



# Authentic Self and Last Resort: International Perceptions of Psychiatric Neurosurgery

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**Abstract** Psychiatric neurosurgery has resurfaced over the past two decades for the treatment of severe mental health disorders, with improved precision and safety over older interventions alongside the development of novel ones. Little is known, however, about current public opinions, expectations, hopes, and concerns over this evolution in neurotechnology, particularly given the controversial history of psychosurgery. To fill this knowledge gap, we conducted a study with eight focus groups in Vancouver and Montreal (Canada;  $n = 14$ ), Berlin (Germany;  $n = 22$ ), and Madrid (Spain;  $n = 12$ ). Focus group texts were transcribed and analyzed using qualitative content analysis in the language local to each city, guided by the theoretical framework of pragmatic neuroethics. Findings indicate that participants

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across all cities hold concerns about the last resort nature of psychiatric neurosurgery and the potential impact on the authentic self of patients who undergo these procedures. The views captured serve to advance discussion on the appropriate timing for psychiatric neurosurgery, promote sound health policy for the allocation of this resource, and foster scientific literacy about advances for mental health internationally.

**Keywords** Psychiatric neurosurgery · Culture · Neuroethics · Public perspectives

## Introduction

Within the field of functional neurosurgery, the race to re-invigorate older surgical interventions as a treatment option to otherwise treatment refractory psychiatric disorders, and to develop new ones, has escalated over the past two decades (Barrett 2017). These conditions rank as the leading causes of disability worldwide and have significant health, social, and economic consequences (Walker, McGee, and Druss 2015; Whiteford et al. 2013), with approximately 30% of adults globally affected at some point during their lifetime (Steel et al. 2014). Despite investigational efforts aimed at enhancing the efficacy of psychopharmacology and identifying biomarkers of psychiatric illnesses, 30–55% affected people fail to respond to medication (Souery et al. 2007; Trivedi et al. 2006; Wiles et al. 2014). In addition to the challenges posed by non-responsiveness to medication, high rates of relapse and side effects from pharmacotherapy, drop-out rates from psychotherapeutic interventions, repeat hospitalizations, and treatment non-compliance all comprise significant hurdles for patients seeking effective psychiatric care.

For treatment refractory patients, the pool of accessible, evidence-based psychiatric therapies beyond first-line treatments is limited. As a result, interest in the development of safe and effective surgical interventions for a subset of treatment refractory patients has experienced a revival (Cleary et al. 2015). These interventions, broadly known as psychiatric neurosurgery, include a suite of neurosurgical procedures used within both clinical and experimental domains (Lipsman, Bernstein, and Lozano 2010; Luigjes, de Kwaasteniet, de Koning et al. 2013; Müller 2017). Examples of modern psychiatric neurosurgery include deep brain stimulation (DBS), vagal nerve stimulation (VNS), ablative microsurgery, radiosurgery, and magnetic resonance-guided focused ultrasound (MRgFUS) (Lozano et al. 2019; Lévêque, Carron, and Régis, 2013; Meng et al. 2017). Studies using animal models have also shown the potential of optogenetics to control the activity of genetically defined neurons with light for the modification of depression- and anxiety-related behaviors (Albert 2014; Deisseroth, Etkin, and Malenka 2015). Taken together, these methods operationalize circuit-level understandings of psychiatric illness beyond the gold standard of subjective report-based psychiatric nosology.

## Perspectives

Little is known about public perceptions and attitudes toward the re-emergence of neurosurgical interventions in psychiatry, yet history has shown that fear and skepticism on the one hand, and overly optimistic views on the other, can stifle scientific progress and safe translation of potentially promising therapeutics equally (Johnson 2014; Lauber et al. 2005; Valenstein 1986).

Patient views toward the use of DBS as a therapy for severe psychiatric illness have been explored in prior research. For example, Leykin and colleagues examined the perceptions of 31 patients with major depressive disorder (MDD) in the USA toward DBS research using self-report questionnaires (Leykin et al. 2011). The authors found a reasonable grasp of risks and benefits, and an overall positive attitude toward research. However, while participants understood the experimental stage of DBS for depression, evidence for therapeutic misconception persisted. In the Netherlands, de Haan and colleagues conducted in-depth interviews with 18 DBS-implanted patients with obsessive-compulsive disorder (OCD) about their personal, social, relational, and existential experiences (de Haan et al. 2015). All participants viewed DBS as their last resort after having tried other treatments unsuccessfully. Participants expressed worries that the device might cease to function properly, but they did not express concerns about having a device physically implanted in their brains. In a secondary analysis of the interview data (de Haan et al. 2017), researchers posited that divergent reports of becoming a different person following DBS implantation hinge on definitional interpretations of the self and personhood.

