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Original Article

Mixed Methods Survey to Identify Barriers to Accessing Deep Brain Stimulation for Movement Disorders in Canada

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ABSTRACT: ***Background:*** Movement disorders (Parkinson's disease, essential tremor, dystonia) are debilitating, progressive conditions that profoundly impact patients' quality of life. Surgical therapies, such as deep brain stimulation (DBS) can provide tremendous relief to patients but remain costly and, therefore, limited in availability. It is critical to understand regional barriers to accessing this service to improve access for all patients who may benefit from it. ***Methods:*** This is a mixed methods survey of stakeholders (patients/family members, advocacy groups, family physicians, neurologists, neurosurgeons) assessing perceived barriers to DBS for movement disorders. Closed and open-ended questions were used. Descriptive statistics were used to highlight regions of Canada where perceived access is poor and to identify barriers to access. ***Results:*** A total of 220 responses were recorded (12 neurosurgeons, 22 neurologists, 30 family physicians, 153 patients and caregivers and 3 advocacy group personnel). Themes included limited resources/centralization of resources, education, burdensome referral patterns and personal patient factors. Barriers included costs associated with travel, waitlists, lack of specific resources and poor understanding of movement disorders, DBS indications and referral pathways. ***Conclusions:*** A number of barriers to access to DBS have been identified, related to geography and centralization of services, referrals and need for further education of indications and safety. The use of virtual care, centralized referral pathways and further research to determine the true prevalence of candidates for this therapy are required to improve access to DBS for movement disorders in Canada.

RÉSUMÉ : Enquête à méthodes multiples visant à identifier au Canada les obstacles qui limitent l'accès à la stimulation cérébrale profonde pour les troubles du mouvement. ***Contexte :*** Les troubles du mouvement (maladie de Parkinson, tremblement essentiel, dystonie) sont des affections débilitantes et progressives qui ont un impact profond sur la qualité de vie des patients. Les thérapies chirurgicales, par exemple la stimulation cérébrale profonde (SCP), peuvent leur apporter un soulagement considérable, mais elles demeurent coûteuses et, par conséquent, leur disponibilité demeure limitée. Il est donc essentiel de comprendre les obstacles régionaux qui limitent l'accès à ces services afin de l'améliorer pour tous ceux et celles qui pourraient en bénéficier. ***Méthodes :*** Il s'agit d'une enquête à méthodes multiples menée auprès des parties prenantes du milieu (patients/membres de la famille, groupes de défense, médecins de famille, neurologues, neurochirurgiens) afin d'évaluer les obstacles perçus de l'accès à la SCP pour les troubles du mouvement. À cet égard, des questions fermées et ouvertes ont été utilisées. De plus, des statistiques descriptives ont été utilisées pour mettre en évidence les régions du Canada où l'accès est perçu comme médiocre et pour identifier les obstacles qui limitent ce même accès. ***Résultats :*** Au total, 220 réponses ont été enregistrées (12 neurochirurgiens, 22 neurologues, 30 médecins de famille, 153 patients et soignants, ainsi que 3 membres de groupes de défense). Les thèmes abordés étaient les suivants : ressources limitées, centralisation de ces mêmes ressources, éducation, modèles d'aiguillage contraignants et facteurs personnels liés aux patients. Les obstacles comprenaient les coûts associés aux déplacements, les listes d'attente, le manque de ressources spécifiques et une mauvaise compréhension des troubles du mouvement, des indications au sujet de la SCP et les mécanismes d'aiguillage. ***Conclusion :*** Un certain nombre d'obstacles limitant l'accès à la SCP ont été identifiés. Ils sont liés à la géographie de même qu'à la centralisation des services, à l'aiguillage des patients et à la nécessité d'une formation plus approfondie quant aux indications et à la sécurité de ce traitement. L'utilisation de soins virtuels, des mécanismes d'aiguillage centralisés et des recherches supplémentaires pour déterminer la prévalence réelle de candidats à ce traitement sont nécessaires pour améliorer l'accès à la SCP dans le cas des troubles du mouvement au Canada.

Keywords: Brain stimulation; functional neurosurgery; health services research; movement disorders; movement disorder surgery; neurodegenerative diseases; parkinson disease; stereotactic surgery; surgery

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Highlights

- Identified barriers to accessing deep brain stimulation in Canada include geographical distribution of resources, centralization of services, referral pathways, and lack of education around DBS and its indications.
- Possible solutions include the use of virtual care, centralized referral pathways, and education programs.
- Future research should be directed to determining the true prevalence of candidates for DBS to target above interventions, and improve access to care.

Introduction

From its inception in 1984, the Canada Health Act has maintained the tenets that provincial and territorial health insurance plans must adhere to, including accessibility.[1] The unique geography and population distribution of Canada create challenges when assessing the accessibility of health services. As the complexity of healthcare delivery has evolved, concerns have grown about accessibility to critical healthcare services, particularly those requiring significant technological investment.[2]

One such area with advancing technology is functional neurosurgery, a subspecialty of neurosurgery that involves the use of neurostimulators, implanted devices and modulation of neurological circuits for the benefit of patients with neurological disease (i.e., deep brain stimulation [DBS] for movement disorders including Parkinson's disease [PD], essential tremor [ET] and primary dystonia).[3,4] As the field of functional neurosurgery continues to evolve and the population of Canada ages, proper access to DBS is essential. Gaps remain in our understanding of the prevalence of disease, burden of disability and access to care.[5]

Previously identified barriers to DBS for movement disorders include race,[6–14] gender,[7,9,12–15] socioeconomic status/insurance status,[6,7,9,12,13,16,17] lack of referrals to tertiary centers/movement disorder clinics[18,19] and geographical distance from tertiary centers.[20–23] The majority of studies have been conducted in the USA, aside from one retrospective study in Edmonton[14] and one retrospective cohort study utilizing ICES data in Ontario (ON).[22] Honey *et al.* conducted the only Canada-wide study to date, a national snapshot of the geographic distribution of DBS services in Canada in 2018, revealing a clear disparity between provinces in terms of access (i.e., excellent access in Saskatchewan (SK) with extremely poor access in Newfoundland and Labrador [NL]).[24] What this study did not investigate was the patient's need for these services to determine equitable access nor identify barriers to access.

There have been no previous attempts to comprehensively analyze access to DBS in Canada, through investigation of the need for these services, matched access and investigation of barriers for patients and practitioners. The literature primarily relies on retrospective surgical data to determine a patient's ability to access functional neurosurgery; however, this method is limited, in that patients have already overcome existing barriers to receive surgical intervention in many of these studies.

The current study utilizes a mixed methods survey approach to barriers and facilitators to accessing DBS for patients with movement disorders from patient and healthcare provider perspectives. The objectives of this study include the identification of perceptions of stakeholders along the DBS care pathway regarding barriers to efficient access to functional neurosurgery among patients with movement disorders.

Methods

This is a population-based mixed methods survey study. The study was approved by the local university ethics committee, the Hamilton Integrated Research Ethics Board (HiREB #15262).

Survey development

Survey questionnaires were developed in English and French and adapted for each of the stakeholder groups of interest along the patient care pathway (patients, family physicians, neurologists and neurosurgeons). External individuals from each of these groups were consulted in the design of each questionnaire. Questions were based on previously identified barriers to accessing DBS (geography, access to subspecialty services, socioeconomic status, race and gender).

Survey validation

Surveys were piloted with two external individuals from each target group (neurosurgeons, neurologists, family physicians, patients/caregivers, advocacy groups) for clarity and comprehensiveness. These individuals were not included in our study sample. Neurosurgeons and neurologists reviewed all surveys for content validity, while individuals from each stakeholder group reviewed respective surveys for face validity.

Survey administration

Surveys were distributed electronically using an electronic link or QR code via email, newsletters and websites to patients and caregivers through advocacy groups across Canada (Parkinson NL, Parkinson NS, Parkinson QC, Parkinson Canada, International Essential Tremor Foundation and Dystonia Canada). Employees and volunteers of advocacy groups were asked to complete a designated survey as well. Family physicians, neurologists and neurosurgeons in Canada were provided a QR code to respective surveys through an electronic faxing service in Canada, utilizing publicly available physician contact information (Scott's Info). Additionally, the Canadian Neurological Sciences Federation listed surveys for neurologists and neurosurgeons on their website and newsletter. Finally, publicly available institutional email addresses were used to distribute surveys to neurologists and neurosurgeons in Canada. A total of two faxes and two emails were sent to maximize responses. See Supplementary Material for survey forms and details regarding recruitment.

