



Rewriting the Script: the Need for Effective Education to Address Racial Disparities in Transcranial Magnetic Stimulation Uptake in BIPOC Communities

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Abstract Depression is a widespread concern in the United States. Neuromodulation treatments are becoming more common but there is emerging concern for racial disparities in neuromodulation treatment utilization. This study focuses on Transcranial Magnetic Stimulation (TMS), a treatment for depression, and the structural and attitudinal barriers that racialized individuals face in accessing it. In January 2023 participants from the Twin Cities, Minnesota engaged in focus groups, coupled with an educational video intervention. Individuals self identified as non-white who had no previous TMS exposure but

had tried at least one treatment for their depression. Results revealed that the intervention did not notably change knowledge or stigma about TMS, but attitudes surrounding traveling for treatment changed. Notably, barriers like affordability, frequency of treatment, and lack of knowledge persist. Participants expressed a desire for more information, personal connection, and a tailored educational approach. The study suggests a need for multifaceted strategies to reduce disparities, focusing on education, community-based resources, and policy interventions. Immediate actions that can be taken include the creation of a TMS education program focused on patient engagement and awareness about TMS.

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Introduction

In the United States it is estimated that 18.5% of adults experience depressive symptoms each year [1]. The prevalence of depression has been rapidly increasing in recent years particularly in young people (ages 12–25) and across sex, racial, income, and education groups [2–4]. The emotional, social, and economic burdens of both diagnosed and undiagnosed depression are felt heavily within racialized groups who carry a higher level of chronic Major Depressive Disorder (MDD) [2].

Of those who receive a diagnosis, a third of adults do not seek treatment for their depression [2, 5–8]. Of those who seek care, between 30–35% do not find relief from these treatments [9–11]. This translates to more than 3 million people living in the U.S. who have treatment resistant depression [11]. As medication options become limited, many people turn to neuromodulation as their next treatment option.

Neuromodulation is a category of treatments that changes neural activity through the delivery of electricity to specific regions of the brain. This treatment operates on the understanding that the brain has a vast number of networks relating to different functions and affect. By engaging and modulating a specific network, we can effectively change the behavioral outcomes for an individual [12]. Examples of neuromodulation treatments include therapies that require implantation into the body like deep brain stimulation, vagus nerve stimulation, spinal cord stimulation, and peripheral nerve stimulation as well as therapies like Transcranial Magnetic Stimulation (TMS) and Electroconvulsive Therapy (ECT) that do not require any elements to be implanted into the body [13]. Neuromodulation can be used to treat both neurological and psychiatric disorders [13].

Just like medication and therapy treatments, neuromodulation therapies are subject to the influences of attitudinal barriers [14]. With neuromodulation there is a persistent barrier of stigma [14, 15], in particular towards ECT which is regarded as one of the most stigmatized mental health treatments [16]. While ECT is one of the most effective treatments for MDD, its long history carries with it significant stigma stemming from the cognitive side effects of treatment [17]. Video education to combat stigma surrounding ECT has moderately been successful [18]. Considering the long-standing stigma surrounding ECT, TMS is generally regarded as a more popular choice for patients with MDD [19].

Previous work examining patient views of different types of neuromodulation showed that TMS has the most favorable views compared to ECT, Deep Brain Stimulation, and adaptive brain implants [20]. In particular, participants assigned to the rTMS condition reported more positive affect, more positive influence on self, greater perceived benefit, lesser perceived risk, and lesser perceived invasiveness.

While neuromodulation therapies like ECT and TMS are being utilized across the U.S to treat depression, there are emerging patterns of racial treatment disparities in access to most neuromodulation treatment modalities [21–26]. From a social justice perspective, *there is a need to understand how racialized patients perceive neuromodulation treatments for depression, as well as the barriers, including attitudinal barriers like stigma, they encounter when trying to access it.* This current study aims to identify structural and attitudinal barriers associated with TMS within a group of individuals self-identified as non-white with depression who had no previous TMS exposure, and the impact of a video-based education on these attitudes.

In this paper we aim to understand the connection between knowledge, attitudes, and barriers on willingness to seek TMS treatment within a depressed BIPOC¹ population. The goal of this study is to explore these topics in healthcare decision making to prompt future studies.