Looking to the future of psychiatric neurosurgery, Klein and colleagues interviewed 15 participants implanted with DBS for MDD or OCD about their perspectives toward closed-loop or next-generation DBS devices (Klein et al. 2016). Unlike open-loop DBS, closed-loop devices rely on machine-learning algorithms to adapt stimulation parameters autonomously. The authors identified control over device function, authenticity of the self, relationships with others, and meaningful consent as major themes. Participants expressed optimism that closed-loop technology could improve upon certain limitations of open-loop devices, particularly the maintenance burden of traditional open-loop devices. In successfully overcoming debilitating aspects of their mental illness with DBS, some patients also discussed experiencing a burden of normality, which has been reported in other narrative inquiries of psychiatric DBS patients (Bosanac et al. 2018).

## Pragmatic Inquiry in a Global Context

Pragmatic inquiry is a powerful way to explore and align the evolving landscape of neurotechnology with societal values through dedicated attention to its ethical, legal, and social benefits and consequences (Racine and Illes 2008; Racine 2010). Pragmatism is a humanist philosophical tradition that endorses empirical research intentionally situated within a continually evolving landscape of human values and interactions (Johnson and Onwuegbuzie 2004). The application of pragmatism to neuroethics emphasizes the importance of pluralistic and inclusive deliberations

about the brain, encouraging evidence-informed solutions to complex societal issues (Racine and Illes 2008; Racine 2008).

Against a backdrop of historical malpractice (Valenstein 1986; Pressman 1998; El-Hai 2005), the re-emergence of psychiatric neurosurgery specifically raises ethical concerns. Beyond matters of research conduct such as conflict of interest, regulatory oversight, and informed consent (e.g., Bell et al. 2012; Carter et al. 2011; Dunn et al. 2011; Kuhn et al. 2009; Lipsman, Bernstein, and Lozano 2010; Mian et al. 2010; Nuttin et al. 2002; Synofzik and Schlaepfer 2011), neuroethicists have also highlighted the importance of concepts such as personality, authenticity, and identity for psychiatric patients who receive modern ablative or neuromodulatory interventions (Gilbert 2015; Gilbert 2018; Johansson, et al. 2011; Kraemer 2013a, b), and the safeguarding of personal authenticity (Goering 2015; Kraemer 2013a, b). The present research seeks to characterize the ethical concerns relevant to members of the lay public through pragmatic, experientially centered inquiry.

Patients with mental health disorders, their family members, and professionals working with them are most directly affected by the prospect of psychiatric neurosurgery, but attitudes of the general public toward mental illness and novel psychiatric interventions can also have a powerful impact on the development and utilization of new treatments, and play an important role in influencing health policy. Indeed, country of residence, cultural perspectives, and the general health of a population all conspire to affect service utilization and the acceptability of novel interventions (Lomber and Illes 2009; Illes and Lou 2019; Sample et al. 2019). In Japan, for example, psychiatric neurosurgery remains forbidden on the basis of political judgment rather than on medical and scientific evaluation (Nudeshima and Taira 2017). Similarly, the stigma and negative lay attitudes that surround modern applications of electroconvulsive therapy have potentially limited the number of people globally who could benefit from its use in the treatment of medically refractory mental health disorders (Wilhelmy et al. 2018; Teh, Helmes, and Drake 2007; Lauber et al. 2005; Golenkov, Ungvari, and Gazdag 2012).

In studying public opinions about psychiatric neurosurgery, systemic difference in healthcare systems cannot be ignored. For the countries in focus of this study, Canada has a universal system, but mental health care services provided by addiction counselors, psychologists, social workers and specialized peer support workers are not funded through the public system (Canadian Mental Health Association 2018). Germany has a universal multi-payer system, but mental health care services are spread across many sectors with considerable regional differences. A key characteristic is the particularly wide gap between inpatient and outpatient services, which are funded separately and staffed by different provider teams (Salize et al. 2007). Spain has a publicly financed National Health Service that provides almost universal health care free of charge at the point of use. Mental health care, however, is one of the most neglected and under-financed areas within that health system, attributable to a longstanding fragmentation of services among various public administration bodies, and reliance on charitable organizations (Salvador-Carulla et al. 2006).

The importance of the information that the public receives from news media plays no less of a role in shaping attitudes. Issues such as regulation, risk, and

informed consent are prominent within North American media about psychiatric neurosurgery, while issues of identity and social control have been an important focus for German media (Cabrera et al. 2018a). Optimistic views are promulgated by Spanish media, and optimism is shared by readers who respond to them. German media promotes, and readers express, comparatively more hesitant views (Cabrera et al. 2018b). Stigma is a pervasive theme in the media-public discourse about psychiatric treatments and the disorders they aim to treat throughout.