Statistical analyses

Descriptive statistics were utilized to summarize patient demographics, region, physician years in practice, estimated number of movement disorder patients in practice and estimated number of DBS candidates in the region. We hypothesized that geographic location may predict perceived lack of access to care among all practitioners and patients, in addition to financial barriers with the lack of available DBS implants among functional neurosurgeons. To test this hypothesis, a binary logistic regression analysis was planned to estimate the lack of access to care, adjusting for geographic location, financial barriers, availability of DBS implants and practitioners. In the event of a low response rate, descriptive interpretation was used.

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Table 1. Response rates among respondent groups

Respondent group	Means of contact	Potential respondents	Actual respondents	Response rate
Patients and caregivers	Parkinson QC	8673 via newsletter	153 (146 English, 7 French)	0.6%
	Parkinson NL	200 via email		
	Parkinson NS	60 via Facebook		
	Parkinson Canada	13,000 via newsletters, email lists, website		
	International Essential Tremor Foundation	788 in Canada via email		
	Dystonia Canada	1700 via email		
Advocacy groups	Parkinson QC	1	3 (3 English)	50%
	Parkinson NL	1		
	Parkinson NS	1		
	Parkinson Canada	1		
	International Essential Tremor Foundation	1		
	Dystonia Canada	1		
Family physicians	Scott's Info database and electronic faxing service	17,442	30 (28 English, 2 French)	0.17%
Neurologists	Scott's Info database and electronic faxing service	855	22 (21 English, 1 French)	3.57%
	Canadian Neurological Sciences Federation	700 staff members between neurology and neurosurgery		
	Publicly available email	457		
Neurosurgeons	Scott's Info database and electronic faxing service	231	12 (11 English, 1 French)	5.04%
	Canadian Neurological Sciences Federation	700 staff members between neurology and neurosurgery		
	Publicly available email	238		

Note: QC = Quebec; NL = Newfoundland and Labrador; NS = Nova Scotia.

Rurality was assumed for non-responses based on answers to other questions, and answers were amended if the described region did not match the criteria described by the respondent. For example, if the population of the municipality reported by the respondent had a population in keeping with an urban center, but the respondent reported the region as rural, the data was corrected as such.

Access was converted to values on a Likert scale (1 = no problem with access; 2 = reasonable access; 3 = poor access; 4 = very poor access) and averaged for each province. Heat maps were produced with open-access software found at heatmapper.ca.

Qualitative themes were extracted from open-ended questions using open coding, utilizing in vivo coding, followed by axial coding and then selective coding to collate codes into potential themes. Themes were refined and named.

Results

A total of 220 responses were obtained from all stakeholder groups surveyed (12 neurosurgeons, 22 neurologists, 30 family physicians, 153 patients and caregivers and 3 directors of advocacy groups). Details of response rates are available in Table 1, with details regarding recruitment strategy and response rates in Figure 1.

The majority of specialists surveyed practiced in urban areas of ON (n = 46, 71.9%). Of these specialists, three neurosurgeons report performing DBS as part of their practice, and 77.27% of neurologists report referring patients for DBS as part of their practice, with just over half reporting subspecialisation in movement disorders.

Family physicians surveyed commonly reported having a poor understanding of indications for DBS (n = 23, 76.7%). Of those reporting a good understanding of indications (n = 7), when asked to describe the ideal candidate for DBS, no respondents were able to accurately describe a good candidate for the therapy, with some examples including "Parkinson's disease" and "motor disorders," without further elaboration. See Table 2 for details of demographics for all surveyed physicians and surgeons.

Among surveyed patients/caregivers, 12.42% (n = 15) had previously undergone DBS. These individuals were more frequently living in an urban region in ON (n = 7) or British Columbia (BC) (n = 4) than the rest of Canada. See Table 3 for demographics of included patients/caregivers. Additionally, see Figure 2 for the geographic distribution of patients who had previously undergone DBS in the study population.

The majority of participants in each physician stakeholder group reported either very poor or poor access to DBS in their region (n = 46, 71.9% of all physician respondents). Of included patients and caregivers, 35.29% (n = 54) reported very poor access to this service. See Figure 3 for details of perceived access by stakeholders.

Perceived barriers to access

The most commonly reported perceived barrier across all physician groups was an inadequate number of specialists to

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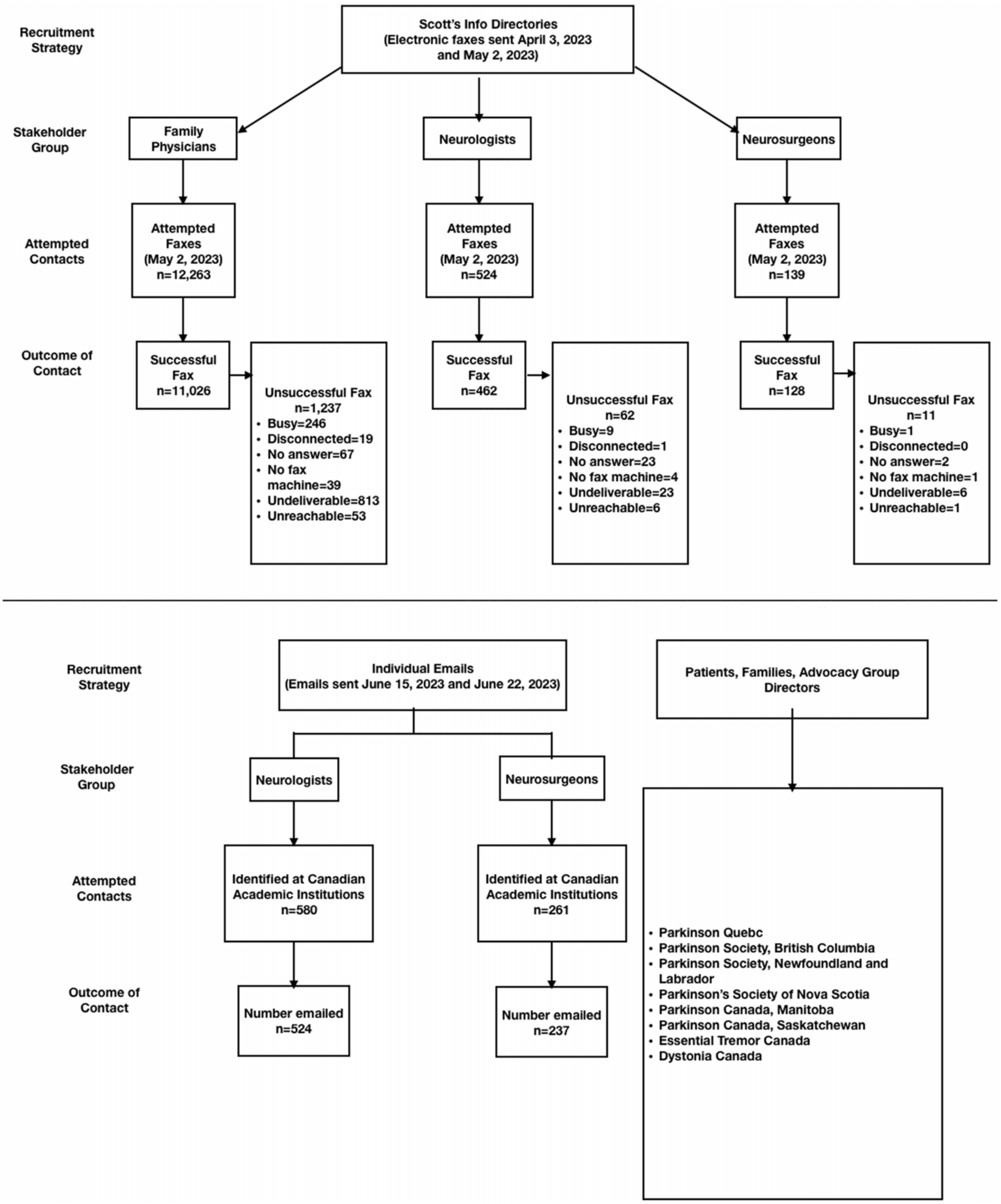

Figure 1. Details of recruitment strategy.

complete initial assessments. This was a commonly reported perceived barrier among advocacy groups as well.