Methods

We recruited individuals from the Twin Cities, Minnesota metropolitan area from December 2022 to January 2023 to participate in one of three focus group sessions held the same month. Individuals self-identified through an online screener that was shared out in communities via flyers and online through paid Facebook ads. Individuals who met core eligibility criteria per the online survey (non-white, have depression, have tried at least 1 type of treatment for their depression, and have not tried TMS), were contacted by the study team. All participants completed the informed consent process and were invited to one of three focus group sessions dependent on their availability.

Participant ages fell into three age categories with a slight skew towards the younger age category. The sample was predominantly female (82%). The racial make-up of our study population was diverse, with representation from 7 distinct racial identities. It is important to note that while our population appears diverse, these racial categories may not fully encompass the identities of our participants. The concept

¹ BIPOC: Black, Indigenous, People Of Color.

Table 1 Demographics

Total <i>N</i>	17 (100%)
Age category (%)	
18–29	8 (41%)
30–49	6 (35%)
50–69	4 (24%)
Gender (%)	
Female	14 (82%)
Male	2 (12%)
Non-binary	1 (6%)
Race (%)	
American Indian or Alaska Native	4 (24%)
Asian	6 (35%)
Black or African American	2 (12%)
Non-white Hispanic	2 (12%)
Bi-Racial	3 (17%)
<i>(1) Alaska Indian or Alaska Native + Other Race</i>	
<i>(1) Alaska Indian or Alaska Native + White</i>	
<i>(1) Black or African American + White</i>	
Years since depression onset (mean)	12.82 Years (0–31 years)
Has at least 1 comorbid mental health condition	15 (89%)
Average number of depression treatments tried	2.7

of race is inherently a social construct [27, 28]. The racial categories used in the US have historically been based on skin color and physical features [29, 30]. As a result, the categories used often neglect the socio-historical characteristics and experiences [27, 28]. In order to remain congruent with previously conducted research we have chosen to use the established racial categories so results could be compared.

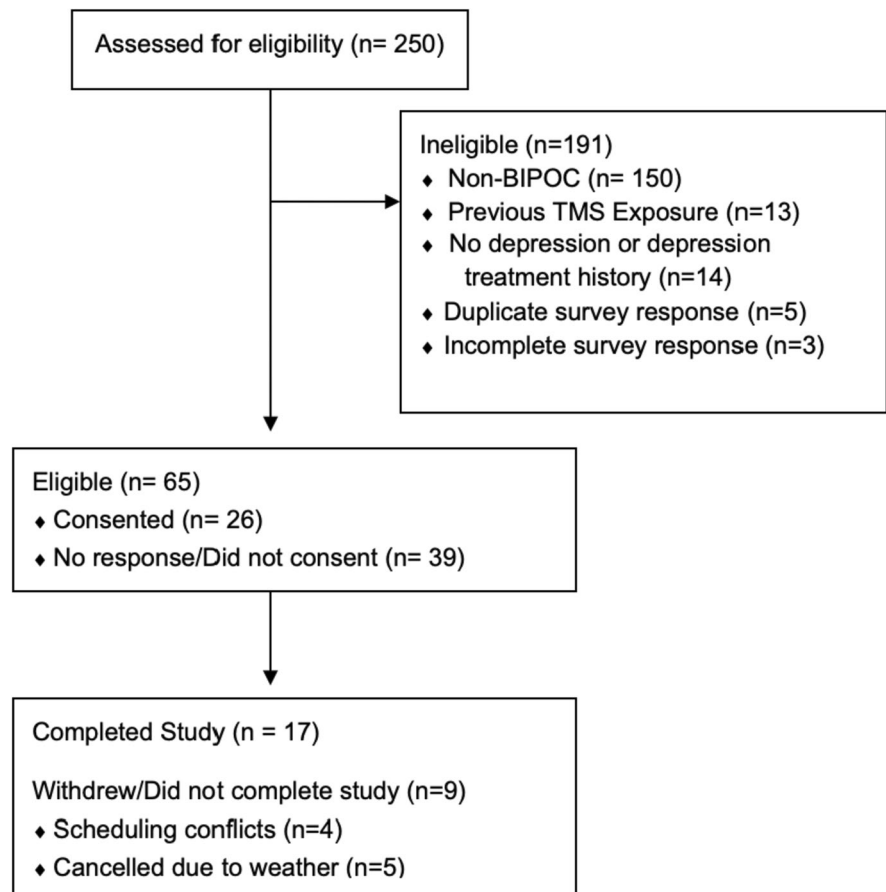
The average number of years since onset of depression was 12.82 years, with a range of < 1 to 31 years. In our population 40% of participants reported having lived with depression for at least one decade. Demographics of the 17 participants are shown in Table 1. Comorbidities were common in our sample with 89% reporting at least 1 comorbid mental-health condition. The most common comorbid condition reported was Generalized Anxiety Disorder (65%) (Fig. 1).