All told, the medical and societal burden of mental illness, historical considerations, cultural distinctions, and differing health and communication systems speak to the imperative of a cross-national investigation of attitudes toward invasive treatments as they progress into clinical translation.

### **Purpose of the Study**

Much work remains to be done to raise public understanding about the benefit-risk ratio of re-emerging and new psychiatric neurosurgical interventions, and to engage different stakeholders in discussions about ethics oversight if these approaches are to find a safe and receptive place in health care. The present study aims to advance the understanding of public attitudes toward contemporary psychiatric neurosurgery toward these goals.

## **Methods**

### **Recruitment and Enrollment**

Focus groups were conducted with members of the general public between October 2017 and June 2018 in four different cities: Vancouver and Montreal (Canada), Berlin (Germany) and Madrid (Spain). These cities were chosen as they represent the home cities of the research team collaborating in a multinational consortium exploring the ethical, legal and social implications of psychiatric neurosurgery. The focus groups aimed to: (a) explore awareness of different psychiatric neurosurgery procedures; (b) characterize the understanding of and values related to the different procedures; and, (c) identify key ethical concerns.

Participants were recruited through mental health community organization newsletters, social media and hard copy postings. We used the term *community conversation* in recruitment media to emphasize the open and interactive nature of the focus groups. Respondents had to be 18 years or older to be eligible to participate, and able to converse in the language in which the focus group was conducted (English, French, German or Spanish). In keeping with the focus of the study on attitudes of the general public, participants were screened through a telephone interview or online survey and excluded if they self-reported an active, clinically diagnosed psychiatric disorder or had undergone one of the procedures under study. There was no exclusion as to the number of focus groups in a city that participants could join.

Eligible participants were scheduled for a focus group held in a convenient location in each city, such as a community center or in a conference room at a university. The research team aimed to achieve a diversity of gender, age, and ethnicity in each group. Participants were compensated for their time and travel expenses with a reimbursement equivalent to \$25CAD (Vancouver, Montreal) or 20 EUR (Madrid, Germany) after completion of the focus group. Approval for the study was obtained from the Institutional Review Boards of each of the universities of the investigators (University of British Columbia (UBC) [H17-00013], Michigan State University as a subcontracting collaborating site to UBC (IRB# x16-520e), Institut des recherches cliniques de Montréal (IRCM) [2018-913], and Charité–Universitätsmedizin Berlin CCM [EA1/123/17]).

### Focus Group Procedures

A facilitator from the research team who was fluent in the local language moderated the sessions in each city (Vancouver: LC, Montreal: ER, Berlin: MB, Madrid: LC). Each focus group took approximately two hours. In the first hour, moderators reviewed consent materials, introduced four relevant interventions (DBS, ablative microsurgery, radiosurgery, and optogenetics) in a slide presentation to prime the discussion, and addressed questions. Moderated focus group discussions were completed during the second hour. All materials were made available in the local language of the focus group. Sessions were audio recorded. A second researcher took field notes to document verbal and non-verbal cues for tone of the conversation and other relevant information.

The moderator followed a detailed, semi-structured focus group discussion guide that was informed by the findings from media and reader comments studies conducted by the research team (Cabrera et al. 2018a, b). An English-language version was developed first, and then translated into German, French, and Spanish before implementation (Table 1).

**Table 1** Semi-structured focus group discussion guide sample questions

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- 1 Why are you interested in the topic of psychiatric neurosurgery?
  - 2 Have you heard of all the different procedures before today? If so, which ones? Where?
  - 3 What are your thoughts regarding psychiatric neurosurgery? Any positive features? Any negative ones? Hopes? Expectations? Perceptions of risk? Benefits?  
Probe: If there is mention of historical issues, ask participants to elaborate. If not, ask about whether they have heard of psychosurgery
  - 4 What do you think are the main challenges surrounding the adoption and acceptance of psychiatric neurosurgery (e.g., patient concerns, reimbursement, regulation)?
  - 5 Is there anything else you would like us to know about you?
-

## Data Analysis

Recordings of the interviews were professionally transcribed verbatim and made software ready in NVivo 12 (QSR International) for analysis, with the exception of the Madrid focus groups that were analyzed using Microsoft Excel. All audio files were transcribed into the local language of each focus group, with the exception of Montreal groups which were professionally translated into English. A member of the research team from each country (LC: Spain; MB: Germany; CC: Canada) corrected transcription errors and clarified inaudible speech and misattributed statements. Non-content words and expressions were removed for readability and analysis.

