PD patients arrive at an optimal treatment decision.

Methods

Survey

An internet-based survey was developed to compare different attitudes and preferences between PD DBS and non-DBS patients and to identify factors that may influence the timing of DBS. Survey items were informed by the results of the qualitative interview phase of the study [6], current literature published on patient attitudes of DBS, and expert opinion from movement disorder neurologists concerning attitudes about DBS and its timing in PD. The survey was further reviewed by patient advocates and clinical experts from the Parkinson's Foundation, Parkinson Alliance, and Michael J. Fox Foundation to ensure quality control. The final survey broadly contained three sections: patient demographics, experiences with PD treatments, and patients' attitudes and perceptions towards the earlier use of DBS. The second section regarding patient experiences with PD treatments contained modified questions depending on whether the patient had already undergone DBS. A combination of multiple choice, free text, ranking, Likert scale, and sliding scale questions were used for assessment. Institutional Research Board approval was obtained from Michigan State University (Study00002041) and Weill Cornell Medicine (Protocol#1901019902).

Data Collection and Sample

The survey was distributed via the Michael J. Fox Foundation Trial Finder (https://www.michaeljfox.org/trial-finder), flyers from the American Parkinson Disease Association, and as a link on the Parkinson Alliance website. Qualtrics was used for administration of the survey for the study period from May 2019 to August 2019. The sole inclusion criterion for the study was PD patients with or without DBS. Participation was voluntary and no compensation was provided. At the beginning of the survey participants review general information regarding the study and the informed consent; continuation to the survey questions was considered implied consent. Responses were kept anonymous and confidential with no identifying patient data present.

Data Analysis

Eligibility criteria for inclusion in the analysis was defined as greater than 50% completion of the survey. For those patients meeting eligibility criteria but not completing the survey, all available data were used in the analysis. Demographic data were summarized descriptively by recording the percentage of responses between DBS and non-DBS patients. General impressions of DBS were assessed by asking patients to rank their top three impressions from a provided list. Response rates for each impression were summarized as percentage of DBS versus non-DBS patients selecting the impression in their top three.

Assessment of specific time frames in which patients view the use of DBS to be too early was performed by asking patients to select from a list (less than 1 year, 1 to 3 years, 4 to 6 years, 7 to 9 years, or 10+years) a time frame when they would personally consider DBS to be too early. Comparison of response rates was reported descriptively as percentage of DBS and non-DBS patients that indicated a specific time frame. Specific concerns regarding DBS were assessed using a 5-point Likert scale presented as (1) not at all concerned, (2) slightly concerned, (3) moderately concerned, (4) very concerned, (5) extremely concerned. We investigated differences in concerns between patients favoring early versus later time frames for DBS by stratifying patients into an "Early DBS" (defined as patients indicating 0 to 3 years after diagnosis being too early) and a "Later DBS" group (defined as 4+years after diagnosis). Differences in concerns between DBS and non-DBS patients within the Early and Later group are summarized as median Likert ratings and interquartile range. Finally, differences in attitudes regarding the use of DBS in early versus advanced PD were assessed by having patients quantify their agreement from 0 (no agreement) to 100 (max agreement) across several domains including: perceived safety; effectiveness; convenience; and risk of the surgery in these time frames. Early PD was presented in the survey as when motor symptoms if present are still managed by medications, and advanced PD as when features of motor fluctuations or dyskinesia are present as a result of levodopa use and are not being adequately treated with medications alone. Differences in mean ratings regarding these domains between DBS and non-DBS patients were assessed using a two-tailed t-test with unequal variances. Statistical significance was set at $\alpha = 0.05$. All data analysis was performed using R version 3.6.3.

Results

A total of 496 individuals participated in the study. Four hundred forty-five met eligibility criteria. Two hundred eighty-five participants self-identified as not having undergone DBS and 160 self-identified as having undergone DBS. The median age at diagnosis was 61 years. Most participants at the time of the survey were retired, college educated, and married. Sixteen participants self-identified as a race other than white. Demographic data for the two groups are summarized in Table 1.