This study is a pre-post study design with a video intervention delivered in a focus group setting. A video intervention was chosen both because this type of intervention has had moderate success

in combating stigma in the field of neuromodulation [18] and is easy to distribute widely if successful. The video used is the same video intervention delivered in Cabrera et al. 2023 [20]. This video was reviewed by three psychiatrists for effectiveness of message delivery.

To better identify and categorize the barriers and stigma associated with TMS within monitored groups three focus group sessions were conducted within the population of interest. All three focus group sessions occurred within 36 h at the Masonic Institute for the Developing Brain (MIDB). Each group followed the same study protocol. Individuals gathered in a meeting room to fill out a depression history form, a TMS knowledge quiz, and a TMS perceptions survey. After completing baseline measures individuals transitioned to a focus group. Three facilitators led the session. The first half of the focus group focused on experiences of living with depression generally and the associated experiences of seeking treatment for their depression. The group was then shown a video vignette that showed two actors portraying a conversation between patient and physician discussing TMS treatment for depression. Following the video the focus group questions focused on thoughts about TMS as a treatment, the benefits, risks, and remaining questions surrounding the treatment option. Following the focus group individuals completed a post-group TMS knowledge quiz and TMS perceptions survey.

We analyzed the data using R version 4.2.0. A series of T-tests tests were used to compare answers from the perceptions survey pre and post intervention. The average score of the knowledge survey was compared pre and post intervention. Stigma variables included likeliness of TMS to cause positive or negative effects, individual likeliness to recommend TMS to someone who needs it, and likeliness to pursue TMS themselves. These variables were scored on a 1–5 likert scale, 1 representing extremely unlikely, 5 representing extremely likely. Willingness to travel for treatment was coded as 0 for not willing, 0.5 for maybe willing, and 1 for willing. Travel distance was an open-ended question that individuals answered in either minutes or miles based on preference. For individuals who entered their answer in miles we converted their number into a time equivalent assuming an average speed of 45 miles per hour to account for highway and city driving.

Fig. 1 CONSORT diagram

After collecting video and audio recordings of the focus groups, we removed all identifying information that would be present as we separated out the transcription and went through each respondent's answer for every identifiable question. Although there was no formal qualitative analysis, we did summarize overarching ideas that emerged in the focus groups based on the raw frequency of a theme appearing. Grouping most answers into recurring topics and ideas, we believed that topics arising organically from discussion rather than premade lists of potential answers would best represent the participants. After tabulating the participants' answers, we further summarized these identified major issues. We created an overview of the collected answers from all participants into major ideas/themes, suggestions, and issues presented in these discussions. Due to the presence of evaluation team members who shared a racial background with the interested and affected parties, the team exhibited a heightened sensitivity and awareness towards these

individuals and the beneficiaries of the TMS Equity project [31]. Consequently, these team members possessed self-awareness when employing qualitative methods, enabling them to consider the participants' context and culture more effectively [31]. This consciousness and positionality also proved beneficial in comprehending the collected data through linguistic and cultural insights. Our results integrate insights from both the qualitative and quantitative work.