Transcript was analyzed qualitatively using a directed content analysis approach (Hsieh and Shannon 2005; Krippendorff 2004). This directed approach employed a codebook developed *a priori* from analysis of media articles about psychiatric neurosurgery (Cabrera et al. 2018a). During initial coding, each researcher (LC, MB, CC) applied codes deductively to segments of the text congruent with codes articulated in the codebook. In subsequent stages of analysis, researchers refined the initial codebook to include codes organic to the focus group texts, adopting an inductive approach to coding that captured new and emerging phenomena of interest.

General principles of content analysis were used throughout the analysis process (Krippendorff 2004). This involved (1) assignment of codes to meaning units identified through line-by-line readings of the text; (2) grouping of codes into pre-existing or emerging categories; (3) identification of broader themes synthesizing the findings. Mentions of specific intervention modalities and mental health disorders by focus group participants were also coded to gauge participants' familiarity with established psychiatric interventions and conditions, as well as to assess depth of discussion about the primed neurosurgical interventions.

Research team meetings and electronic communication were used to discuss questions about coding and accuracy of the codes. A major theme was defined by its

**Table 2** Examples from content analysis of transcripts

Meaning units	Code	Category	Theme
How do you earn consent from someone with a [psychiatric] condition?	Informed consent	Ethical or philosophical issues	Choice and consent
You make the choice because you can make the choice now, but later on you might not be able to	Autonomy	Ethical or philosophical issues	Choice and consent
I can only imagine the backlash [if I underwent one of these procedures]	Stigma	Social issues	Stigma
It's a completely different method of treatment that can help people as a last resort and who have no other options	Last resort; desperation; optimism	Outcomes and patient expectations	Last resort

frequency and presence in the discussion in both focus groups in a city, as well as its assertion by more than one participant within that city. Iterative research team discussions were used to select interviewees' statements that were regarded as typical or representative of a theme. These processes were repeated until consensus regarding the final presentation of the results was reached (Table 2).

## Results

We conducted eight focus groups, each with 3–13 participants in four different cities ( $n = 48$  participants) (Table 3).

Contributions from the two participants who attended both Madrid focus groups were counted separately for analysis as they were different for each group.

## Interventions and Conditions

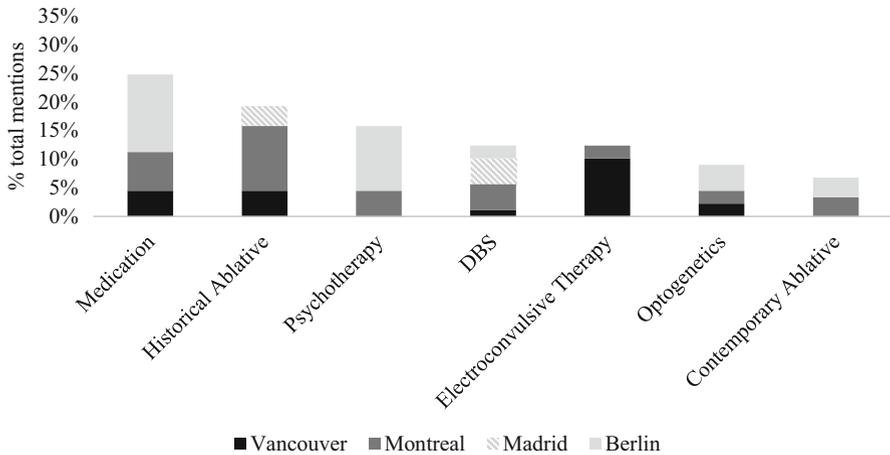
DBS was the only intervention discussed by participants across all focus groups. Psychiatric medication, historical ablative procedures (e.g., lobotomy, trepanation), and psychotherapy were the interventions most frequently mentioned overall (DBS: 11/89 [12%] total intervention mentions; medication: 22/89 [25%]; historical ablative procedures: 17/89 [19%]; psychotherapy: 14/89 [16%]) (Figure 1). Depression and obsessive-compulsive disorder were discussed in focus groups across all cities (depression: 20/70 [29%]; OCD: 12/70 [17%]). Parkinson's Disease was discussed frequently with reference to DBS, while anorexia nervosa was mentioned exclusively by participants in the Madrid focus groups (Figure 2).