Patient Perceptions of DBS

The top two impressions of DBS amongst all patients, with and without DBS, were that "DBS in PD allows for better management of disease symptoms than medications alone" and "Patients with PD should be able to obtain DBS even when the disease is still manageable by medications." However, a greater proportion of DBS patients indicated that more patients should have the opportunity to obtain DBS (65% DBS vs. 47% non-DBS) and believe that DBS in PD allows for better management of disease symptoms than medications alone (82% DBS vs. 68% non-DBS). In contrast, a greater proportion of non-DBS patients believe early DBS surgery has a higher risk of complications than when used later (21% non-DBS vs. 4.7% DBS), and that DBS in PD should only be considered after all medication options have been tried (54% non-DBS vs. 27% DBS) (Table 2).

Patients' Attitudes Regarding Timing of DBS

A greater proportion of DBS patients (n = 128, 80.0%) compared to non-DBS patients (n = 144, 50.5%) indicated that less than one year to three years after diagnosis was too early to obtain DBS. About 2% (n = 3) of DBS participants compared to 12.6% (n = 36) of non-DBS participants indicated 7+years was too early (Fig. 1a).

Table 1 Demographic characteristics

Participant's Attributes		DBS N (%)	Non-DBS N (%)
Sex			
	Male	90 (56.3%)	160 (56.1%)
	Female	70 (43.8%)	125 (43.9%)
Age			
	< 30	0 (0.0%)	2 (0.7%)
	30–40	2 (1.3%)	4 (1.4%)
	41–50	12 (7.5%)	20 (7.0%)
	51–60	43 (26.9%)	51 (17.9%)
	61–70	75 (46.9%)	125 (43.9%)
	71–80	27 (16.9%)	72 (25.3%)
	81–90	1 (0.6%)	10 (3.5%)
	Prefer not to report	0 (0%)	1 (0.4%)
Marital Status			
	Married	116 (72.5%)	229 (80.4%)
	Widowed	6 (3.8%)	13 (4.6%)
	Divorced	30 (18.8%)	28 (9.8%)
	Separated	1 (0.6%)	2 (0.7%)
	Never married	7 (4.4%)	11 (3.9%)
	Prefer not to report	0 (0.0%)	2 (0.7%)
Highest level of school completed / Highest degree received			
	Less than high school degree	2 (1.3%)	0 (0.0%)
	High school degree of equivalent	9 (5.6%)	10 (3.5%)
	Some college but no degree	21 (13.1%)	37 (13.0%)
	Associate degree	11 (6.9%)	20 (7.0%)
	Bachelor degree	59 (36.9%)	69 (24.2%)
	Graduate/Advanced degree	58 (36.3%)	149 (52.3%)
Employment status at time of diagnosis			
	Employed, working 1–39 h per week	25 (15.6%)	47 (16.5%)
	Employed, working 40 or more hours per week	86 (53.8%)	123 (43.2%)
	Not employed, NOT looking for work	10 (6.3%)	13 (4.6%)
	Not employed, looking for work	2 (1.3%)	1 (0.4%)
	Retired	37 (23.1%)	101 (35.4%)
Current employment status at time of survey			
	Employed, working 1–39 h per week	18 (11.3%)	34 (11.9%)
	Employed, working 40 or more hours per week	14 (8.8%)	58 (20.4%)
	Not employed, NOT looking for work	26 (16.3%)	27 (9.5%)
	Not employed, looking for work	8 (5.0%)	0 (0.0%)
	Retired	94 (58.8%)	166 (58.2%)
Member of any foundation or support group for Parkinson's disease			
	Yes	103 (64.4%)	170 (59.6%)
	No	57 (35.6%)	115 (40.4%)

DBS, deep brain stimulation

We investigated if patients who favored later DBS versus those who favored early DBS had differing concerns regarding the surgery which may influence its timing. We found that amongst non-DBS patients the top concerns were similar regardless of their favoring later or early DBS: fear that DBS could