Another commonly reported perceived barrier among neurologists, family physicians and patients and caregivers was an inadequate number of functional neurosurgeons. Patients in ON and BC more frequently reported access to subspecialist care (both functional neurosurgery and movement disorder neurologists) as a perceived barrier than Atlantic Canadian patients and caregivers,

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Table 2. Demographics of physician respondent group

Survey questions		**Neurosurgery** *N* = 12	**Neurology** *N* = 22	**Family medicine** *N* = 30
Province/territory	Newfoundland and Labrador	0	0	6
	Nova Scotia	0	0	1
	Prince Edward Island	0	0	0
	New Brunswick	0	0	2
	Quebec	1	1	1
	Ontario	10	12	10
	Manitoba	0	0	1
	Saskatchewan	0	0	2
	Alberta	0	4	2
	British Columbia	1	5	5
	Territories	0	0	0
	No response	0	0	0
Urban vs. rural	Urban	12	16	18
	Rural	0	1	12
	No response	0	5	0
Duration of practice	<5 years	N/A	7	8
	5–10 years		3	6
	10–20 years		6	5
	>20 years		5	11
	No response		1	0
Movement disorder/functional neurosurgery subspecialization	Yes	4	12	N/A
	No	8	10	
Distance required for patients to travel to see a functional neurosurgeon	<100 km	7	17	14
	100–500 km	4	5	7
	500–1000 km	1	0	3
	<1000 km	0	0	6

who most commonly perceived geographic location as a barrier to access.

Geographical location was reported as a barrier by 43.33% of family physicians surveyed (n = 13). This differed by region, in that all family physicians in NL reported geographical location as a barrier. Geographical location was reported as a barrier by 45.45% of neurologists and only 16.67% of neurosurgeons. Again, all specialists surveyed reported practicing in urban areas.

Specialists did not commonly perceive poor understanding as a barrier to referral (40.90% of neurologists and 41.67% of neurosurgeons). However, family physicians frequently reported a lack of understanding of indications for DBS themselves, and 60% of family physicians surveyed did report a lack of understanding as a barrier to patient access to DBS. The majority of ON family physicians reported this factor as a barrier.

In terms of cultural and socioeconomic patient factors, socioeconomic status was the most commonly reported barrier among all groups surveyed (neurosurgery 50%; neurology 63.64%; family medicine 43.33%; patients/caregivers 22.22%; advocacy groups 100%).

Ethnicity and gender were far less commonly reported across all groups, except family physicians from urban areas, who commonly reported ethnicity as a barrier. Gender was uncommonly reported across all groups. See Table 4 for a summary of perceived barriers by stakeholder group.

Qualitative themes

Four themes emerged from all stakeholders surveyed, including *Education*, *Limited Resources/Centralization of Resources*, *Patient Factors* and *Referral Process*. Ideas from four of five surveyed groups fit into these themes. See Table 5 for a summary of themes and associated ideas for each group.

An insufficient number of advocacy group responses were available to generate qualitative themes; however, ideas were expressed regarding poor understanding of dystonia as a barrier to accessing treatment, and limited resources and availability of DBS in some regions present physical and financial challenges to patients who require travel to access the service.

Education

All stakeholder groups for which qualitative analysis was possible reported ideas related to the concept of education. Ideas related to education from neurosurgeons include the concept that DBS is a

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Table 3. Demographics of patient and caregiver respondents

Survey questions		**Previously received DBS (N = 19)**	**Have not received DBS (N = 134)**	**Total (N = 153)**
Participant description	Patient	15	109	124
	Family member of patient participating on own behalf	1	12	13
	Family member of patient participating on behalf of patient	2	8	10
	No response	1	5	6
Region	Newfoundland and Labrador	2	13	15
	Nova Scotia	0	6	6
	Prince Edward Island	0	0	0
	New Brunswick	2	3	5
	Quebec	0	9	9
	Ontario	7	58	65
	Manitoba	2	3	5
	Saskatchewan	1	3	4
	Alberta	1	16	17
	British Columbia	4	19	23
	Territories	0	0	0
	No response	0	4	4
Urban vs. rural	Urban	15	93	108
	Rural	4	35	39
	No response	0	6	6
Diagnosis	Parkinson’s disease	6	33	39
	Essential tremor	3	47	50
	Dystonia	10	53	63
	No response	0	1	1
Time since diagnosis	<5 years	1	45	46
	5–10 years	5	36	41
	10–20 years	5	27	32
	>20 years	8	24	32
	No response	0	2	2
Duration of symptoms prior to diagnosis	<6 months	1	9	10
	6 months–1 year	4	17	21
	1–2 years	6	31	37
	2–5 years	5	37	42
	5–10 years	2	14	16
	>10 years	1	24	25
	No response	0	2	2
Diagnosing physician	Neurologist	17	96	113
	Family physician	2	35	37
	No response	0	3	3
Physician ever discussed DBS with patient/family	Yes	17	31	48
	No	1	102	103
	No response	1	1	2

(*Continued*)

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Table 3. Demographics of patient and caregiver respondents (*Continued*)

Survey questions		**Previously received DBS (N = 19)**	**Have not received DBS (N = 134)**	**Total (N = 153)**
Interested in pursuing DBS if offered	Yes	Not applicable	56	75
	No		13	13
	Unsure		56	56
	Have never heard of DBS		9	9
	No response/not applicable		0	19
Of those who had received DBS, duration between diagnosis and referral for surgery	<6 months	0	Not applicable	0
	6 months–1 year	1		1
	1–2 years	5		5
	>2 years	12		12
	No response/not applicable	0		135
Of those who have received DBS, duration between referral and implantation	<6 months	1	Not applicable	1
	6 months–1 year	7		7
	1–2 years	5		5
	>2 years	6		6
	No response/not applicable	0		134

Note: DBS = deep brain stimulation.

good treatment that is underutilized due to a lack of understanding of the treatment, stigma related to undergoing brain surgery, biases for pharmacological therapy and delayed referrals due to a poor understanding of the existence of this therapy.

Neurologists noted the importance of education around indications and follow-up for these patients for non-movement disorder neurologists and there exists an overestimation of surgical risk, with underappreciation of the value of DBS. This lack of education prevents the timely referral of patients who may be good candidates for DBS.

Family physicians primarily focused on physicians' understanding and misunderstandings about DBS. For example, many family physicians reported "know(ing) very little on this subject," being unsure of available centers and indications and the invasiveness of DBS as a therapy. In terms of misunderstanding, family physicians echoed similar statements regarding the uncertainty of the availability of the service. For example, one physician reported that patients in their region (New Brunswick [NB]) would have to travel to ON for DBS; however, the treatment is available nearby in Nova Scotia (NS).

Patients and caregivers discussed patient understanding (i.e., a number of patients reported uncertainty about what DBS is), misconceptions (that DBS is not offered in Canada, or only in ON, and that it is only used as a "last resort"), physician understanding (including delayed diagnosis as a result of unfamiliarity on behalf of physicians) and the fact that DBS is not discussed with patients as a potential therapy. Themes around education were most commonly reported by patients in Quebec [QC], ON and BC, as well as in patients with ET and dystonia.

Limited resources and centralization of available resources

All stakeholder groups for which qualitative analysis was possible reported ideas related to limited resources and centralization of available resources as a barrier to accessing DBS. Neurosurgeons identified ideas related to specific resources, specifically scarcity of movement disorder neurologists and device funding, centralization of access to larger cities and presence of long wait times (reported as 2–3 years).

Ideas shared by neurologists related to this theme can be further broken down into limitations on number of patients/implants available annually, limited access to alternative therapies such as high-intensity focused ultrasound, limited access to specialists (neurologists, functional neurosurgeons), limited operating room availability, limited access to specialized nursing care and neuropsychology and the consequences of centralization of services, including travel, limited funding directed to regions outside of major centers, and long wait lists resulting in medical complications while patients wait for surgical assessment. Neurologists shared that access to DBS may be improved by increasing utilization of virtual care.

Family physicians reported frustration with the limited number of patients that may receive DBS annually per province, that they have referred patients who are not deemed eligible after significant delay and inconvenience to the patients to undergo formal assessment and that they are also reluctant to refer patients given the significant burden of travel required for the initial assessment.

Patients and caregivers reported long wait times, from six months to four years for specialist appointments, a lack of availability in some regions (NL, NB, Southwest ON, Manitoba [MB] and Mainland BC), lack of specific resources in regions (including neurologists, movement disorder specialists, functional neurosurgeons, family physicians, interpreters, social support groups, treatment and counseling, device restrictions, operative time and hospital beds). Additionally, patients and caregivers identified ideas about the impact of COVID-19 on the delivery of functional neurosurgery. Ideas related to the theme of limited resources among patients and caregivers were most commonly reported in the Atlantic provinces and in patients with PD.

