Gauging Public Perception of Neurosurgery for Obsessive-Compulsive Disorder: A Qualitative and Descriptive Analysis of Online Forums

Samuel Hornstein, Adriel Barrios-Anderson, Rochelle K Rosen, Benjamin D Greenberg, Steven Rasmussen, Nicole CR McLaughlin

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Abstract

Background: Psychiatric neurosurgery, including deep brain stimulation (DBS) and neuroablative procedures, has shown significant promise in treating severe, intractable Obsessive-Compulsive Disorder (OCD). The emergence of innovative neurostimulation techniques and neuroablation targets has catalyzed discussions in mainstream media. Online chat forums such as Reddit and Quora serve as particularly valuable resources for gauging public perception of medical interventions and technologies, making them crucial for researchers and clinicians in understanding how these procedures are viewed by the public.

Objective: This study aims to evaluate public perceptions of psychiatric neurosurgery for OCD, as expressed in online chat forums, and to identify prevalent discussion topics and misinformation.

Methods: We conducted a qualitative thematic analysis of 254 online posts discussing psychiatric neurosurgery for OCD, posted between 2008 and 2020 on popular forums. Three independent reviewers coded the posts, determining key discussion topics, characteristics, and misinformation. The data were analyzed using Applied Thematic Analysis (ATA) to identify structural and interpretive components and statistical analyses to quantify post characteristics.

Results: There has been a burgeoning interest in psychiatric neurosurgery for OCD on these forums since 2008, with analyzed posts amassing over 25,000 cumulative online views. Thematic analysis identified three primary discussion topics: the efficacy of neurosurgical procedures, the existence of these procedures as treatment options, and their associated risks and benefits. Notably, statistical analysis found that 30.6% of posts contained misinformation, with a significantly higher rate of inaccuracies in posts expressing negative views of surgery compared to those expressing neutral or positive views ($p=0.0079$). Posts often began with users seeking information or sharing personal experiences, highlighting a gap between public perception and clinical evidence.

Conclusions: Our findings reveal significant interest and engagement in online discussions about psychiatric neurosurgery for OCD, accompanied by substantial misinformation. These insights underscore the need for targeted educational interventions to bridge the gap between public perception and clinical evidence. Addressing misinformation and enhancing public understanding could improve patient outcomes and referral patterns for those considering psychiatric neurosurgery. This study provides valuable data for clinicians aiming to better comprehend and navigate public concerns and misconceptions in this rapidly evolving field.

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Gauging Public Perception of Neurosurgery for Obsessive-Compulsive Disorder: A Qualitative and Descriptive Analysis of Online Forums

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Keywords: Psychiatric Neurosurgery, Obsessive-Compulsive Disorder, Online Qualitative Research, Online Chat Forum, Neuroablation, Deep Brain Stimulation.

Abstract

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Conclusions: Our findings reveal significant interest and engagement in online discussions about psychiatric neurosurgery for OCD, accompanied by substantial misinformation. These insights underscore the need for targeted educational interventions to bridge the gap between public perception and clinical evidence. Addressing misinformation and enhancing public understanding could improve patient outcomes and referral patterns for those considering psychiatric neurosurgery. This study provides valuable data for clinicians aiming to better comprehend and navigate public concerns and misconceptions in this rapidly evolving field.

Introduction

Obsessive-Compulsive Disorder (OCD) is a psychiatric condition characterized by intrusive thoughts and repetitive behaviors. First-line treatments for OCD include exposure and response prevention (ERP) therapy and medications such as selective serotonin reuptake inhibitors and clomipramine [1]. However, 40 to 60% of OCD patients exhibit residual symptoms following monotherapy or initial treatment [1]. For these patients, psychiatrists may recommend pharmacological augmentation [2]. In cases of pharmacological and therapeutic treatment failure characterized by severe, chronic, refractory OCD, neurosurgical interventions may be considered [3,4]. Neuroablative surgery, such as ventral capsulotomy or cingulotomy, and deep brain stimulation (DBS), have been used safely for OCD since the late 1990s, demonstrating considerable efficacy in reducing OCD severity [3,5].

Understanding public perception of medical interventions is crucial for the implementation and success of treatments. Previous research has explored perspectives on OCD neurosurgery among providers and patients, indicating that these views can significantly impact referral rates and treatment utilization [6,7]. Survey studies suggest that clinicians, including neurosurgeons and psychiatrists, generally hold positive views towards psychiatric neurosurgery for OCD [6,7]. However, studies of OCD patients reveal considerable skepticism and gaps in knowledge regarding these surgical interventions [7]. Broadly, the general public, as assessed through media coverage and commentary, tends to hold negative and pessimistic views of neuroablative procedures for psychiatric illnesses, often expressing distrust of medical professionals [8]. Despite this, little is known about the general public's perception of modern psychiatric neurosurgery for OCD.

Online chat forums are increasingly used for medical information gathering and health-seeking behavior [9]. As a result, these forums can be valuable for gauging public perception of medical information and treatments. Recent studies demonstrate the utility of analyzing online chat forums to understand views on a range of medical topics [10-13]. This approach has been particularly useful for gaining insights into unconventional and experimental treatments for refractory mental illnesses [13,14]. Members of the public often turn to online sources before consulting their physicians. The latest Health Information National Trends Survey report highlights this trend: only 15.3% of respondents sought advice from healthcare providers as their initial source of health-related information, while 68.7% utilized the internet [15]. Popular online forums often reach — and may influence — higher numbers of people than many peer-reviewed publications. Further, when these individuals encounter and share misinformation online, it propagates farther and faster than accurate information [16]. Thus, examining the internet provides an optimal mechanism to understand perceptions, misinformation, and other clinically relevant perspectives on psychiatric neurosurgery for OCD in broader communities. Psychiatric neurosurgery and its predecessor, psychosurgery, have an extensive history of shifting public perceptions, misconceptions, and relative obscurity in the modern era, making it essential to gauge current public perceptions.

To date, no study has examined or classified online discussions surrounding psychiatric neurosurgery for OCD. This study aims to characterize and analyze thematic content in posts about psychiatric neurosurgery for OCD on various online forums. We will consider why individuals initiate and respond to online discussions, how often posters cite misinformation versus evidence-based information, and what impressions people have regarding neurosurgical interventions for OCD. Additionally, we will classify the positionality of posters (e.g., prior experience with OCD) to understand how perceptions may vary among different subsets of the online population.