**Table 3** Focus group demographics

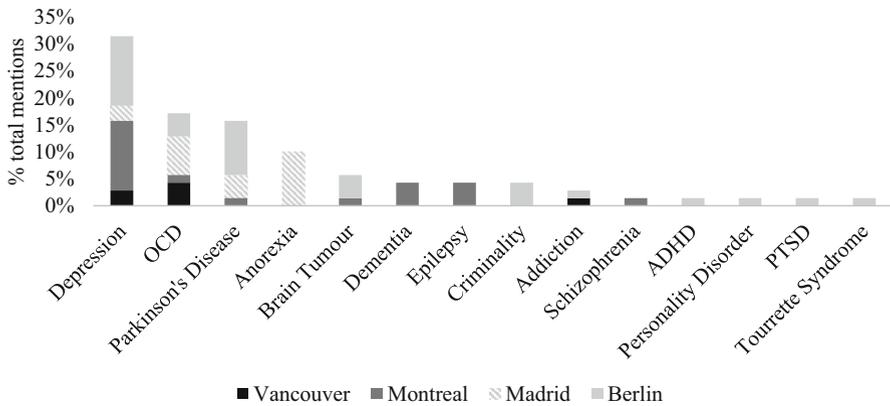
City, Country	Number of participants	Gender	Age range (years)
Vancouver, Canada	FG#1: 3	2F/1M	18–75
	FG#2: 3	2M/1F	
Montreal, Canada	FG#1: 5	3F/2M	20–51
	FG#2: 3	2F/1M	
Berlin, Germany	FG#1: 9	6F/3M	18–78
	FG#2: 13	10F/3M	
Madrid, Spain	FG#1: 7	4F/3M	18–70
	FG #2: 5	5F/2M**	

\* German privacy laws prohibit collection of data regarding ethnic origin

\*\*Two attended both Madrid focus groups



**Fig. 1** Interventions mentioned across cities



**Fig. 2** Psychiatric and neurological conditions mentioned across cities

### Major Themes

Two major themes emerged from the focus group content analysis for all cities, capturing areas where participants had either substantial concurrence of an opinion or a marked disagreement:

- *Authentic self*: This refers to the capability of a neurosurgical intervention to interfere with expression of the authentic self, including perceived risks to personality, identity and authenticity of surgery recipients.
- *Last resort*: This refers to the use of psychiatric neurosurgery interventions only after other treatment options have been exhausted.

The intersection of *choice and consent* was also a prominent combined theme, emerging with substantial frequency in all focus groups except Madrid. *Stigma*

toward mental health conditions was the most prevalent theme in Vancouver groups, and was also frequently mentioned in Madrid. *Mental health literacy* was the most prevalent theme that emerged in focus group discussions in Madrid.

### Authentic Self

Participants across all focus groups discussed the potential for psychiatric neurosurgery to alter the personality, identity, or authenticity of a recipient (Vancouver: 15/233, 6% of all meaning units; Montreal: 9/136, 7%; Berlin: 14/187, 7%; Madrid: 12/194, 6%). This was raised through (1) a belief that the invasive nature of psychiatric neurosurgery increases the potential for iatrogenic harm, which in turn could undermine the expression of a recipient's authentic self after surgery, and (2) a concern over the potential misuse of psychiatric neurosurgery in pursuit of an ideal or socially acceptable personality type.

Respondents expressed worries about the precision of the interventions, as well as the integrity of the motive for surgically interfering with the circuitry of the brain. The latter of these concerns tended to be expressed by participants who viewed mental illness as an intrinsic feature of a person's identity, and to try to interfere with this would constitute an attack on the authentic self.

“I would also be afraid that some of these operative methods might change my personality, which I feel is a risk” (Berlin Focus Group 1, Female 1, translated by MB).

“...you might come out a different person, and that's something I feel like could be probably one of the main reasons people would be kind of afraid of [psychiatric neurosurgery], or against it” (Vancouver Focus Group 2, Male 2).

“... is this treatment to treat the patient or just to make the patient fit better in society?” (Montreal Focus Group 1, Female 2).

Some participants expressed that the effects of psychiatric neurosurgery necessarily alter personality, as mental illness itself hinders the ability to experience an authentic self. These participants stressed that psychiatric neurosurgery could bring about desired changes to personality traits, and specifically improve traits that are pathologic or dysfunctional. Some participants viewed psychiatric neurosurgery in its capacity to alter the authentic self as no different than modern psychiatric medications. Competing societal views about psychiatric illness and neurological illness were also highlighted in this context, particularly with regard to how questions of identity or personality are unlikely to be raised in the context of neurosurgery to remove a terminal brain tumor.

“... well I think [personality change is] the whole point of [psychiatric neurosurgery], isn't it? We don't want [patients] to have OCD, we don't want them to have Parkinson's, we don't want them to have [mental health disorders] – that in itself is personality change” (Vancouver Focus Group 1, Female 2).

“But don’t drugs also do that? If you take antidepressants for years, it also changes your personality” (Berlin Focus Group 2, Female 3, translated by MB).