Table 2 Impressions of DBS amongst patients with PD

	DBS Patients Ranking in Top 3 (n = 148)	Non-DBS Patients Ranking in Top 3 (n = 227)
DBS in PD allows for a better management of disease symptoms than medications alone	122 (82.4%)	154 (67.8%)
Patients with PD should be able to obtain DBS even when the disease still manageable by medications	97 (65.5%)	128 (56.4%)
More patients should have the opportunity to obtain DBS	97 (65.5%)	107 (47.1%)
DBS in PD should only be considered after all medication options have been tried	40 (27.0%)	124 (54.6%)
DBS is a completely reversible procedure	28 (18.9%)	30 (13.2%)
DBS in PD is more cost effective than medications alone	23 (15.5%)	21 (9.3%)
DBS should be offered only in large centers	17 (11.5%)	41 (18.1%)
Other	13 (8.8%)	29 (12.8%)
Early DBS surgery has a higher risk of complications than when used later	7 (4.7%)	47 (20.7%)

Differences in impressions of DBS between PD patients who have and have not undergone the surgery. Data are number and percentage of DBS versus non-DBS patients who ranked impression in top three. DBS, deep brain stimulation; PD, Parkinson's disease

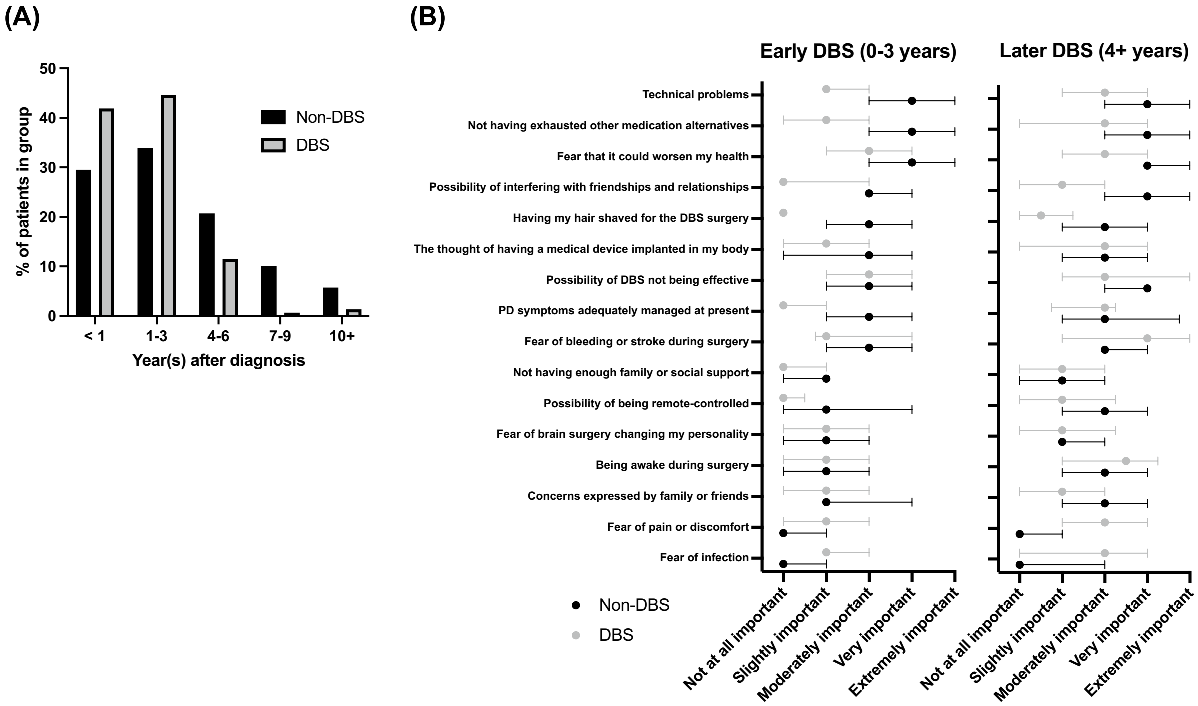

Fig. 1 Timing of DBS and associated concerns. **A** Patient reported timing of when the use of DBS is 'too early' in years after PD diagnosis between DBS and non-DBS patients. Data are percentage of patients in group who indicated timing category. **B** Concerns for DBS and non-DBS patients who indicated zero to three years (Early DBS) and four or more years (Later DBS) after diagnosis was too early to receive DBS. Data are median Likert rating and interquartile range. DBS, deep brain stimulation; PD, Parkinson's disease