Methods

Study Design

In this study, we utilized a retrospective qualitative approach to examine individual written posts on online chat forums discussing psychiatric neurosurgery for OCD. We employed Applied Thematic Analysis (ATA), a rigorous method for analyzing text data to identify and explore discussion topics (Supplementary Figure 1) [17,18]. ATA allows researchers to identify both structural and interpretive components of qualitative data in order to identify themes relevant to both the form and content of written data [17]. This method is widely used in the medical and psychological literature [19–22].

Sample and Data Collection

We generated our sample by querying five online chat forums identified from preliminary Google searches for discussions related to neurosurgery for OCD. These five online forums were chosen based on their popularity and high prevalence of OCD-related posts: Reddit, Yahoo Answers, Quora, Mental Health Forum, and OCD Action. Two researchers (SH and ABA) conducted queries on these platforms using search terms carefully curated to maximize identification of relevant online posts. These search terms included e “OCD Treatment,” “OCD surgery,” “Psychosurgery,” “Surgery for OCD,” “OCD Gamma knife,” “OCD Deep Brain Stimulation,” “OCD Surgical Treatments,” “OCD Brain Surgery,” “Obsessive-Compulsive Disorder Surgery,” “OCD Neurosurgery,” and “OCD Cingulotomy.”

Researchers read through each online thread, starting with an original post or question followed by responses or ensuing discussion among posters. Transcripts were made of all threads and the posts that comprised them. Upon review by two independent researchers (SH and ABA), threads that did not explicitly mention or discuss neurosurgery for OCD were excluded, as were extraneous posts within relevant threads. Information collected on each post included the exact text posted, online chat source, search phrase used, post type (original or response post), date posted, and where possible, number of views at the time of data collection. This data was recorded using SurveyMonkey Software (SurveyMonkey Inc., San Mateo, California, USA) and compiled into a Google Sheets spreadsheet (Google.com) (Supplementary Figure 2).

Data Analysis

Qualitative methods

Three independent researchers (SH, ABA, and NCM) read through all individual posts, identifying key concepts and features of each post, which served as the foundation for qualitative coding. They then discussed and synthesized their individual lists to develop a preliminary coding framework for data analysis. Subsequently, the researchers met with an independent qualitative reviewer (RKR), who guided the team in refining and finalizing a unified coding structure with overarching categories (“parent codes”) and corresponding subcategories (“subcodes”). Explicit definitions were established for each code to ensure a shared understanding of its meaning and application.

To assess the reliability and utility of the coding structure, the three researchers (SH, ABA, and NCM) independently applied the codes to a randomly selected subset of 10 online threads. This process resulted in the identification of seven additional codes, yielding a final coding scheme consisting of 57 codes across 11 distinct categories (Supplementary Figure 1). The finalized coding scheme was then applied to all posts.

Threads were imported as transcript documents into NVivo 12 (QSR, Melbourne, Australia), a qualitative data analysis software. The finalized coding structure was also imported into NVivo 12 and verified for accuracy. Two independent reviewers (SH and ABA) then used the software to apply all relevant codes to each thread. Following independent coding, both reviewers met to discuss and resolve discrepancies through a “double-coding” process, during which they verified and refined the application of codes. A final review meeting was conducted to discuss findings and address any remaining inter-rater inconsistencies, ensuring the credibility of the analysis [23].

To differentiate between misinformation and clinically validated information, posts were categorized as either “evidence-based” or “non-evidence-based,” corresponding to whether they cited medical data or personal opinions. Posts were further coded as containing misinformation, evidence-based information, neither, or both. Reviewers highlighted specific statements within posts that corresponded to these classifications. This categorization was verified through a literature review and validated by the senior researcher (NCM).

Quantitative methods

Descriptive statistics were used to quantify and characterize posts based on year of publication, number of views per post, and website source. NVivo 12 was utilized to quantify threads by code and to perform descriptive statistical analyses on relevant codes of interest. Additionally, using the “Query” and “Coding Stripes” features in NVivo 12, researchers identified posts that contained multiple codes. This approach

allowed for the examination of associations between certain themes (e.g., “impression of surgery” and “authority-positionality of the poster”) and enabled comparisons across multiple thematic categories.
Where applicable, percentage breakdowns were calculated for specific discussion topics and types of posts within threads. A significance level of $P < 0.05$ was applied to all statistical analyses. The Shapiro-Wilk test was used to assess whether the data followed a normal distribution. Simple linear regression was performed to evaluate trends in the number of online posts over time, while Fisher’s exact test was used to analyze differences in misinformation rates. Statistical analyses, including the Shapiro-Wilk test, linear regression, and Fisher’s exact test, were conducted using GraphPad Prism version 9.0 (GraphPad Software, San Diego, CA, USA, www.graphpad.com).