“In the case of a brain tumor people do not think about ... touching something that may alter your personality, or your way of being” (Madrid Focus Group 2, Female 1, translated by LC).

## Last Resort

The notion of psychiatric neurosurgery as a last resort treatment for mental health disorders was a major theme arising in all focus group locations (Vancouver: 11/233, 5%; Montreal: 13/136, 10%; Berlin: 17/187, 9%; Madrid: 18/194, 9%). Most participants mentioned that psychiatric neurosurgery should be used only after other, less invasive therapeutic options have been exhausted. A commonly raised concern was the reductionist nature of neurosurgical interventions. Participants felt that neuromodulatory or ablative procedures alone were unlikely to have an effect on the broader psychological, sociological or environmental contributors to mental health disorders. Another concern raised by participants was a lack of formal guidance about when in the course of a psychiatric disease a patient should be deemed eligible to receive a neurosurgical intervention. Some participants also considered the potential devastating effects of neurosurgical treatment failure.

“To me it would be a last resort... [depression is] a very severe disease that we don’t really have any solutions for, so if you suffer a lot and it affects you every day, and there’s no therapy to help cure you, then I would consider surgery, but in general, the way I see the brain, I look at people as a mix of personalities, and it’s not just the brain that makes somebody depressive” (Montreal Focus Group 1, Female 1).

“Well, I think it’s a pretty good idea to keep this in the backhand only as a last resort, because it contains an irreversible aspect” (Berlin Focus Group 2, Male 2).

“Is it legitimate to decide to use this because a person is highly suicidal?” (Montreal Focus Group 1, Female 2).

“If it is used as a last resort, going through that whole brain surgery must be really complicated and then [if] you leave, and it doesn’t work, it must really hit you, especially for the person and their family. They have to live with that” (Montreal Focus Group 2, Female 2).

By contrast, some participants questioned the rationale behind reserving psychiatric neurosurgery as a last resort treatment option, particularly considering the speed at which some interventions can bring about symptom relief. Participants expressed empathy for those suffering from mental illness and supported accessibility to psychiatric neurosurgery procedures for those with severe, debilitating conditions. Some participants advocated for more liberal access to procedures like DBS despite their relative infancy in treating psychiatric conditions. Ultimately, most participants agreed that they would prefer to see more research

before they could fully support widespread use of psychiatric neurosurgery for the treatment of mental illnesses.

“I think [DBS] should be more accessible, I think it’s a shame that it’s a last resort... if you are going through a period of depression ... you go through individual therapy, medication, and often it doesn’t work, it’s often complicated and it takes a long time to access the services, so I’m very “for” that type of intervention that can be almost instantaneous and help people” (Montreal Focus Group 2, Female 2).

“These are patients that have tried several medications and that they are so extreme that nothing else can help them” (Madrid Focus Group 2, Female 4, translated by LC).

“I have seen patients that were in such desperate OCD ... I was in so much pain seeing them, and I think if I was one of them, I would want [psychiatric neurosurgery]” (Vancouver Focus Group 2, Female 1).

“...when people [have a severe mental health condition] and tell you about their suffering, if this is the solution for them and there’s informed consent and it is proven, then it might be worth going forward” (Montreal Focus Group 1, Female 4).

## Choice and Consent

The intersection of choice and consent was the most frequent theme arising in focus groups held in Montreal (15/136, 11%) and Berlin (21/187, 11%) and was also discussed frequently among participants in Vancouver (23/233, 10%). This theme encompasses ideas related to patient decision-making, self-advocacy, and capacity to consent to a procedure. Most participants agreed that although the decision to undergo a psychiatric neurosurgical procedure should be made exclusively by the potential recipient, significant barriers exist that may limit the ability of physicians and researchers to obtain unbiased informed consent within this clinical population. Of major concern to most participants was the way in which the manifestations of mental illness can impact an individual’s capacity to adequately weigh the risks and benefits associated with psychiatric neurosurgical interventions. Participants in the Canadian focus groups mentioned alternative consent paradigms such as advanced directives and proxy consent. A few participants also raised concerns about the possibility of physician or family coercion in the decision-making process. Ultimately, participants held a common view that a transparent consent process that clearly establishes the risks and benefits of any candidate procedure would be the most ideal approach in ensuring respect for patient autonomy.

“... these surgical procedures are obviously invasive... how much we can push someone else to [have] surgery if they’re not mentally in the right place?” (Vancouver Focus Group 2, Male 2).

“... one’s own consent is extremely important, and I just wonder to what extent a young person who is perhaps not medically educated and is in a distressed situation because he or she is really sick and suffering ... can really assess these risks” (Berlin Focus Group 1, Female 3, translated by MB).