Results

Pre-intervention Findings

The focus groups identified a variety of themes of both depression generally and themes specific to TMS (Table 2). Overall, these focus groups encompassed a range of backgrounds, experiences, and views from racialized participants who live with

Table 2 Focus group themes

General depression	
Themes and subthemes	
Experiences with previous care	Most individuals had generally mixed or negative experiences in their previous experiences with care for their depression. Exploring, researching, and attempting treatment options felt time consuming. A common thread was difficulty finding a good provider, with many describing finding meaningful therapists as difficult
Time needed to find care	<i>Finding and deciding on a treatment “went on and on forever, and it still goes on”</i>
Time spent finding a good provider	<i>“It gets hard to open up again. You don’t know how long you’ll see this person.”</i> <i>It is “very frustrating” to start the process over again to find somebody</i>
Dislike of medication	<i>“Don’t like taking pills”</i> <i>“I want to get better. I don’t want to be depressed all my life. I hate medicine, I hate pills.”</i> <i>“I’m high-functioning [and] I can’t stop what’s going on. I’ve tried many medications.”</i>
Sense of isolation	As a general trend for those in our focus groups was a sense of isolation from their peers. Some defined this sense of isolation as a symptom of their depression, as it takes them so long to leave the house <i>Depression affects ability to “maintain relationships, family, functions, and work”</i> <i>“That’s what depression WANTS us to do! Stay home!”</i> <i>As a Black woman: “Culturally it’s a little harder, because there’s a lot of weight on me to be strong. If I did try to talk to people, it gets minimized.”</i>
TMS specific	
Themes and subthemes	
Desire for information	Participants had many questions about the treatment, the side-effects, treatment effects, and how long these effects lasted. They questioned how common these side effects would be, and felt a lack of understanding on what the intended effects were supposed to be <i>In terms of side effects, “[the video] said mania! Is that reversible?”</i> <i>it is very important that they are “feeling prepared for something” before trying it</i>
Time commitment	The concerns surrounding time commitments were multifaceted. They included concerns about the time it takes to get to and from appointments as well as the number of consecutive treatments needed in total <i>“What happens if you miss one appointment?”</i> <i>“I think this sounds like a really difficult treatment for low income people. Five days a week? It sounds really hard to access”</i> <i>“I work with students who don’t have their own cars. If I heard that spiel and, if I was that student, I would think that’s not for me. It’s made for that rich white person who stays at home and doesn’t work and stays at home and has their own car.”</i> <i>“Are you able to drive after? Or get on the bus after? After Novocaine I can’t get on the city bus, can I after this?”</i>
Treatment incentives	Participants were asked about ways that they as individuals and their communities in general could be incentivized to start and complete a course of TMS. Most identified incentives touched on previously identified barriers or the importance of the treatment referral source
Transportation	<i>“Bus pass, gas money. Or Uber money.”</i> <i>“Yeah come to my area, come to me. That would eliminate driving, finding your way on the bus line, etc.”</i>
Co-pay support	<i>“Especially if you have a high-deductible plan, that would make this impossible”</i>
Recommendation from a trusted source	<i>“I personally feel like if one psychiatrist was like ‘Hey this is the next step’, I’d consider it. Like medical professionals are authority figures.”</i> <i>“I’d want to find somebody open and transparent, that’s more important. But I know others in my culture, if you looked like them, and suggested it, they would follow suit. They would probably try it. It’s a problem in general for any healthcare barriers, finding somebody who is like you and trusting you.”</i>

Table 2 (continued)

Try it before committing	<i>“Like a minute to see what it feels like on your head, to make it less scary [...] Like if you never had a massage but you have somebody work on your shoulders at a fair”</i>
Make it convenient	<i>“Making it more accessible, do you know if they have the ability to do this at a Minute Clinic, or at a gym? I don’t know, somewhere you can stop in and get it done convenient-wise”</i>
Congruent social identities	A key difference identified in the groups is that real life reflection of social identities carries more value than having representation in educational videos. This view was not shared universally, but even those who said representation in the video is important had reservations about the authenticity of said representation. For most people answering, they agreed that if the doctor or patient in real life shared their social identity, they would be more willing to trust them
Congruence irrelevant	<i>“As long as there’s facts, figures, testimonials, I don’t care who is in the video”</i> <i>“I think if you replaced the patient or the provider with like somebody who shares a social background as me...I don’t think I changed my opinion”</i>
Congruence carries some weight	<i>“I think if they had the doctor as somebody of a relating social background, it would be more convincing. And accessible to...and seem more accessible to people”</i> <i>“If the doctor had reflected me a bit more, like race or background, I would trust them more...I would have my apprehensions about this, but if they thought that this was the best option I would trust them more than a white doctor”</i> <i>“Ideally, you’d talk to a person of color who went through this”</i> <i>“I want to see success stories from people like me. If I was a student, I’d want to hear from a student like me. I’d definitely want to know if someone who was working full-time, how they managed it.”</i>