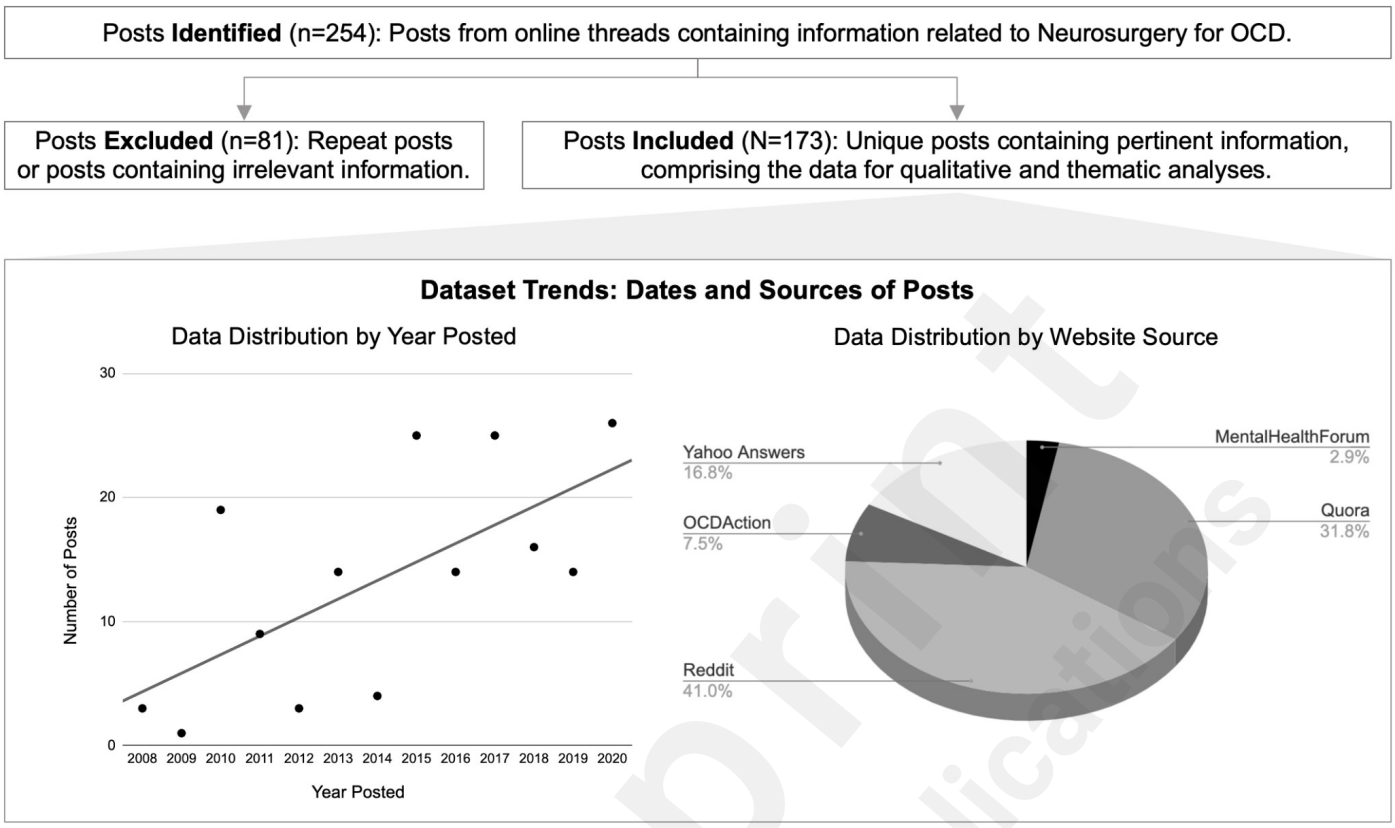
Results

Data Summary and Engagement Metrics

Our initial search revealed 254 relevant posts or comments. Of these posts, 81 met one or more exclusion criteria: 1) posts with copy/pasted content, 2) identical re-posts from other threads, and 3) posts not discussing OCD neurosurgery (n=81). A total of 173 posts from 73 different online threads posted from 2008-2020 met the inclusion criteria and were included in the final analysis. Figure 1 shows the number of posts by year, which appears to increase gradually over time. Simple linear regression was completed to assess the trend of posts by year. The line of best fit for the data demonstrated a statistically significant positive slope, indicating an increase in the number of posts from 2008 to 2020 ($F=8.309$; $p<0.05$). We also calculated the percentage and number of posts that were sourced from each online chat website (Figure 1). Reddit.com was the source of the greatest percentage of posts in our sample (41.0%; n=71), with Quora.com supplying the second most posts (31.8%; n=55).

Figure 1. Characterizing Online Posts on Neurosurgery for OCD:

Dataset Integration and Breakdown of Posts by Year & Website Source



(Top) Methodology for obtaining our final dataset.

(Left) The number of posts per year exhibited a statistically significant increase from 2008 to 2020 ($F=8.309$, $p<0.05$), indicating a growing interest over time.

(Right) Number of posts collected from each source: Reddit (n=71), Quora (n=55), Yahoo Answers (n=29), OCDAction (n=13), and MentalHealthForum (n=5). The percentage displayed below each website represents its proportion of the total posts (N), calculated as ($\% = n/N \times 100$).

In order to capture the level of engagement with online chat posts, we documented the number of views for each post at the time of data collection. In total, all of the posts included in our analysis had a cumulative number of 25,609 views. The greatest number of views for an individual post was 3,100. The most viewed posts were all original posts or posts that started online threads, including some of the following:

"Which medical precedents of leucotomy (lobotomy) and stereotactic surgery are performed nowadays in psychosurgery? What are their indications, and where are they performed?" (3100 views);

"What's the best kind of medication for OCD?" (2600 views);

"Is surgery with a gamma knife capable of getting rid of anxiety or OCD? If so, how and how long does the treatment last for its full potential?" (1900 views);

"What would be considered a last resort in treating an extreme case of OCD?" (1600 views);

"How many are the surgical treatments for anxiety or OCD, and do they really work?" (1500 views).

Characterizing Online Chat Communication

To aptly depict online chat communication, we sought to answer several key questions: 1) Who are the individuals posting on online threads about psychiatric neurosurgery for OCD? 2) What themes characterize the posts that initiate these online threads? 3) What kinds of responses are found in these online threads? and 4) What is the rate of misinformation and evidence-supported information on online chat forums about psychiatric neurosurgery for OCD?

1) Who is posting on online threads about psychiatric neurosurgery for OCD?

We sought to label the individuals posting online by developing a code titled “authority or positionality,” which characterized the poster based on written data explicitly stated in their online post. Table 1 displays the distribution by post of the authority and positionality of those posting. Distinct patterns emerged in how online contributors chose to identify themselves, if they did, in relation to the topic of the post or the medical field more broadly. Most posts lacked an explicit reference to poster identity and were characterized as “unspecified” positionality (76.9%; Table 1). However, it was not uncommon for a poster to share an aspect of their positionality relative to OCD. For instance, a number of online posts indicated a level of experience with OCD, either from personal experience or from close family or friends with OCD. One poster stated, “I have OCD and it can be excruciating at times.” These codes suggest that a portion of the online community engaging on the analyzed forums are individuals with personal experience with OCD.

Table 1. Frequency of Self-reported Authority or Positionality among Online Posters [a]

Authority/Positionality	n (%)
Unspecified	120 (76.9)
Experience with OCD [b]	28 (17.9)
Personal experience (self)	25 (16.0)
Personal experience (second-hand family or friend)	3 (1.9)
“Not a clinician” [b]	9 (5.8)
Clinician	1 (0.6)

[a] The total number of posts (N=156) reflects those that included data coded as addressing authority or positionality of the poster. The "unspecified" category was used when the poster alluded to but did not specify authority or positionality. Posts that only provided links to relevant information (n=16) or directly copied text from a website or article (n=1) were excluded from this analysis.