“It seems very difficult, when you are depressed, imagining that you could not be depressed anymore, just with surgery... if ever you get treated and become happy, then ‘yes, thankfully I accepted the surgery,’ but you will never know unless you do the surgery... it’s difficult to impose something on someone who doesn’t want it, but at the same time, is it someone who will be able to judge whether they will feel better or not?” (Montreal Focus Group 1, Male 1).

“... it is empowering for the person, to be able to choose [psychiatric neurosurgery] and have it work, I think there needs to be a feeling of finally controlling your life, which must be without equal” (Montreal Focus Group 2, Female 2).

## Stigma

Stigma was the most prevalent theme arising in the Vancouver focus groups (25/233, 11%) and was also a major topic of discussion among participants in Madrid (22/194, 11%). Participants from these cities highlighted the problematic consequences of societal views that endorse mental illnesses as less deserving of medical attention than clinical conditions with physical origins. Some expressed worry that recipients of psychiatric neurosurgery would incur stigma or marginalization greater than those treated for mental health disorders via more conventional methods. Participants further considered the role that media plays in shaping public perception, as well as the potential for public resistance to limit research that aims at improving the safety and efficacy of psychiatric neurosurgical interventions.

“... there’s a lot of ignorance about mental health. People don’t see it as an illness, [they just think] ‘snap out of it, smarten up’... unless you have someone very close to you who is going through this extreme pain ... you think they’re just being lazy” (Vancouver Focus Group 2, Female 1).

“People do not see mental health disorders as disorders, but as weaknesses of the will” (Madrid Focus Group 2, Female 4, translated by LC).

“[Modern psychiatry] is just painted in a very bad light, I think there has to be better media, better ways than it’s portrayed” (Vancouver Focus Group 2, Male 1).

“Stigma... [hinders] funding ... [for] research and access” (Vancouver Focus Group 1, Female 1).

## Lack of Knowledge

Knowledge about mental health was the most prevalent theme arising in Madrid focus groups (37/194, 19%). This theme pertained to knowledge accrued about mental health disorders, mental health interventions, and knowledge gaps relating to accessibility of this information. Participants from Madrid voiced the existence of a substantial, systemic lack of information around both mental illnesses and relevant treatment options. This theme often complemented the remarks made by participants about stigma, that is, if the public knew more about psychiatric disorders,

people would have a different perspective around these conditions and the interventions used to treat them.

“... [there is a] lack of knowledge about how bad these disorders themselves can be...if people knew what these patients go through, they will get a different perspective” (Madrid Focus Group 1, Male 3, translated by LC).

“... if there was more information about those disorders, it would help people make a correct idea but there is a lot of ignorance and lack of information” (Madrid Focus Group 2, Female 1, translated by LC).

For the other cities, findings on this theme were inconsequential.

## Discussion

In this cross-national, multi-site qualitative study we examined opinions, concerns, hopes, expectations and ethical challenges about contemporary psychiatric neurosurgery. The study explored key topics identified in two previous stages of this large-scale effort to investigate the social implications of contemporary psychiatric neurosurgery, and to explore other relevant issues, such as familiarity with psychiatric neurosurgery procedures. The results support findings from prior work that center on identity, personality and authenticity (Cabrera et al. 2018b; de Haan et al. 2017). Many participants framed their concerns in terms of the brain as the seat of the self, endorsing that direct modification of the brain can bring unwanted changes to behavior and personality. Others supported the idea that severe mental illness can undermine personal authenticity; suggesting that neurosurgical modifications may help patients to regain a true sense of self. In this regard, our findings are in line with previous research looking at patients with DBS for refractory OCD in which researchers posited that divergent reports of becoming a different person following DBS implantation hinge on definitional interpretations of the self and personhood (de Haan et al. 2017). It is important to emphasize that concepts such as authenticity, self and personhood are deeply inflected cultural issues (Lenton et al. 2014; Slabu et al. 2014). While definitions of authenticity—the sense of being one’s true self—are more aligned with Western views of the self, cross-cultural research has suggested that authenticity may be a universal phenomenon that is contingent on cultural norms (Slabu et al. 2014). In addition, while most cross-cultural research has considered differences of these constructs between Western and Eastern cultures (Markus and Kitayama 1991), it is possible that different Western cultures hold nuanced conceptualizations and meanings of the authentic self.

Beyond concerns about post-operative experience (Kraemer 2013a, b; Gilbert et al. 2017; Gilbert 2018), implanted neural devices must be regarded the same as any “causal element [in] a system of relationships” and monitored within multidisciplinary care teams to promote the best interests of patients (Specker Sullivan 2019, p. 493). Clinical trials of implanted devices also raise ethical questions at the intersection of informed consent and the evolving, post-operative values of DBS-implanted patients (Gilbert 2015; Kubu et al. 2018; Sankary and Ford 2019). In the present study, members of the public highlighted informed

consent largely in the context of vulnerability, desperation and capacity of patients to execute decisions around both invasive and reversible interventions.