worsen one's health; technical problems; the possibility of DBS interfering with friendships and relationships; and not having exhausted other medication alternatives. Both DBS patients favoring early or later DBS expressed greater fear of infection and of pain or discomfort. In general, non-DBS and DBS patients who favored early DBS had similar concerns than those who favored later DBS, but they were less concerned (Fig. 1b).

We found different attitudes between DBS and non-DBS patients regarding the surgery's use in early versus advanced PD. Compared to the treatment of advanced Parkinson's, non-DBS patients rated DBS as significantly less safe (mean, 75.4 DBS vs. 60.4 non-DBS, $p < 0.001$), less effective (83.0 DBS vs. 67.9 non-DBS, $p < 0.001$), less convenient (62.2 DBS vs. 46.3 non-DBS, $p < 0.001$), and riskier (41.3 DBS vs. 61.7 non-DBS, $p < 0.001$) than their DBS patient counterparts. No significant difference was observed regarding perception of DBS cost. We found the same pattern for the treatment of early PD, when motor symptoms are still managed with medications. Overall DBS patients saw the use of DBS in early PD as riskier, less safe and less effective compared to its use in advanced PD. Non-DBS patients also saw the use of DBS in early PD as less safe and effective and with similar risks to its use in advanced PD (Fig. 2).

Discussion

The results of this study demonstrate a spectrum of attitudes regarding DBS and its timing in the disease course amongst patients with PD in the United States. This range of responses highlights the importance of engaging patients in shared decision-making when considering DBS as a treatment option early in the disease progression.

Patient Attitudes and Perceptions of DBS

Overall, we found relatively strong support among both DBS and non-DBS patients regarding the perceived efficacy of the surgery, as well as a general desire for its accessibility. These findings are consistent with previous reports examining how the surgery is perceived for mid to advanced PD [7–9]. These perceptions are likely due to over two decades of use of DBS for PD in the clinic since its approval by the FDA in 1997, with an estimated 150,000 implants worldwide, greater than 90% of which are for movement disorders such as Parkinson's disease, resulting in overall motor symptoms improvement. However, further research exploring how these attitudes may change as DBS is initiated at earlier stages of disease, when motor symptoms are not disabling, is limited. Moreover, recent work has noted the importance of considering the potential effects of long-term DBS, which may present additional considerations for patients, including increase in the number of battery changes (although possibly mitigated by rechargeable batteries), as well as the possibility of increased life expectancy, which exposes patients to more of the non-motor complications, like cognitive decline [10]. This is the result of DBS being an effective treatment primarily for debilitating motor symptoms of PD, such as tremor, rigidity, stiffness, slowed movement, and levodopa-induced complications, but not