[b] While nearly all codes in this category were developed to avoid overlap, n=2 posts were “double coded” when the poster indicated that they were both "not a clinician" and had "experience with OCD." As a result, the total number of Authority/Positionality codes sums to 158, which represents 156 distinct posts.

Additionally, a small percentage of posts indicated authority or positionality in relation to clinical experience or the medical field. One post in our sample explicitly stated that the person posting was a clinician with experience in the field of psychiatric neurosurgery for OCD. Of note, a slightly more commonly identified code for authority/positionality related to medical experience was when the author of the online post explicitly stated that they were “not a clinician” (5.8%). For instance, one such post included the phrase “I am no MD, but…,” which we found recapitulated in various forms among a number of posts in our sample.

Most posts in our study sample gave no indication in the body of the text who was posting in the online threads. Those that did specify included a subset of individuals who indicated that they had “experience with OCD” that was either personal (i.e., they themselves have experienced OCD) or second-hand (i.e., a family or

friend had experience with OCD). A smaller subset of online contributors indicated that they were or more commonly were not clinicians with formal expertise on the subject matter.

2) What are the predominant topics discussed on online threads?

To characterize the content of online threads, we first identified predominant themes in original posts or posts starting online threads. Table 2 summarizes the primary discussion topics among these original posts (N=73). Those starting online threads pertaining to psychiatric neurosurgery for OCD were interested in: 1) seeking information, 2) providing information, 3) seeking experiences of others, 4) discussing "cures" for OCD, 5) soliciting opinions, or 6) discussing personal experiences of new or worsening OCD. Representative examples of original posts included:

> *"Any clue about Gamma Knife Surgery for OCD?"*
>
> *"does psycho surgery help in some refractory cases of Obsessive compulsive disorders?"*
>
> *"These treatments have been around for decades and effectively treat depression, OCD, Parkinson's etc. But they involve brain surgery and therefore carry a certain amount of risk. What is your opinion about such treatments?"*

Original posts often included self-disclosure of personal experiences with OCD, providing context before asking for information, opinions, or experiences from others:

"Has anyone here had surgery for their OCD? I know it's a long shot, but I was wondering if anyone here has had surgery for treatment resistant OCD? Specifically, any personal experiences with either gamma knife surgery or deep brain stimulation? I'm looking for personal anecdotes, not studies on efficacy. (Note: I've tried nearly every medication, have done intensive CBT/ERP, and had transcranial magnetic stimulation. None of these treatments has given me lasting, sufficient relief. A recent consult recommended I pursue gamma knife surgery, but I haven't contacted a center that does it yet.)"

These posts generally sought to inform the poster by soliciting data or experiences from the online community. Notably, 37% of original posts were coded as "information providing" as their primary aim appeared to be informing the online audience about data, experiences, or new discoveries in psychiatric neurosurgery for OCD:

> *"Deep brain stimulation has helped people with conditions from Parkinson's disease to OCD. Now researchers figured out how to stimulate neurons deep in the mouse brain from the skull surface, without having to surgically insert electrodes."*

Table 2. Frequency of Topics Discussed in Original Posts

Topic (Parent Code)	n (%) [a]
Information Seeking	42 (57.5)
Information Providing	27 (37.0)
Experience Seeking	12 (16.4)
Cure for OCD	10 (13.7)
Opinion Seeking	8 (11.0)
New or Worsening OCD	8 (11.0)

[a] "n" represents the number of original posts in which a given topic was discussed. "%" represents the percentage of *total* original posts (N=73) that were coded under each particular topic (% = n/N * 100).

The majority of original posts (57.5%) were "information seeking," indicating the primary intention was to solicit information about psychiatric neurosurgery for OCD. These posts were further characterized by the subtopics that individuals were most commonly interested in discussing, as exhibited in Table 3. Most of these posts focused on the efficacy of psychiatric neurosurgery for OCD, the existence of such surgical options, and the risks and benefits associated with surgery:

"Surgery for OCD.....? ive heard that there are procedures where surgeons go in your head and remove nerves and stuff like that for severe OCD.....does anyone know where i can look up/ get information on this?"

"Is psychosurgery available if you have no other way? I heard it's in experimental stage but what if I wanna volunteer? Pills and counseling don't work for me."

"What are the risks and inclusion criteria associated with anterior cingulotomy?"

Table 3. Frequency of Subtopics Discussed in Information Seeking Posts

Subtopic (Subcode) [a]	n (%) [b]
OCD Surgery Efficacy	25 (60.0)
Does OCD Surgery Exist?	17 (40.5)
Surgical Risks/Benefits	14 (33.3)
How to get Surgery	8 (19.0)
Cost of OCD Surgery	4 (9.5)

[a] Some posts in this analysis discussed more than 1 subtopic and received multiple subcodes; thus, the percentages referenced in this table do not sum to 100%.

[b] "n" represents the number of "information seeking" original posts in which a given subtopic was discussed. "%" represents the percentage of "information seeking" original posts (N=42) that were subcoded as pertaining to each particular subtopic (% = n/N * 100).

Individuals in online chat groups appear to initiate threads about neurosurgery for OCD primarily to ask for information, opinions, and experiences about the efficacy, existence, or risks and benefits of surgery. Many other posters (37.0%) started online threads with the intent to provide or share information related to neurosurgery for OCD.

3) What kinds of responses are found in these online threads?

To understand the nature and content of discussions in online threads, we analyzed the response posts, comprising all replies and discussions stemming from original posts. Table 4 summarizes the predominant topics identified in these responses. A significant feature among response posts was the expression of impressions about psychiatric neurosurgery for OCD. These impressions were coded as "Impression of Surgery" and categorized as negative, neutral, or positive based on the tone and content of the posts.
Negative impressions were the most prevalent, accounting for 32% of response posts and 43.8% of posts expressing an impression of surgery. Posters with negative impressions often expressed skepticism about

surgical intervention as a treatment for OCD. Most commonly, individuals raised concerns about the efficacy and safety of surgery; some expressed hesitancy about surgery as a treatment option:

> *"Ok. I'm sorry but this is just... No, I mean, come on, no! Brain surgery for OCD? Has the person considered other options?"*

The remaining posts endorsed neutral or optimistic views of neurosurgery for OCD. Neutral impressions comprised 26% of response posts and 35.6% of posts expressing an impression of surgery, often tending to balance the discussion by acknowledging both potential benefits and risks. Positive impressions were the least common, making up 16% of response posts and found in 22.0% of posts expressing an impression of surgery. These posts typically highlighted successful outcomes or the potential for significant improvement.