The last resort status of psychiatric neurosurgery procedures, a significant theme in the normative and empirical literature on the topic (Kuhn et al. 2009; Glannon 2010; Woopen and Christiane 2012; Klein et al. 2016), was discussed by study participants with a noticeable polarity of opinions. A recent study of public information-seeking behaviors about DBS for movement and psychiatric disorders (Robillard, Cabral, and Feng 2018) also uncovered mixed opinions about whether DBS should be introduced early in the course of clinical care or reserved until all other options have been exhausted. Currently, the only DBS psychiatric indication approved by the Food and Drug Administration and the European Medicines Agency (EMA) is OCD under a Humanitarian Device Exemption (Fins et al. 2011). Procedural features like irreversibility and invasiveness deterred some participants from supporting the use of psychiatric neurosurgical procedures, however, continued innovation within the mental health landscape was unanimously endorsed.

Stigma toward mental health conditions, mediated in part by lack of knowledge about treatment options, remains an ongoing concern. Participants commented that there are still many people who see mental health disorders as a weakness of the will, putting into question the etiology of these disorders. Lack of information and understanding about both mental health disorders and viable treatment options only perpetuate distorted perceptions of these conditions and may stifle the progress of emerging invasive therapies. Stigma and lack of knowledge also relate to key aspects of the health care systems of each of three countries where, in spite some form of universal health care among them, mental health is not as well funded or supported as other health conditions (Corrigan, Druss, and Perlick 2014). Moreover, in most Western countries, the law allows for court-mandated involuntary commitment or compulsory treatment for a person whose mental health condition poses a likelihood of serious harm to herself or others (Raboch et al. 2010; Jacobsen 2012; Steinert et al. 2010; Udawadia and Illes, *in press*).

The largely investigative status of the neurosurgical interventions at present and the fact that there are no meta-analyses comparing different modalities in terms of safety and efficacy, prohibit comment on policies directed to particular interventions. Nonetheless, the participants in the present study were positive about the need for more efficacious and safe therapies to treat mental health disorders, and for the need for further knowledge and discovery within this landscape.

## Limitations

Focus groups are a well-established research method to gather views from participants as they explore phenomena of interest and interact with others about them in a discrete time and context (Kitzinger 1995). Resulting findings can be used only to generate, but not to test, hypotheses. Findings also represent a range of opinions from a small and selected sample of participants, in a limited number of cities and countries. All participants were interested in the subject by definition, and

many vested in the topic by virtue of an association with a person with an active or prior mental health disorder. And, while it was essential to provide participants with a briefing to ensure they had a shared understanding of the topic, this procedural step may have had an impact on the discourse. Even though the process for recruitment followed the same protocol for the four cities, participant numbers were different for the resulting eight focus groups. Larger and smaller numbers may have affected group dynamics and subsequently impacted the number of meaning units and themes generated in analysis. In addition, while we met online to discuss analytic procedures and to ensure maximum coding reliability, the ideal of having two coders per location was not possible given funding constraints. The findings obtained in this study are still meaningful as a starting point to investigate lay knowledge and perceptions of psychiatric neurosurgery in Western countries and to detect potential cross-cultural differences. Further research is needed to explore more fully the issues raised by this study.

## Conclusion

Concerns about the last resort nature of psychiatric neurosurgery and the potential impact on the authentic self of patients who undergo these procedures are heretofore undocumented concerns that cut across all four cities included in the present research. Our findings serve to advance clinician-patient interactions (Cabrera et al. 2020), decisions about patient fit, and the choice and timing for different interventions. They are also an important starting point to understand scientific literacy and cultural norms regarding concepts such as authenticity in Western countries with intersecting cultural backgrounds.

**Author Contributions** LC led the project. CC participated in data collection and led data analysis for Canada; LC participated in data collection and led data analysis for Madrid. MB participated in data collection and led data analysis for Berlin. SM and RM participated in data collection for Berlin and Madrid; ER participated in data collection for Montreal. All authors contributed to the writing. JI is the study Principal and participated in the conceptualization of the work, data analysis, and writing.

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## Compliance with Ethical Standards

**Conflict of interest** L. Y. Cabrera, C. Courchesne, M. Bittlinger, S. Müller, R. Martinez, E. Racine, and J. Illes declare that they have no conflict of interest

**Ethical approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed consent** Informed consent was obtained from all individual participants included in the study.

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