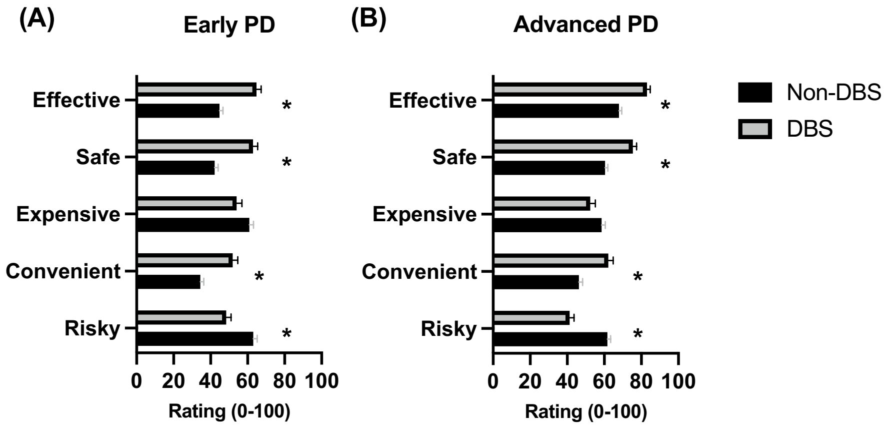

Fig. 2 Attitudes regarding the use of DBS in early versus advanced PD. Differences in attitudes between DBS and non-DBS patients regarding the use of DBS for (**A**) early and (**B**) advanced PD. Larger values represent greater agreement. Data are means and standard error. *two-tailed t-test with unequal variance $p < 0.0001$. DBS, deep brain stimulation; PD, Parkinson's disease

so effective when it comes to addressing non-motor symptoms such as speech and cognitive function. As Gilbert and Lancelot rightly pointed out, this introduces further considerations to previous neuroethical discussions over the long-term consequences of DBS treatment [10], as well as the assessment of benefits versus risks, and health and well-being costs of having alleviated motor symptoms but not addressing the progression of neurodegenerative PD symptoms. Furthermore, health status at baseline presents PD patients with different considerations. For example, patients with vulnerable cognitive status on neuropsychiatric testing or moderate to severe hypophonia and dysarthria at baseline are at risk for worsening these symptoms after invasive neurosurgery. Similarly, while dyskinesia may improve, if patients are falling and losing balance at baseline, these gait symptoms may not improve with DBS. All of these are key considerations for patient informed decision making, as each patient will have different values to weigh in when considering the possibility of undergoing this elective procedure. For some patients the trade-offs between debilitating motor symptoms and potential future with exacerbated non-motor symptoms will be a clear one, for others detailed conversations will be needed to help them elicit what truly matters to them, not only in the short term but also long-term.

An additional consideration for patients is that having DBS may exclude them from clinical trials investigating other novel therapies such as cell-based therapies and ultrasound ablation. Although neither of these therapies have been proven to address non-motor symptoms, they offer patients novel advanced therapeutic strategies for their motor symptoms apart from standard available therapy. For those interested in participating in clinical research, this exclusion may delay their choice of having DBS and should be discussed with patients during DBS counseling as an important aspect of SDM. From an ethical point of view, there are still discussions on whether it is fully justified at this point in time, where the therapy is an established one for movement disorders, to exclude individuals with DBS from other types of clinical studies.

Although there appears to be some agreement regarding personal views of DBS among the patients in our study, some differences were observed between DBS patients in comparison to non-DBS ones. For example, we found approximately one in two non-DBS patients to indicate that DBS in PD should only be used when all medication options have been exhausted compared to about one in four DBS patients. Other studies in different countries have documented similar sentiments amongst PD patients viewing DBS as a treatment of last resort [7, 11]. Considering that this view is less pervasive amongst patients with DBS, possibly reflecting greater education regarding the surgery and their own experiences with DBS, these results suggest that an important component of shared decision-making would be the opportunity to interact with patients who have undergone DBS. Some providers already enable these interactions by pairing patients with similar profiles, but this is not standard practice. Having greater exposure to the benefits and risks of undergoing the treatment from people who are already recipients of it, could enable non-DBS patients to balance their expectations of the treatment as well as to have more information to consider when weighing on the type of trade-offs between benefits and risks. However, as shown in previous studies [7, 11], it is likely that for some patients, the idea of brain surgery, which as any other major surgery carries associated risks, together with having an electrode implanted in their brain, will be,regardless of how much information they are given, the last option to explore.

Timing of DBS

Regarding the differences in views around the timing of DBS for advanced versus early PD among the two groups of patients, our findings suggest once more that patients with PD have different values and preferences regarding their health care, not only regarding the type of interventions but also their timing during the course of their disease. These distinct values and preferences are an important component of the decision-making process of patients considering DBS and its timing.