A related but distinct feature in some response posts was the expression of opinions on whether individuals should undergo psychiatric neurosurgery for OCD. These opinions were often framed in response to personal narratives shared in the original posts. Posts advising against surgery were more common, typically citing a lack of robust data on efficacy and concerns about potential risks:

> *"There is, not enough data to support this type of treatment, in my opinion. I have ocd and it can be excruciating at times. I would not do this"*

Conversely, posts in favor of considering surgery were less prescriptive, emphasizing the need for thorough evaluation and understanding of individual circumstances:

> *"It's a really big step but if you really just can't function at all because of OCD I definitely understand why you might give it serious consideration."*

Another prevalent subtopic in response posts involved detailed discussions of the risks and benefits associated with various neurosurgical treatments for OCD. These posts often directly responded to queries about surgical risks:

> *"Risks - the lesions created by the procedure could be too large or in the incorrect locations and cause the anterior cingulate cortex to stop error checking correctly and possibly cause autonomic dysregulation."*

> *"So not only there is no guarantee that the surgery will help a given mental problem, but it also carries a huge risk of causing additional problems such as deficits in impulse control, judgement, learning, memory, problem solving or language abilities to name a few."*

Table 4: Summary of Topics Discussed in Response Posts

Topic (Parent Code)	n (%) [a]
Impression of Surgery	73 (73.0%)
Negative [b]	32 (32.0%)
Neutral [b]	26 (26.0%)
Positive	16 (16.0%)
Opinions on Whether or Not to Do Surgery	16 (16.0%)
Against	12 (12.0%)
In favor	4 (4.0%)
Surgical Risks and Benefits	33 (33.0%)
Online Referral	10 (10.0%)

[a] "n" represents the number of response posts (total N=100) coded for each discussion topic (e.g., "impression of surgery") or subtopic (e.g., "negative" impression). "%" represents the percentage of total response posts that these topics or subtopics comprise (% = n/N * 100).

[b] While these codes were developed to avoid overlap, one post (n=1) indicated *both* neutral and negative impressions of surgery. Thus, the total "impression" posts sum to 74, representing 73 distinct posts.

A noteworthy subset of response posts (10.0%) involved what we termed "online referrals," where individuals recommended that others seek formal evaluation by a mental health expert or a specialist in psychiatric neurosurgery. Often responding to posters disclosing personal experience with OCD, this practice suggests a level of community care and an attempt to provide constructive support:

> *"If you are considering this option, you should talk to your psychiatrist and carefully consider whether the potential benefits you would like to achieve are worth the risks associated with psychosurgery."*

> *"Also, try to get in touch with surgeons that perform this surgery..."*

In summary, response posts in online threads about psychiatric neurosurgery for OCD reflect a spectrum of impressions, opinions, and detailed discussions on the risks and benefits of surgery. The community also displayed instances of supportive behavior through online referrals, indicating a complex and multifaceted online discourse.

4) [Mis]information

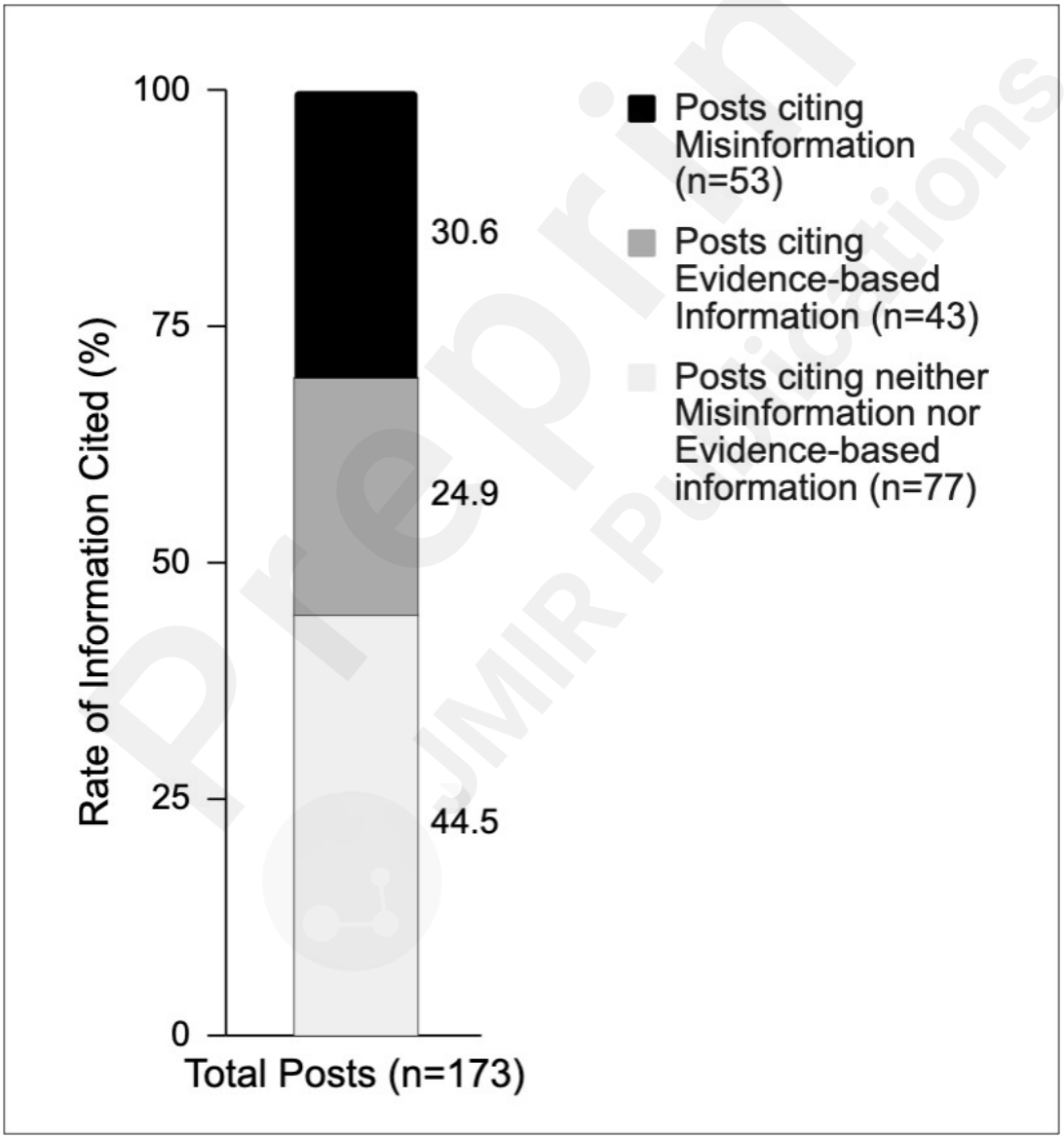
We assessed the accuracy of the information shared in online discussions by evaluating the prevalence of misinformation and evidence-based information in posts about psychiatric neurosurgery for OCD. Our analysis revealed that 30.6% of the 173 posts contained misinformation (Figure 2), citing explicit statements unsupported by existing literature and going against the standard of medical care. This misinformation varied in content and severity, often including inaccuracies about the efficacy, safety, side effects, and complication rates of neurosurgical interventions for OCD. Some posters referenced misinformation regarding the capabilities of these treatments, suggesting a latent fear or skepticism of neurosurgical intervention:

"They can take memories out and put memories in at will. They can make you feel pain and pleasure you would have never known were possible and so much more. And it's all done remotely and it's all being done right under our noses."

In contrast, 24.9% of the posts provided evidence-based information (Figure 2), aligning with current literature or correctly encapsulating medical practice guidelines. These posts frequently cited relevant studies and offered detailed insights into the efficacy, risks, and benefits of neurosurgery. Some posters provided insights into the underlying neuroscience of neuroablation and neurostimulation:

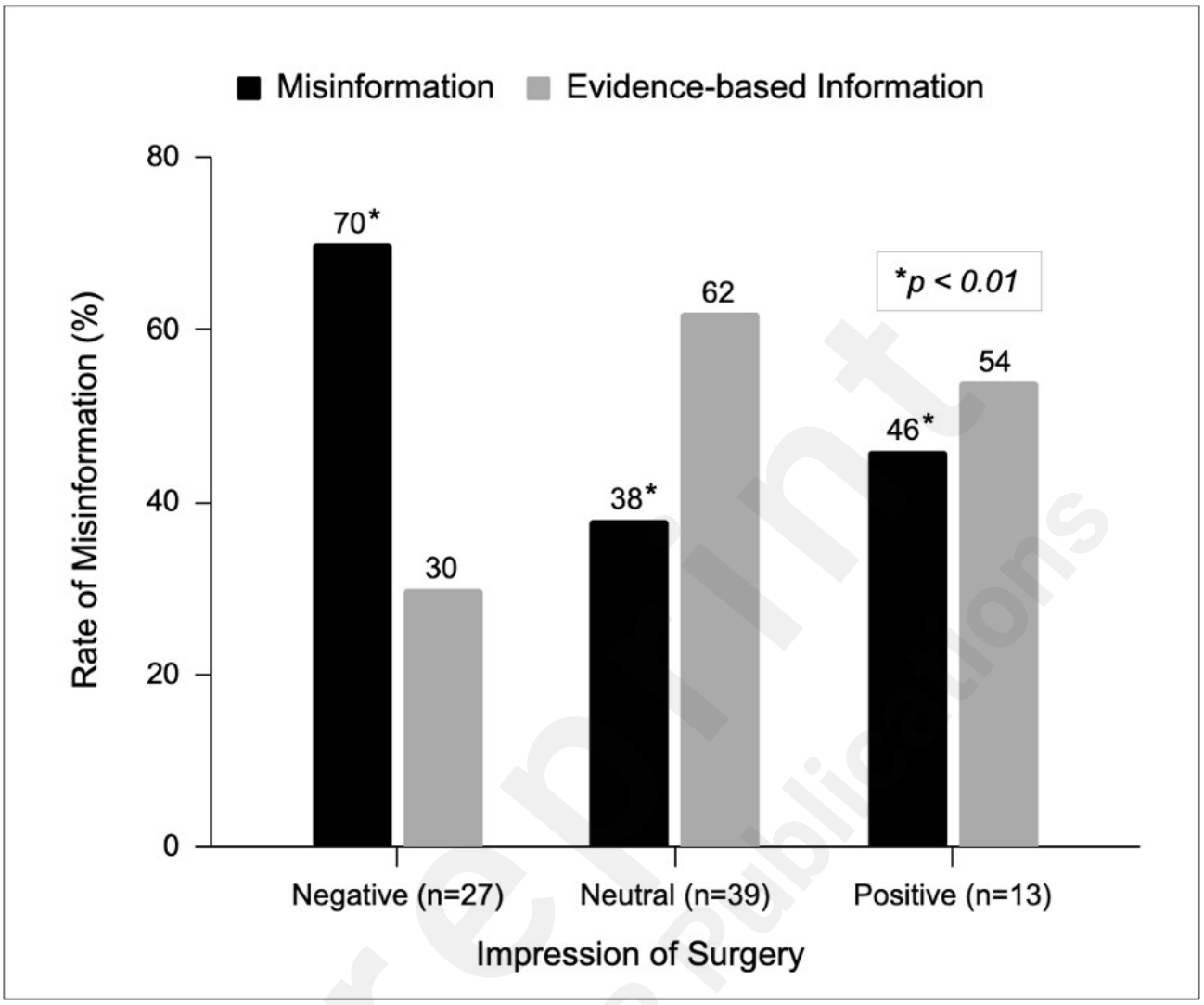
> *"Depending on location, after intensive CBT and multiple medication trials deep brain stimulation and psychosurgery may be tried. The DBS can involve sub thalamic stimulation and psychosurgery can involve lesions created on the cingulate cortex."*

Figure 2. The Prevalence of Misinformation: Distribution of Information Types in Online Posts on Neurosurgery for OCD



Rates of misinformation and evidence-based information were determined relative to the total number of online posts (N=173). Cumulatively, 96 posts explicitly mentioned or referenced medical information – coded as "evidence-based vs. non-evidence-based" – while the remaining 77 posts did not.

Figure 3. Rates of Misinformation by Impression of Surgery for OCD



Where feasible, rates of misinformation and evidence-based information were further stratified by the posters' impressions of surgery for OCD. Posts in this analysis were coded as both "evidence-based vs. non-evidence based" and "impression of surgery" (n=79).