In patients and caregivers, ideas relating to centralization of services include the perception of access in larger cities, whether

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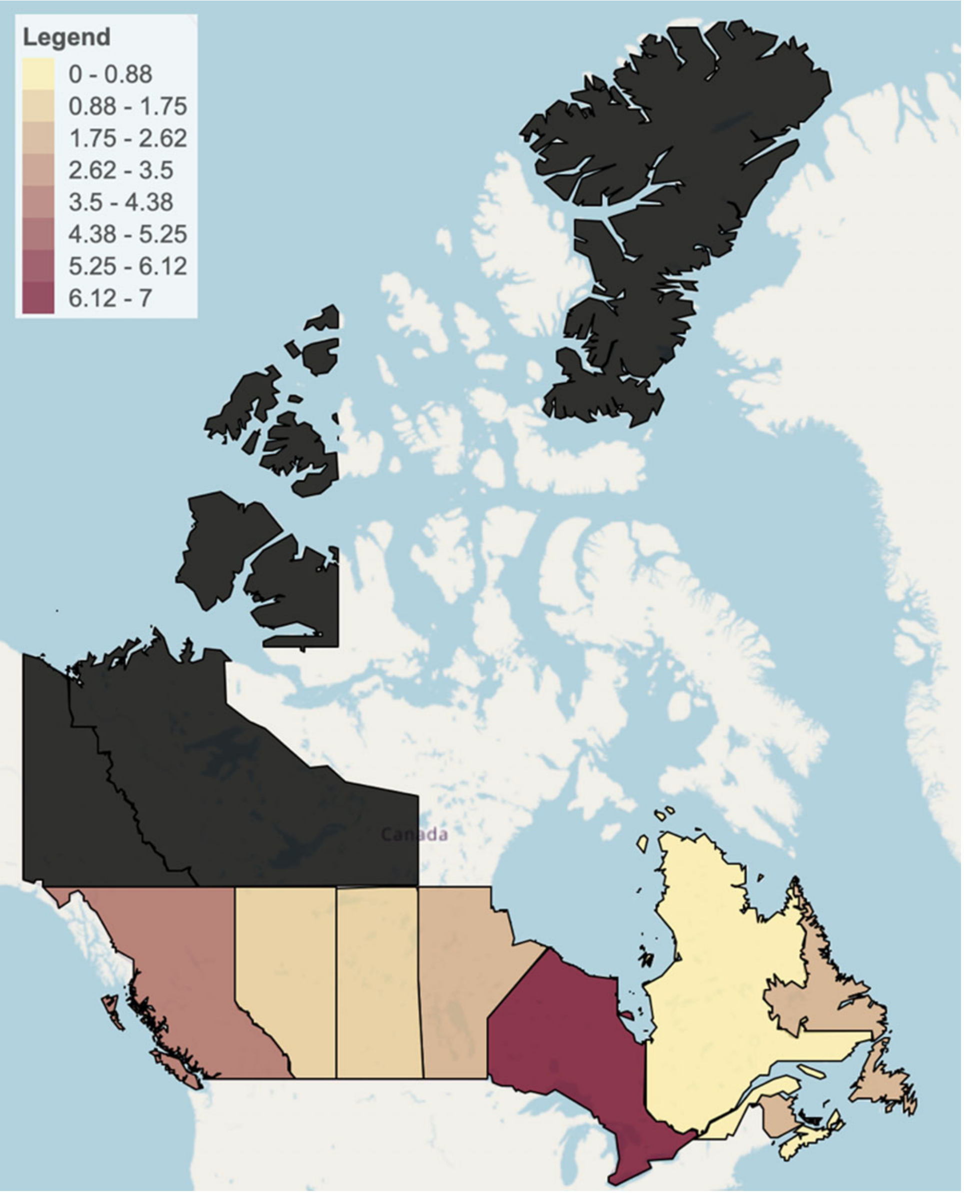

Figure 2. Geographical distribution of patients previously having undergone deep brain stimulation. Shaded black areas represent regions without stakeholder respondents.

access is truly available or not, the burden of travel and transportation on accessing functional neurosurgery and the cost associated with traveling for appointments. Ideas relating to centralization were most commonly reported in ON, BC, Alberta (AB) and the Atlantic provinces.

Patient factors

Neurologists described a number of patient factors that limit access to DBS on an individual level. Primarily, socioeconomic status in that patients may not be able to travel or obtain transportation for multiple appointments, even if they live close to a major center. This burden is greater in populations who live further away from major centers where DBS is offered. Additionally, social support and language barriers were reported to affect access to DBS for patients.

Patients also cited personal factors as reasons they had not previously considered DBS, including mild symptoms or adequate medical management, advanced age or havingi learned to cope with their disease. Some patients reported no interest in pursuing DBS as they have a fear of undergoing surgery.

Referral process

Family physicians described frustration with obtaining any specialty assessment for their patients, with onerous referral processes for patients living with movement disorders. This was not described for other stakeholder groups surveyed.

See Figure 4 for a summary of barriers across the referral pathway for DBS in patients with movement disorders.

Discussion

Previous attempts have been made to describe access to DBS, utilizing retrospective data from patients who have received DBS and attempting to determine what facilitators exist in that population of patients that lead them to be successful in obtaining the service.[6–9,13,14,23,25] This approach has considerable limitations,

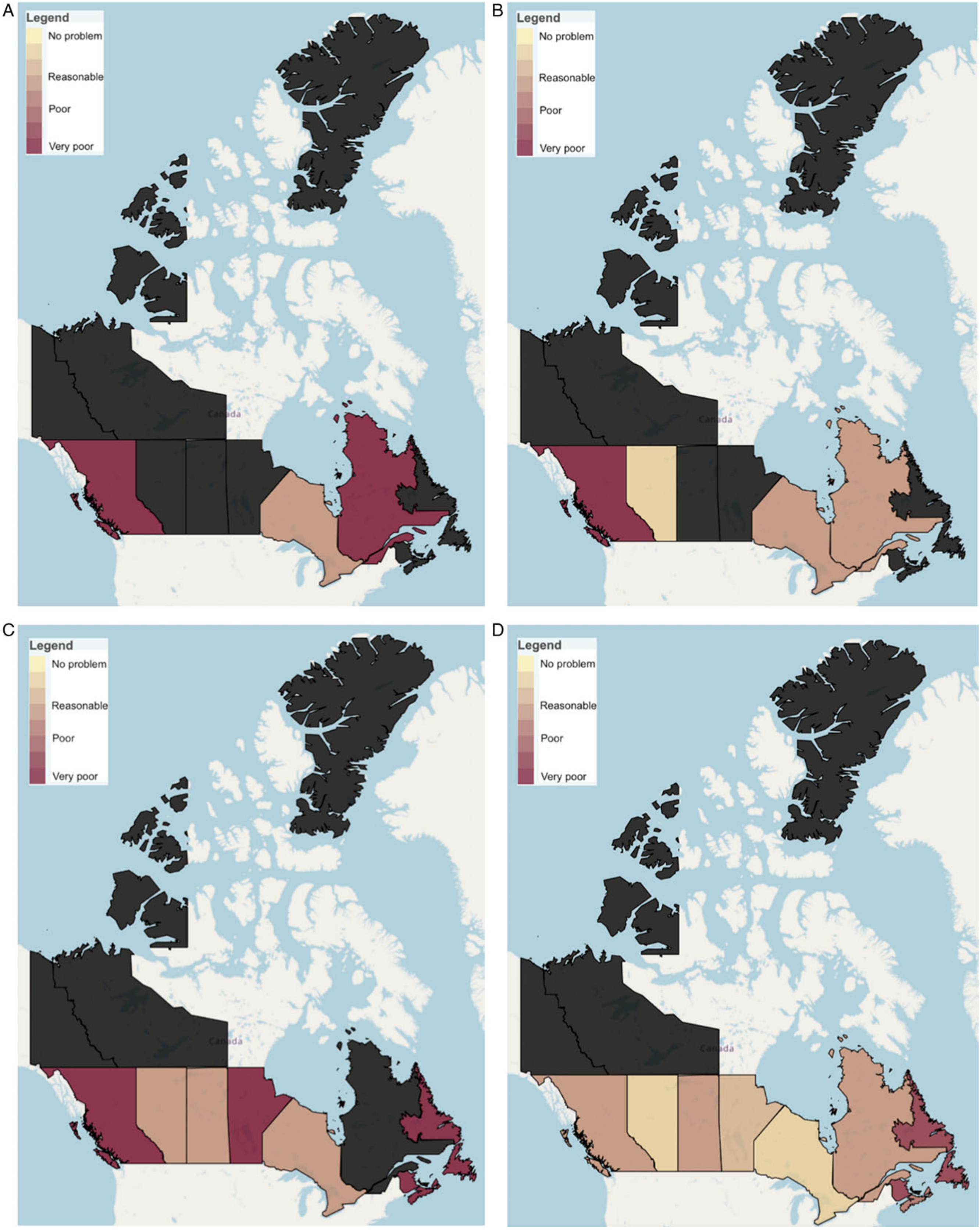

Figure 3. Perceived access to deep brain stimulation across Canada by respondent group. (A) Perceived access by neurosurgeon respondents; (B) perceived access by neurologist respondents; (C) perceived access by family physician respondents; (D) perceived access by patient and caregiver respondents. Shaded black areas represent those without stakeholder respondents for each group.