Although additional work will be required to further elucidate the values underpinning specific patients' attitudes and perspectives, we identified specific areas of relative concern for patients which provide insight into important considerations regarding if and when to undergo DBS treatment. We found the possibility of technical problems to be of relatively higher concern for patients especially those without DBS. While the possibility of technical problems exists, the probability of these occurring is rare. Yet, when confronted with having a brain implant malfunctioning the threshold of what is acceptable might be very different than if we were discussing having a knee implant malfunctioning. Patients who have previously undergone the procedure might also have technical concerns, but they already made a choice about the type of trade-offs they are willing to undertake to have some alleviation of their motor symptoms. Furthermore, considering that previous DBS recipients already have first-hand experience with the treatment, they are an important source of information to patients who are already thinking about having the procedure. For patients who are still considering the surgery, conversations with patients who already have DBS and clinicians, can assist in elucidating what truly matters to them, helping them prioritize their values and preferences.

The possibility of not having exhausted other non-invasive methods of symptom control appears to also be of relatively high importance for patients. We found that patients who have DBS and favored earlier time frames gave *not having exhausted other medication alternatives* a median concern rating of 'slightly important' compared to 'very important' for non-DBS patients favoring earlier time frames. A balanced discussion regarding medication options and invasive alternatives should play an important role in the decision-making process especially when considering the early use of DBS as patients may have significant differences in preferences and concerns regarding the use of more invasive types of treatments. For some patients not having to deal with side-effects of medications is a better outcome than waiting until all possible medication regimes have been tried. For others, surgery will always be an option of last resort.

Upon further assessing differences in concerns between DBS and non-DBS patients favoring earlier time frames, we found the possibility of DBS interfering with friendships and relationships to be of differing levels of concern. While non-DBS patients gave a median concern rating of 'moderately important,' patients with DBS gave a median rating of 'not at all important,' possibly reflecting improved motor outcomes and more socialization. This may represent an important factor for some considering DBS and should be further explored with patients who are considering the surgery.

Education regarding DBS likely plays an important role in the decision to proceed with surgery and influences expectations following the surgery [12, 13]. Improved counseling and peer discussions with others who have had the surgery may be an effective strategy [6, 14], especially when considering the use of DBS earlier in the disease course. The challenge for patients considering *early DBS* is that the pool of people who have undergone such an early stage of the procedure is limited to a few small trials, and the data for the long-term use of DBS is still being collected and analyzed from this cohort. In any case, as part of the counseling process, clinicians need to clearly explain the trade-offs found in the early use of DBS compared to those found in its use for mid- or advanced PD.

In assessing attitudes regarding DBS, non-DBS patients viewed the procedure as significantly riskier for both the treatment of early and advanced PD. This finding potentially reflects the fact that these patients have not yet achieved a value threshold where the potential benefits of the surgery outweigh the risks. Here, it is of ethical importance when considering DBS early in the disease progression, to keep in mind the variable rates of disease progression, and the potential of misdiagnosing patients with idiopathic PD when in fact they might have atypical parkinsonian syndromes, for which DBS not indicated [15]. These factors change the risk and benefits equation in important ways that need to be communicated to patients deciding on their treatment path.

In terms of the cost of the surgery, we found no significant difference between groups for either early or advanced PD. While in theory the cost of the device and the surgery itself should not change if performed earlier or later in disease, there are additional cost considerations from the patient's livelihood perspective, which may influence overall expense when factoring the timing of surgery [16]. Potential long-term cost saving measures include reducing medication costs [17, 18], and supporting patients' ability to continue working for a longer time. An increase in physical independence also potentially translates to less cost spent on home care services [16]. In contrast, possible increased costs include additional battery replacements, and increased medical expenses resulting from infections or malfunction of device. Shared decision-making between physicians and patients should take all these issues into consideration [19].