Figure 2 illustrates the rates of misinformation and evidence-based information relative to the total number of posts, which were not significantly different (Fisher's exact test; p=0.2798). We further stratified these rates based on the posters' impressions of surgery for OCD, as depicted in Figure 3. This analysis yielded a statistically significant association between the impression of surgery and the prevalence of misinformation. Among total posts (N=173), expressing negative impressions of surgery had the highest rate of misinformation among total posts (n=19; 11.0%), followed by neutral impressions (6.4%), and positive impressions (3.5%) [$\chi^2 = 9.67$; p=0.0079].

Discussion

Study Design

The overall objective of this study was to examine online chat posts to glean information about public perception and characterize online chatter about psychiatric neurosurgery for severe, intractable OCD using qualitative analysis. Online chat forums are becoming an increasingly utilized source of data for qualitative analysis, especially as the use of online forums for medical advice and discussion increases [9,24]. We utilized

ATA, a well-established, rigorous method for qualitative inquiry that has been effectively used for written data derived from online resources including online chat forums [17,18,25]. Previous studies have employed qualitative methods to study patient lived experiences and media coverage of psychiatric neurosurgery [8,26–29]. Our qualitative study analyzed a large sample of online discussion posts from 2008-2020 that specifically discussed psychiatric neurosurgery for OCD, marking the first analysis of its kind.

In this study, the online discussion forums examined came from five websites, with the greatest representation from Reddit.com and Quora.com, two high-traffic discussion websites. Online posts in discussion forums increased over time in our sample from 2008-2020, suggesting increasing online discussion of psychiatric neurosurgery for OCD, mirroring an increase in online media coverage of psychiatric neurosurgery [28]. The aggregate number of views accrued by the 173 online posts included in our final analysis exceeded 25,000, supporting the impact and high level of engagement with online discussions about psychiatric neurosurgery for OCD. However, the view data depended on the website where the online threads were posted and the time of posting, indicating that these view numbers are almost certainly an underestimate.

Principal Results

Our qualitative analysis of the online discussions allowed us to assess the identities of posters, the topics initiating online threads about psychiatric neurosurgery, views among respondents, and the presence of misinformation on online discussion forums.

Regarding “who is posting,” our analysis revealed that from these online discussion forums, where user data was primarily anonymous, it was often impossible to ascertain the level of authority or specific positionality of the poster based upon the content of their post alone. In 76.9% of posts, not only was the user’s identity unknown, but their professional or academic expertise, knowledge of OCD or neurosurgery, or background was also unknown. This is common for online chat forums in general and has been increasingly reported in online chat forums on topics of mental illness [30,31]. Previous literature has demonstrated that the anonymity on online forums often encourages self-disclosure [30,31]. Our study aligns with these findings, as a significant portion of posters self-identified as individuals with OCD or family/friends of those with OCD. These data were further underscored by extensive self-disclosure about symptoms, experiences with OCD, and treatment for OCD. In addition to positionality in relation to OCD, another form of self-disclosed positionality was regarding proximity to clinical expertise. One post in our sample was from an individual who disclosed that they were a “clinician in mental health,” while a relatively larger number of individual posts specified that the poster was “not a clinician” in some form or another. These findings suggest that the culture of online discussion around psychiatric neurosurgery for OCD includes individuals with OCD, their friends and family, clinicians, and non-clinicians, yet the vast majority of those posting have an unspecified background or relation to the topics of discussion. Individuals often turn to the internet for medical advice [15], and having a majority of information/opinions/views on online threads written by unknown sources may be problematic given the limited trust and credibility of sources [32]. For neurosurgical management of OCD in particular, where procedures are rare and only conducted at a few specialized sites, studies have shown many mental health clinicians in the field express limited experience with and knowledge about the subfield [33–36].

In terms of “original posts,” those that initiated online discussions, qualitative analysis revealed that individuals start online threads to ask the online community for information, share experiences, and provide opinions about psychiatric neurosurgery for OCD (Table 2). Many posts posed questions about the safety and efficacy of surgery for OCD, such as if surgery “really works” (Table 3). This highlights a disconnect between established literature and public perception, as neurosurgery for OCD has been proven efficacious and safe for many with intractable OCD over the past two decades [3–5]. This gap between established scientific literature and public perception or knowledge was further underscored by the second most common subtopic in information-seeking posts: the discussion of whether or not neurosurgery for OCD “exists.” Interestingly, many of these posts were from the past 5-6 years, indicating that questions about the existence of such surgeries are not confined to the early 2000s. Individuals also expressed interest in the risks and benefits of surgery, access to surgery, and its cost. These posts, while less predominant, were often detailed and indicated a level of background knowledge of neurosurgery for OCD, while providing key insight into questions that may be at the forefront of patients' minds that present for evaluation to psychiatric neurosurgery teams. Some “original posts” focused primarily on providing information, sharing literature, media, and/or personal

experiences. This practice may also present a barrier to surgical evaluation for some patients who may benefit, and further study is warranted to understand these dynamics better.

Our data also revealed that responders on online threads provide their impressions of surgery for OCD, opinions on whether or not specific individuals should undergo or consider surgery, discussions of the risks and benefits of surgery, and "online referrals" for one another. Our data showed that the greatest percentage of responders who indicate an impression of surgery in the tone or explicit content of their post indicated a negative impression (Table 4). This finding is notable because it speaks to continued skepticism about psychiatric neurosurgery in the public eye, and this finding is consistent with a prior study of internet comments to media reports about psychiatric neurosurgery, which were also largely negative in tone [8,36]. Previous literature suggests that the ethically contentious history of psychosurgery that predates modern psychiatric neurosurgery may still influence public perception of these procedures, and indeed a number of posts cited the history of psychosurgery by referencing "lobotomies" of the "early 1930s," as one user described [8,36]. This view is significant because it may impact patient engagement, evaluation rates, and possibly even referral patterns for treatment among individuals with severe, intractable OCD.