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Table 4. Summary of perceived barriers among respondent groups

Barriers	Neurosurgeons (n = 12)	Neurologists (n = 22)	Family physicians (n = 30)	Patients/ caregivers (n = 153)	Advocacy groups (n = 3)
Inadequate number of specialists to complete initial assessment	75.00%	77.27%	70.00%	35.95%	66.67%
Inadequate number of functional neurosurgeons	41.67%	59.09%	66.67%	40.52%	100%
Inadequate device funding	58.33%	40.91%	30.00%	23.53%	0
Inadequate access to operative time for surgeons	41.67%	54.55%	26.67%	32.03%	66.67%
Geographical location	16.67%	45.45%	43.33%	32.68%	66.67%
Poor understanding of indications limiting referral	41.67%	40.91%	60.00%	30.07%	33.33%
Patient socioeconomic status	50.00%	63.64%	43.33%	22.22%	100%
Patient ethnicity	25.00%	31.82%	10.00%	4.58%	0
Patient gender	0	4.54%	3.33%	4.58%	33.33%

as these patients have already overcome barriers to receiving DBS. This study attempts to understand barriers to accessing DBS from a population of primarily potential candidates for DBS and the healthcare providers treating these patients.

Many respondents across all provider groups estimated that less than 10% of referred patients ultimately undergo DBS. However, the four neurosurgeons surveyed who reported performing DBS themselves reported much higher estimations. Neurologists and family physicians more frequently reported lower proportions of referred patients undergoing DBS, but neurologists specializing in movement disorders did more often estimate a higher proportion of patients referred would ultimately undergo surgery. Those more likely to formally assess potential candidates for DBS or ultimately perform surgery are likely more able to estimate that referred patients are implanted. One previous American study found that approximately half of the referred patients for DBS were found to be good candidates for surgery,[26] consistent with our findings.

While movement disorder neurologists and functional neurosurgeons were found to estimate the proportion of referred patients who go on to receive DBS more accurately, we proposed that even general neurologists would be better able to estimate this than family physicians or patients, given their patient population. Interestingly, neurologists from the most populous province in Canada (ON) estimated fewer referrals than other regions. Nearly all neurosurgeons surveyed were practicing in ON, with results consistent with those obtained from neurologists. It is therefore possible that there are a greater number of referrals in Western Canada for DBS, even though BC has been reported to have a lower DBS rate compared with the national average (80%), and AB has a similar rate to ON when compared with the national average (120% vs. 126%, respectively).[24] It is also possible that neurologists in less populous regions of the province work in a less subspecialized manner, and general neurologists practicing in more remote regions may therefore have a greater number of patients with movement disorders than a subspecialty neurologist in the Greater Toronto Area, who exclusively sees epilepsy patients, for example. This is an area for future work, as poor referral rate was mentioned across physician groups as a barrier to access; therefore, identification of regions with lower referral rates and improving referral patterns may improve access.

Qualitative themes

There was considerable overlap in ideas obtained from all groups. All groups endorsed limited resources and centralization of resources, regarding travel and its associated costs as a barrier to access for patients. Additionally, respondents from every group expressed concerns about long wait times and the impact of a limited number of movement disorder specialists and functional neurosurgeons. All respondent groups also shared similar concerns about the need for education of patients and care providers regarding diagnosis and treatment of movement disorders and the benefits and availability of DBS along with its indications.

In general, concerns regarding travel and lack of resources were more commonly expressed in respondents from Atlantic Canada and patients with PD, although the increased reporting of this concern in patients with PD may be due to the high number of PD patients/caregivers from NL in our study population. Therefore, it may be a reflection of a regional concern as opposed to disease-specific issues.

Concerns with education were more common in Central Canada and BC, as well as patients with ET and dystonia. It is possible that these regions have better access to DBS (or at least the perception of better access), and therefore, individuals are able to identify additional barriers beyond geographic and unavailability of services in their region. These themes may also be more common in ET and dystonia as these diagnoses may be more poorly understood than PD. This is supported by family physician responses, where fewer respondents provided estimates for the prevalence of these two conditions than PD and commonly responded with comments like “I have no idea” when asked about these two diagnoses. See Table 6 for a regional summary of barriers and facilitators to DBS access across Canada.

DBS patients surveyed

The included patients who have undergone DBS were not reflective of previously reported access to DBS. For example, 13% of patients receiving DBS in our study were residing in NL, the province that has historically had the poorest access to this service, with one previous retrospective study of all DBS patients in Canada over a

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Table 5. Summary of qualitative themes among respondent groups

	Neurosurgery (N = 12)	**Neurology (N = 22)**	**Family medicine (N = 30)**	**Patients/caregivers (N = 153)**
Education	*Good treatment that is underutilized:* - "Under penetrated therapy with excellent evidence and underutilized by a factor of 3–4." Education: - "Stigma related to brain surgery for treating a disorder remains." - "Patients are not informed of existence of therapy, referring physicians misinformed of existence of therapy, referring physicians misinformed of existence or criteria for DBS, evaluation of drug options before referral too long, long multidisciplinary assessments and greater neuropsychological fears for surgery compared to pharmacological treatments." - "Biases for pharmacological treatments exceed those for surgical treatments without necessarily there being an equivalent basis in the assessment of benefits and risks. E.g.: medication-induced dyskinesia is often not perceived as a significant complication of pharmacological treatment but rather as the progression of the disease. This is then a risk, which is not described as a complication. So we do not fear this risk of pharmacological treatment. DBS makes it possible to avoid increasing medication or even reducing medication and reduces the risk of this complication." *Delayed referrals:* - "No problem with access. Bottlenecks are related to referrals."	*Physician understanding:* - "Greater educational exposure to reasons for DBS is helpful for non-motor neurologists to be educated on." - "The challenge is determining eligibility and then follow up. I don't feel comfortable managing the referral process or aftercare adjustment of medications." *Overestimation of surgical risk:* - "Under appreciation of the value and overestimation of adverse effects and complacency with non-surgical treatments by treating neurologists." *Lack of timely referral*	*Physician understanding:* - "Unsure of available centers and which patients qualify." - "Unfamiliar with this mode of treatment." - "I would like to know about indications and to know where to refer." - "I know very little on this subject." - "How invasive is this procedure?" *Misunderstanding:* - "Patients would need to travel to Ontario (from New Brunswick) for treatment."	*Patient understanding:* - "I'm not really sure what deep brain stimulation is exactly." *Physician understanding:* - "Initial diagnosis is an issue. Referral to movement disorders specialist can be problematic as most practitioners are not familiar with dystonia." *Misconceptions:* - "To my knowledge, DBS doesn't exist in Canada." - "Seems to be used more on Parkinson's patients and not much experience with dystonia." - "Only offered in Ontario." - "Doctors are advising against it unless absolutely the last resort." *Not discussed with patients:* - "I have never heard of any information concerning this therapy from anyone." Most commonly reported in Quebec, Ontario and British Columbia, as well as in patients with essential tremor and dystonia.