Implications for clinical care

Considering the noted concerns and the variety of views regarding the timing of DBS, SDM could have a real impact in helping patients navigate the different trade-offs made, as well as aligning their values, preferences and goals when deciding if and when to undergo DBS in their treatment course. SDM has frequently been framed to include both building empathic relationships and sharing evidence with patients to support informed and collaborative decision making [20]. However, the emphasis has often been on choices between clinically viable treatment alternatives in “equipoise” situations, where the alternatives yield similar expected mortality or morbidity, and is frequently seen as requiring a patient decision aid to communicate evidence on risks and benefits of alternatives [21]. Decision aids are tools which facilitate SDM and may help PD patients arrive at an optimal treatment decision. These tools directly present information regarding different treatment options alongside each other in a patient-friendly format, and help patients reflect on their goals and preferences to arrive at a decision [22]. The use of decision aids has been shown to reduce decisional conflict and improve knowledge about various options [23, 24], by supporting communication with the best medical evidence, as well as providing a standardized structure for weighing advantages and disadvantages of treatment options [25]. Available patient-oriented materials through foundations such as the Parkinson Foundation and the American Parkinson’s Disease Association do not often compare existing therapies with each other or with newer modalities, making it challenging to rely solely on them. In addition, misinformation regarding experimental treatments such as cell-based and other advanced therapies may provide false sense of hope or safety [26] requiring detailed counseling and setting of expectations for newer therapeutic options. Future research exploring the development and efficacy of decision aids for PD is needed.

Limitations

Our study has some limitations. First, our survey was a predominately White and college-educated sample, and as such does not capture the demographic representation of all patients with PD in the United States. Moreover, the attitudes and preferences described above are not fully generalizable to those outside the scope of this survey. We found 92.5% of DBS patients completed the survey compared to 79.6% of non-DBS patients. It is possible that differences in rates of non-responses may have contributed to some differences observed between the two groups. In addition, we did not directly ask those who had not had DBS if they were offered DBS at the time of the surgery so it is conceivable that those without DBS who answered the survey may not be considered DBS candidates as per standard practice. Lastly, the breakdown of early, later and advanced was established based on the FDA approval of earlier use of DBS and this grouping may not be readily used in the clinical literature, affecting generalizability of the results. Nonetheless, our study has significant strengths: its national scope spanning the geographic United States and not limited to a single medical center; the number of PD patients participating in the study; fairly equal gender distribution among both groups; and lastly, a broad range of questions in the survey encompassing many patient centered aspects of DBS, which were reviewed by patient advocacy groups. This contribution from patient groups provides valuable insight on patient perspectives on the use of DBS for PD.

Conclusions

There is support for the use of DBS in earlier time frames amongst patients, however a range of views exists particularly amongst patients without DBS. SDM should play a critical role in the decision to proceed with DBS as the shift of its use into earlier time frames in the disease course continues. Information discussed as part of this process, with both clinicians and other patients who have already undergone the surgery, should include information regarding the long-term safety and efficacy of DBS, assessment of expectations about symptoms for which DBS is effective, DBS use related to the timing of medications, and the trade-offs made when deciding to undergo DBS earlier rather than later. Engaging in SDM while utilizing a PD DBS-specific patient decision aid will facilitate a patient-centered and ethical communication approach, enabling the patient and provider to negotiate and achieve a care plan that incorporates the patient's preferences, values, and goals when considering the use and timing of DBS.

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Author Contribution 1. Research project: A. Conception, B. Organization, C. Execution;

2. Statistical analysis: A. Design, B. Execution, C. Review and Critique;

3. Manuscript Preparation: A. Writing of the first draft, B. Review and Critique;

JM: 2A, 2B, 3A, 3B
HS: 1A, 1C, 2C, 3B
KKB: 3B
LYC: 1A, 1B, 1C, 2C, 3B

Declarations

Ethics Approval Institutional Review Board approval was obtained from Michigan State University (Study00002041) and Weill Cornell Medicine (Protocol#1901019902). The study was performed in accordance with the ethical standards of the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Consent to Participate After receiving information regarding the study, continuation to the survey questions was considered implied consent.

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LYC: None.

Competing Interest None.

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