A smaller but highly important subset of response posts included a clinically noteworthy phenomenon: opinions about whether or not to undergo or consider surgery for OCD (Table 4). Often in response to posts where participants present a personal narrative of their experience with OCD, which often took the form of a detailed psychiatric and medical history, posts that provide opinions about surgical decision-making most often advised against considering or undergoing surgery. This finding speaks to the negative impressions of surgery among posters and the general negative view in the community about neurosurgery for OCD. It also demonstrates that individual online community members, many of whom have unspecified authority in the space, are weighing in about decisions for individuals who may need formal evaluation for psychiatric neurosurgery. This can be a potentially harmful practice if posters are using the free, easy-to-access online forums as a surrogate for formal evaluation or asking a qualified clinician, which some literature shows is already the case for a variety of medical issues [15]. This practice may also present a barrier to surgical evaluation for some patients who may benefit, and further study is warranted to understand these dynamics better.

While some online participants weighed in on medical decisions, others opted for what we term "online referrals" in this paper. The observed practice of "online referrals" demonstrated some care within these online communities that may be a positive health-promoting practice: responders encouraged other online community members to seek formal evaluation by a mental health expert, functional neurosurgeon, neuropsychologist, or specific psychiatric neurosurgical team. This approach can be described as "directive support," a feature reported in the literature on online mental health forums, where peers provide resources or suggestions for one another [11].

We also aimed to assess the rate of misinformation about psychiatric neurosurgery for OCD, in this study. Medical misinformation has become an increasing problem with the rise of social media and other online platforms, such as online chat forums that are rarely regulated [37,38]. By drawing from collective expertise in the space from researchers at our institution, which has been a leader in the field of psychiatric neurosurgery for OCD for decades, we quantified the number of posts that had either evidence-based information or misinformation among all the posts that shared information intended to be broadly applicable. We found the rate of misinformation was 30.6%, while that of evidence-based information was 24.9%. The rate of evidence-based information suggests, positively, that a significant proportion of the posting population are highly informed individuals who are gaining access to up-to-date, evidence-based resources. These data also suggest a nearly equal representation of clinically valid information and inaccurate information on online chat forums. Consequently, countless users who seek medical information on online forums may encounter large volumes of conflicting information to parse through. Unfortunately, most users may not have the expertise to distinguish valid information from inaccuracy.

This analysis provides insight about what kinds of misinformation is pervading public perception about these often contentious and highly specialized neurosurgical procedures. Misinformation, which alone can be dangerous, may also directly affect impressions of surgery for OCD: the rate of misinformation was higher for those with negative impressions of surgery and lowest for those with positive impressions, a trend that reached statistical significance (Figure 3). This finding underscores the critical impact of misinformation on public perception. Negative impressions of psychiatric neurosurgery for OCD were more likely to contain inaccuracies, which can perpetuate skepticism and fear surrounding these procedures. More broadly, pervasive

misinformation about psychiatric neurosurgery may underlie some of the negative perceptions that remain about modern psychiatric neurosurgery [37]. Addressing misinformation in online discussions is essential to ensure that individuals receive accurate, evidence-based information when considering treatment options for OCD.

Limitations and Strengths

This study has important limitations. First, as a qualitative study of anonymous online chat data separated by time, this study may lack key information about public perception and the nuances underlying certain discussions. These topics may be more comprehensively captured in study designs that occur in real time, such as in-person interviews or observational studies. Our research team represents a diverse cohort of researchers with extensive collective experience engaging in clinical research on psychiatric neurosurgery for OCD. We aimed to mitigate potential bias in post analysis by developing an extensive and robust coding scheme that we developed with three independent reviewers and validated with a fourth independent reviewer with expertise in ATA. We then employed a rigorous, discussion-based approach to analyzing and verifying the coded data as a team after independent review.

Another limitation of this study is the lack of data on individuals engaged in online chat communities. We attempted to mitigate this by coding authority and positionality of the poster based on written data in each post, and we also argue that the relative anonymity of most online chat participants is an important piece of qualitative data in and of itself, as discussed earlier. We can only speculate about the possible impact of these online communities on individuals with intractable OCD who qualify for surgery. Nonetheless, this study was developed after numerous individuals being evaluated for psychiatric neurosurgery at our institution indicated that they had specifically obtained information or participated in online chat forums to learn about the neurosurgical treatment of OCD.

Future Directions

Further research examining the pervasiveness of specific misinformation about psychiatric neurosurgery for OCD is critical. Given the significant presence of misinformation identified in this study, it is essential to understand the specific types of misinformation being propagated and their potential impact on patient decision-making. Investigating the sources of misinformation and developing strategies to counteract it could enhance the quality of information available to patients and the general public. Moreover, addressing the consistently identified phenomenon of negative perceptions of neurosurgical treatment for OCD is vital. Understanding the historical and psychological factors contributing to these negative perceptions can inform targeted educational campaigns aimed at correcting misconceptions and providing balanced, evidence-based information. This effort could potentially improve patient receptivity to neurosurgical options and facilitate better-informed decisions.

Future studies should also explore the clinical implications of these findings. For instance, examining how online discussions influence referral patterns and patient engagement with psychiatric neurosurgery could provide valuable insights for clinicians. Additionally, implementing educational interventions in clinical settings, where patients are guided to reliable online resources, could bridge the gap between clinical advice and online information. In summary, this study highlights the need for ongoing research and proactive measures to address misinformation and negative perceptions related to psychiatric neurosurgery for OCD. By understanding and addressing these issues, clinicians and researchers can improve public awareness, influence referral patterns positively, and ultimately enhance patient outcomes.

Conclusions

This is the first qualitative study, to our knowledge, of online chat forum discussion on psychiatric neurosurgical treatment for OCD. We observed that those engaged in these forums are largely anonymous but include individuals with OCD. Questions about efficacy, safety, and risks and benefits of surgery pervade. These specific online chat forums involve sharing information, experiences, and opinions about neurosurgery for OCD. The community of individuals on these online chat forums is largely supportive, with numerous

practices that aim to offer support to one another through sharing experiences, answering questions, and suggesting resources such as referring individuals to expert clinical evaluation. Misinformation about psychiatric neurosurgery for OCD is also highly prevalent in online chat forum discussions, and further study of online communication and public perception about psychiatric neurosurgery will be of significant value as functional neurosurgery advances in this space and the internet continues to be increasingly utilized as a primary source of medical information.

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Conflicts of Interest

None declared.

Abbreviations

ATA: Applied thematic analysis
DBS: Deep brain stimulation
ERP: Exposure and response prevention
OCD: Obsessive-compulsive disorder

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Supplementary Files

Multimedia Appendixes

Untitled.
URL: http://asset.jmir.pub/assets/5826f0fbf98c523ff27a147ee421a616.docx