(*Continued*)

Table 5. Summary of qualitative themes among respondent groups (*Continued*)

	Neurosurgery (N = 12)	**Neurology (N = 22)**	**Family medicine (N = 30)**	**Patients/caregivers (N = 153)**
Limited resources and centralization of resources	*Limited specific resources:* - “Movement disorder neurologists.” - Device funding: “the capacity to actually perform the procedure. Device funding is a major barrier that prevents the recruitment and/or retention of functional neurosurgeons at many tertiary centers.” *Access in larger cities:* - “Currently patients need to be referred to London or Toronto for DBS. Hamilton has a large population that is underserved for DBS.” - “Population base is large and mostly not serviced due to lack of availability at the academic neurosurgery regional center.” - “No access to DBS in large provincial region and all referrals need to go to the major referral center in a different health authority.” *Wait times:* - “Limited resource, patients will have to be referred to London or Toronto, where wait times can still be 2–3 years.”	*Provincial caps:* - “Currently in British Columbia . . . there is funding for 75 patients per year.” *Alternative therapies to decrease strain on wait times:* - “There is also a lack of high-intensity focused ultrasound in British Columbia which would be of benefit to patients with moderate to severe essential tremor that is medication-refractory. Many of these patients who are waiting for DBS would also benefit from HIFU, which would also help to reduce the wait list for DBS.” *Neurologists (common in Quebec):* - “The main barrier is the lack of neurologists trained to manage these patients as well as access to the operating room.” - “Wait times to see movement disorder specialists and specialists being mostly located centrally.” *Functional neurosurgeons (common in British Columbia and Ontario):* - “Only one surgeon in all of British Columbia doing this procedure with a wait time of 3–5 years” - Nursing, neuropsychology *Travel:* - “No neurosurgery available in our region at all. Patients must travel at least 1.5 hours if not much more for neurosurgical assessment.” *Centralization:* - “Government gives funding to Vancouver and not to other health regions that could create a service.” *Patients develop medical complications waiting:* - “Four-year waitlist to see the single surgeon and then 12–18 months from then to surgery. So, referral isn’t useful. Many patients lose time they would benefit from surgery. Some develop health complications or psychiatric issues before being able to benefit. We have to use Duodopa for those who would be good DBS candidates. Very morally distressing not to have a standard of care treatment.” - “It’s waiting list times that are the biggest barrier in my region.” *Role of virtual care:* - “I believe it is getting easier to refer as the current DBS expert is making inroads to optimizing selection with use of virtual care.”	*Device funding limits number of patients*: - “I was told that about 20 patients per year are funded for DBS in all of British Columbia, that would make my region eligible for only a handful whereas there must be several hundred good candidates out of the population of 5 million every year.” *Specialists:* - “Only recently found out that (local functional neurosurgeon) is still performing this procedure, (they) have very limited surgical time.” - “We don’t even have a full-time neurologist in our region. Closest neurosurgeons are in St John’s (700 km) and they do not perform this as far as I know.” *Travel:* - “I have become reluctant to refer patients as it is a long drive to be evaluated and have not had one person get implanted.” - “Travel distance, costs and lack of funded transport services for consults and procedures impact patient care.” - “To my understanding patients would have to leave the province, which is not something they can afford,”	*Long wait times:* - “I was scheduled for DBS. My movement disorder specialist recommended the Duodopa pump in the meantime. The surgeon took me off the list.” - “Traveled outside province as waitlist in British Columbia too long.” Neurology: 6 months–4 years Assessment: 6 months–2 years Surgery: 7 months–1 year *Lack of availability in many regions:* Newfoundland and Labrador, New Brunswick, Southwest Ontario, Manitoba, Mainland British Columbia *Lack of specific resources:* - Neurologists – underservice of general neurology as well as movement disorder specialists - Functional neurosurgeons – “one functional neurosurgeon for all of Atlantic Canada,” “one functional neurosurgeon in British Columbia,” “the one functional neurosurgeon in Manitoba left.” - Family physicians - Interpreters and social support groups, treatment and counseling - Device restrictions - Operative time, hospital beds *Impact of COVID-19* *Perception of access in city:* - “would be provided in Calgary.” - “Barriers to access . . . getting into a facility in Toronto or Hamilton.” - “I live 2 hours’ drive from Toronto and Kingston. I feel that this option may be available if referred by my neurologist.” *Travel/transportation:* - Difficulty traveling with disability, unable to travel when caretaker for others - Many patients reported having to travel >2 hours to tertiary center to access - Patients unable to drive themselves *Cost:* - Limited medical coverage for travel - Self-employed patients unable to travel for multiple appointments Limited resources most commonly reported in the Atlantic provinces and patients with Parkinson’s disease. Centralization most commonly reported in Ontario, British Columbia, Alberta and the Atlantic provinces.

Table 5. Summary of qualitative themes among respondent groups (*Continued*)

	Neurosurgery (N = 12)	**Neurology (N = 22)**	**Family medicine (N = 30)**	**Patients/caregivers (N = 153)**
Patient factors		*Socioeconomic status:* - "Lower socioeconomic populations tend to live further away, have fewer means and support for repeated visits to surgery center." - "Ability to drive or have access to a ride for that distance is an issue." - "Ability to attend appointments (e.g., self-employed, cannot afford gas or car to get to tertiary care center)." *Support:* - "Social support (marital status) and education are contributing factors." *Language:* - "Language barriers and social factors that limit access to medical care generally also impact referral/evaluation for DBS."		*"Haven't considered DBS":* - Symptoms adequately managed with medical therapy - Symptoms mild - "Learned to deal with it" - Advanced age *Not interested* - Fear of undergoing surgery Reported across Canada
Referral process			*Onerous referral process:* - "We must go through multiple consultations with neurology." - "Can't even (get a neurology consultation for a) patient with essential tremor, much less DBS." - "Hard to refer to any neurosurgeon."	

Note: DBS = deep brain stimulation.

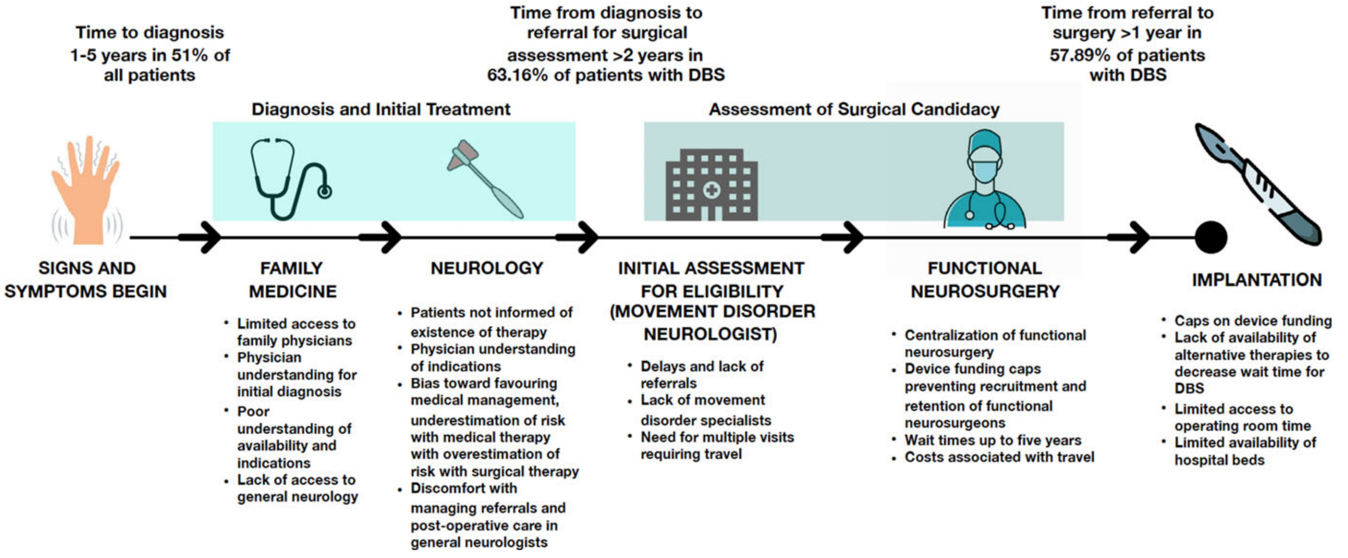

Figure 4. Summary of referral pathway for patients and associated barriers.

two-year period reporting 0.006% of their cohort from NL.[24] This overrepresentation from NL may be a result of an enthusiastic PD advocacy group in the region that effectively recruited patients to the study.

Nearly all patients who had received DBS in this study received their formal diagnosis from a neurologist, as opposed to a family physician. It is likely that neurologists have a better understanding of indications and availability of DBS and are therefore more likely to refer appropriate candidates. Literature supports the notion that movement disorder specialists are more likely to refer good candidates for DBS than other providers,[26] so access to neurology and specifically movement disorder neurologists is likely an important facilitator.

In terms of the timeline for diagnosis and treatment of these patients, nearly all patients reported being diagnosed more than five years ago, with most being diagnosed more than 20 years ago. Most patients report experiencing symptoms between 1 and 5 years prior to diagnosis. Once diagnosed, the majority of these patients were referred for surgery more than two years after diagnosis and underwent surgery more than six months after referral, with 40% of patients reporting a period greater than two years between patient referral and surgical implantation. Qualitative responses from all groups indicate waitlists of 2–5 years for DBS across Canada. It is unclear at what time patients who received DBS were implanted, so it is possible that delays associated with COVID-19, or any other number of factors, have increased wait list times since these patients underwent surgery. This is one area for future research to determine the duration of waitlists and solutions to decrease surgical wait times for DBS patients.

Proposed solutions

A number of policy changes are required to address access to DBS in Canada, with varying approaches between regions of the country. The first potential solution is increasing resources, including the number of movement disorder specialists and functional neurosurgeons. It should be noted that this could provide a long-term impact; however, time is required for the training of additional specialists that could improve access. This would ameliorate some of the burden of waitlists and, to some extent, travel for individual patients. However, beyond increasing the number of providers in population-dense regions, this would not decrease the burden of travel and expenses for Canadians living in isolated regions of our country, like Atlantic Canada, MB and Northern Canada, where patients must travel long distances for multiple appointments (assessments, surgical bookings, follow-up, reprogramming) and have limited access to emergency neurosurgical care should complications arise. In these cases, increased use of telemedicine may provide improved access to patients. The COVID-19 pandemic necessitated the use of telemedicine for many providers. Available literature suggests telemedicine provides an effective alternative to in-person care for patients living with movement disorders.[19,20] Patients were able to access care for surgical assessments and follow-ups and undergo re-programming, all without the inconvenience and costs incurred by traveling. Creation of telemedicine movement disorder clinics throughout the country may be an alternative to current healthcare allocation strategies, to ensure that access to care is improved for all Canadians. Increasing funding to provide travel stipends to patients may alleviate some of the financial burden reported as a barrier to accessing this service as well.

Provincial caps on the number of DBS implants available annually are a previously identified barrier.[24] By removing this restriction, SK has the best access in Canada.[24] Previous studies have shown that DBS is a cost-effective treatment strategy compared with best medical therapy alone, when considered over the lifetime of implanted patients. DBS has been shown to decrease medication costs, as well as hospitalizations and delay institutionalization of patients living with movement disorders, even accounting for costs of potential complications and hardware replacements.[27] Therefore, providing increased access to operative

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time and implants at a provincial level may be a cost-effective approach that could further increase access to this beneficial therapy.

Improved education is required for patients and practitioners regarding the diagnosis of movement disorders, indications for DBS and referral patterns. Among family physicians, 76.7% reported not having a good understanding of indications for DBS, and among the seven family physicians reporting that they did have a good understanding, when asked to describe the ideal candidate for DBS, responses were vague (i.e., “someone with Parkinson’s”) or incorrect, with many family physicians believing that the ideal candidate would be a patient with medically refractory symptoms or that surgery is a “last resort.” These beliefs were reiterated by patient comments that they have been given similar information by physicians. Providing education both to patients and care providers about indications for DBS would help ensure more potential candidates for this efficacious therapy are screened and potentially assessed for DBS. Existing educational resources may improve understanding on behalf of these stakeholder groups. For example, the remote, patient-centered education platform, DBS Select,[28] is an educational tool to inform patients and caregivers about DBS. It is continuously updated by a team of neurologists, neurosurgeons and neuroscientists from Belgium and provides an interactive, intuitive web platform to answer many questions patients and their loved ones have. Sharing resources like this with patients upon diagnosis may ameliorate some fear and misunderstanding regarding this treatment.

Previous literature has described the ideal candidate for DBS in PD as having a disease duration of at least five years, allowing atypical forms of parkinsonism to manifest, and they should have a positive response to levodopa (defined as a greater than 30% improvement in Unified PD rating scale motor score), fluctuations, dyskinesia or refractory tremor that remains disabling despite reasonable medical optimization and should not have pre-existing dementia, psychosis or severe depression. Additionally, patients should undergo MRI to rule out secondary diagnoses or structural concerns and should be medically optimized.[29] Both patients and family physicians frequently cited age as an exclusion criterion for DBS; however, while evidence suggests younger patients may have improved outcomes, there is no formal age cutoff for the procedure.[29] For ET and primary dystonia, patients should have one of these diagnoses with symptoms that interfere with the patient’s quality of life and functionality in spite of reasonable medical management, intact cognition and absence of severe psychiatric illness.[26] For all diagnoses, patients should have realistic expectations about what symptoms can be improved by DBS and should have willingness to participate in surgery. With respect to willingness to participate in surgery, few patients reported fear of surgical intervention as a reason they would be unwilling to undergo DBS. The availability of “incisionless” lesioning procedures (i.e., MRI-guided high-intensity focused ultrasound) should also be explained, providing the understanding that these procedures are also invasive with potential complications and cause permanent brain lesions, compared with DBS, where stimulation can be switched off.

Combining the above approaches requires significant collaboration. Although the Canada Health Act stipulates that individual provincial/territorial governments are responsible for overseeing and carrying out the principles of the act in their respective region, national collaboration may be warranted to

Table 6. Regional summary of barriers and facilitators to accessing deep brain stimulation

	Atlantic Canada	**Central Canada**	**Prairie Provinces**	**Coastal Canada**	**Northern Canada**
Description of region	Easternmost region, including NL, NS, PEI and NB.	Most populous region of the country, encompassing QC and ON.	Includes MB, SK and AB.	BC only.	Canada’s territories: YT, NT, NU.
Population	2,566,037 (24).	24,145,217 (24).	7,225,987 (24).	5,431,555 (24).	129,545 (24).
DBS center(s)	One functional neurosurgeon and multidisciplinary assessment team are located in Halifax, NS.	Multiple functional neurosurgeons at many sites and multidisciplinary assessment teams, as appropriate. Referral sites in QC are Université de Montréal (one surgeon), McGill (one surgeon), Sherbrooke (one surgeon) and Laval (one surgeon). In ON, the largest referral sites are located in Toronto, with Toronto Western (three surgeons) and Sunnybrook (one surgeon). Additionally, there are centers in Ottawa (one surgeon) and London (one surgeon).	A total of four referral centers are located in this region. Two centers in SK, Regina and Saskatoon, with three practicing surgeons. AB has sites in Calgary (one surgeon) and Edmonton (one surgeon). MB previously had one functional neurosurgeon, who had retired several years ago. In recent years, a functional neurosurgeon has provided locum coverage to perform DBS cases for the region.	Vancouver. At the time of this survey’s distribution, only one surgeon was practicing at the site. One additional surgeon has since been hired.	No available DBS centers in the region, and major referral sites would be in SK, AB, BC and ON.

(*Continued*)

Table 6. Regional summary of barriers and facilitators to accessing deep brain stimulation (*Continued*)

	Atlantic Canada	**Central Canada**	**Prairie Provinces**	**Coastal Canada**	**Northern Canada**
Identified barriers and facilitators	Atlantic Canada found to have the poorest perceived access among patients and family physicians, supported by previous literature finding NL in particular to have the poorest access to DBS in Canada (21). Most apparent theme is limited resources and centralization of resources, given all patients must be assessed in Halifax, NS. There are significant costs incurred for patients related to travel as a result. Many patients and providers have, therefore, reported cost as a barrier to access. There is no budgetary cap on the number of annual DBS cases in NS; therefore, it has historically provided higher than a national average rate of DBS in the province (108% of national average) (21). However, this does not appear to translate to improved access in the region as a whole.	Central Canada is the only region where a small number of participants from all cohorts reported adequate access to DBS. However, barriers to access remain, notably the need for education was evident in this region. A number of physicians reported having a poor understanding of indications for DBS, as well as the diagnosis of the conditions of interest. Patients reported similar perceptions, particularly for patients with essential tremor and primary dystonia. A number of patients reported significant delay in diagnosis for these conditions, calling for improved understanding on behalf of family physicians. Previous research has reported very poor access to DBS in QC (40% lower than the national average) citing budgetary constraints as a cause for this (21,31). This idea was reiterated by neurologists respondents, with waitlists to see movement disorder specialists frequently cited as barriers. Nearly half of respondents who had previously undergone DBS in this study were located in ON, while no patients in QC had received DBS. One previous study considered disparities in DBS use for patients living with Parkinson's disease in ON, finding that individuals in northern ON were more likely to receive DBS. This surprising finding was not observed when medication use in older adults was accounted for (19). Unsurprisingly, regular neurologist care and multiple medications for Parkinson's disease were positively associated with DBS. This is reiterated in the current study, where nearly all patients who had received DBS were formally diagnosed by a neurologist. Readily available neurology services could therefore be considered a facilitator to accessing DBS. Additionally, greater than half of patients in ON reported that their care provider had discussed DBS as a therapy with them previously. This is higher than any other province.	In spite of locum coverage in MB, limited resources were commonly reported there, with a number of respondents citing the retirement of one functional neurosurgeon in the province as a significant barrier to access there. SK has been reported to have the best access to DBS in Canada, with a DBS rate 374% higher than the national average. This has been attributed to the absence of budgetary constraints in the province and the presence of three functional neurosurgeons in the region. SK has been reported to have the highest ratio of practicing functional neurosurgeons to provincial population in Canada (1 per 0.37 million) (21). Interestingly, patients and providers in the province did not perceive adequate access there. Half of the patient respondents in SK reported "very poor" access to DBS, while the remaining patients reported "adequate" access.	Like Central Canada, the predominant theme was the need for education, again regarding diagnosis, indications and referral pathways regionally. The significant wait list of the single functional neurosurgeon in BC was frequently reported by both physicians and patients as a barrier to accessing the service in this region. A previous study found that DBS rates in the region were 80% of the national average. Given the recent hiring of an additional surgeon, one would expect that access to DBS in the province may improve as a result.	

Table 6. Regional summary of barriers and facilitators to accessing deep brain stimulation (*Continued*)

	Atlantic Canada	Central Canada	Prairie Provinces	Coastal Canada	Northern Canada
Limitations	No responses from providers from NS or PEI, no neurologists or neurosurgeons from Atlantic Canada, limits the ability to draw conclusions regarding access from expert opinion. All patients from NL diagnosed with Parkinson's disease (likely due to the recruitment strategy with engaged an advocacy group for Parkinson's disease distributing the survey). No responses for PEI from any groups. Although province has small population and neurology is available, there is no provincial access to neurosurgery with referrals sent to NB and NS.	ON is the only province where patients and family physicians overestimated access to DBS. Frequent responses included "would have to travel to Hamilton to see neurosurgery" or "would be available nearby in Kingston," although functional neurosurgery is not offered at either of the aforementioned sites. Improved understanding of referral patterns in the province may, in this case, lead to a decrease in perceived access.			No responses were obtained from Northern Canada. Limited evidence exists regarding the prevalence of movement disorders in this region, and given the sparse population, vast geographical sparse and great distance patients would need to travel to access even basic healthcare in some areas, this is an important Canadian population to seek perspectives from.

Note: NL = Newfoundland and Labrador; NS = Nova Scotia; PEI = Prince Edward Island; NB = New Brunswick; QC = Quebec; ON = Ontario; MB = Manitoba; SK = Saskatchewan; AB = Alberta; YT = Yukon; NT = Northwest Territories; NU = Nunavut; DBS = deep brain stimulation.

improve access across Canada. Providing educational resources and clear referral pathways in each region with a regional triage system would ensure that patients residing in provinces/territories without access to this service would have the ability to be referred to a centralized service for their region. For example, a patient living in NL could, in collaboration with their family physician, receive a referral to an expanded virtual movement disorder assessment clinic in Halifax, responsible for screening and triaging patients to determine if a more comprehensive assessment is warranted. Literature suggests that patients referred for DBS by movement disorder specialist neurologists were more likely to be good candidates for DBS than patients referred from other providers.[26] Therefore, ensuring patients are first assessed by movement disorder specialists, both for diagnosis, therapeutic optimization and determination of candidacy, would ensure smooth referral pathway flow for patients.

Further investigation is required to better understand how the prevalence of DBS candidates varies across Canada. Currently, no national database exists to answer this question. Improved understanding of the distribution of prevalence of these conditions is critical. It is impossible to comprehensively assess access to a service without an in-depth understanding of the candidates for that service, defining the need for it to determine if that need is being met.

Limitations

A number of limitations exist for the current study. First, there are biases inherent to survey studies, including reporting bias and issues with response rate.

Although limited in number of responses, the representativeness of the Canadian population in patient responses is fair in terms of the proportion of responses by province/territory. There are both an overrepresentation of patients/caregivers from NL (9.8% of responses compared with 1.4% of Canadian population from NL[30]) and an underrepresentation of respondents from QC (5.9% of responses vs. 22.2% of the Canadian population[30]), in spite of the survey being offered in both French and English. Unfortunately, there were no responses from Prince Edward Island (PEI), Yukon (YT), Northwest Territories (NWT) or Nunavut (NT). It is important to consider these patient perspectives, given the likely poor access to care in these regions;[31,32] however, low response rates may be expected, given the low populations in these areas (0.4% of the Canadian population for PEI and 0.1% of the national population in each of the territories[30]). All other regions were represented within 2% of the national proportion of the population residing in the respective provinces.

In terms of physician groups, family physicians from NL are again overrepresented (20% of respondents compared with the 2.1% of Canadian family physicians practicing in NL), QC is again underrepresented (3.3% of responses vs. 24.4% of Canadian family physicians[33]) and AB is underrepresented (6.6% of respondents vs. 13.0%[33]). All other regions are within 4% of the proportion of Canadian family physicians for each province and territory. Again, no responses were obtained from family physicians practicing in PEI (0.4% of Canadian family physicians[33]) or the territories, which collectively represent 0.3% of family physicians in Canada.[33] The overrepresentation of physicians from NL may have resulted from an active PD society in the province, with advocates eager to promote improved access in the region, as indicated by their contact with us in the early stages of study design. Although we attempted to promote recruitment in QC through the inclusion of French

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language studies, this may not have been clear to potential participants, as English language information about the study was presented prior to French study information in all correspondence.

Both neurology and neurosurgery were limited in responses, with 22 neurologists responding from 4 provinces and 12 neurosurgeons responding from 3 provinces. This paucity of data from regions of Canada with probable limited access signifies an important missing voice in this narrative. While multiple attempts were made at recruiting participants from these groups, including two faxes and two separate emails, the low response rate may have resulted from recruitment strategies. Many physicians and surgeons receiving faxes would need to be provided the faxed information by administrative personnel. Previous research suggests that physicians are more responsive to mail surveys and that response rates to email are traditionally in the range of 25–30%, due to survey fatigue, competing demands and privacy concerns.[34] Additionally, nearly all responses from neurologists and neurosurgeons are from practitioners in urban settings. Barriers identified by these physicians and surgeons may be vastly different from those in rural settings elsewhere in the country. It is important to note, however, that of all groups surveyed, neurologists and neurosurgeons see patients who have already overcome many barriers to access specialist services, and the ability of these specialists to identify barriers to care may be skewed as a result. The ideas obtained from family physicians and patients/caregivers likely provide a more realistic picture of access.

In terms of estimations of the proportion of patients referred for DBS who go on to receive the treatment, the broad scope of practice of respondents likely hinders the estimations provided. Specifically, only half the neurologists responding were movement disorder specialists. Stroke neurologists, for example, would not be expected to understand the proportion of patients referred for DBS who go on to receive it. Similarly, half of the neurosurgeon respondents reported providing DBS as part of their practice. A spine surgeon would not be expected to understand the complexities of the referral pathway for DBS and therefore is unlikely to make an accurate estimate as to the proportion of referred patients who undergo DBS. Even functional neurosurgeons may not be able to predict the likelihood of a patient undergoing DBS, given that they are situated at the endpoint of this complex referral pathway, as discussed previously. Confidence in these estimations is therefore limited; responses from movement disorder neurologists are more in keeping with literature estimates, and we would expect the most reflective of true referral patterns.

Conclusion

This study surveyed stakeholders for DBS in Canada to identify barriers to accessing DBS. This was an attempt to address limitations of previous studies investigating access to DBS in Canada. A number of themes were generated, describing the beliefs of stakeholders for DBS in Canada regarding barriers, including limited resources/centralization of resources, education, individual patient factors and burdensome referral processes that were determined to be common barriers to accessing DBS. We propose improving education, centralized referral pathways and the use of virtual care to improve access to DBS across Canada and further research to determine the true prevalence of candidates for this therapy to better understand variability in the need for this service across the country.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/cjn.2025.71.

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