treatment-resistant depression. Two people (12%) had previous knowledge of TMS. Overarching themes of the groups included the desire to learn more about TMS, strategies and incentives to overcome barriers to TMS treatment, and a desire for a personal connection with their mental health care providers to discuss TMS with. The main limiting factors in participant perceptions of TMS and their willingness to consider it as a treatment option was affordability, frequency of treatment, time commitment, travel time, and knowledge.

Video Intervention

Participants did not feel that the video intervention adequately addressed their questions and concerns, but agreed that video is an effective way to distribute health information. Many comments stressed that the lack of information in the video intervention limited their willingness to consider TMS. Multiple individuals noted their desire for access to available TMS data which would close this information gap as they could then make their own educated opinion based on research. The desire for racially congruent figures in future education videos was mixed. Participants noted that personal connection was more important

than someone simply sharing their own social or racial identity in the video. Instead, participants noted the importance of finding a mental health provider who shared their social identities to build a personal connection. Hearing first-hand accounts from someone who had gone through TMS was also noted as a needed improvement for the video intervention.

Post Video Intervention

The focus group paired with a video intervention did not significantly increase knowledge or decrease stigma on an individual level (See Table 3). However, willingness to travel for treatment increased between the two timepoints. Pre-focus group 53% of individuals reported willingness to travel for TMS compared to 82% of individuals reporting willingness to travel post-intervention. Using a linear mixed model we find that the pre/post change in the distance an individual was willing to travel for TMS significantly decreased ($p < 0.001$). Considering that participating in a focus group and consuming a short educational video did not significantly impact knowledge or stigma surrounding TMS in our participant but had a positive influence on an individual’s willingness to travel for TMS as a treatment,

Table 3 Descriptive statistics

Variable	Range of possible values	Mean score pre (SD)	Mean Score Post (SD)	Change pre → Post <i>p</i> -value (unadjusted, adjusted)	Linear mixed-effects model <i>p</i> -value
Knowledge	0–12	8.65 (2.89)	9.00 (3.18)	1, 1	1
Positive effects	1–5	3.40 (0.63)	3.47 (0.80)	0.432, 0.567	0.9796
Negative effects	1–5	2.69 (0.79)	2.82 (0.64)	0.486, 0.567	0.9863
Likelihood to recommend	1–5	3.00 (0.89)	3.29 (0.77)	0.432, 0.567	0.9690
Likelihood to pursue	1–5	3.125 (0.96)	2.88 (0.99)	0.206, 0.481	0.9582
Willing to travel	Yes/No *Open ended; allowed for “maybe” answers	0.53 (0.51)	0.82 (0.39)	0.0823, 0.481	0.9514
Travel distance	Measured in minutes	82.22 (62.61)	48.21 (47.26)	0.199, 0.481	<0.001

more research is needed to see if this holds with a larger sample of participants. In particular, having more accurate information of what the treatment requires (e.g. number of sessions) provides a more informed decision process shaping the willingness people have to travel longer distances.

Discussion

As shown in previous research [14, 20], there is general openness to try TMS within racialized communities but there are significant concerns that must be addressed to translate openness into treatment utilization. Despite concerns about TMS as a treatment option, the experiences of our focus group participants point to an openness to additional non-medication-based treatments for depression. Lack of knowledge around TMS is a clear barrier to people seeking it as a treatment option. Our results suggest that in order to make TMS a realistic treatment option for more people, we must address the barriers identified and provide better education to prospective patients.

Many of the barriers identified in this focus group and previous research require individual, community, and structural level changes to address, but education is an avenue that can be immediately adapted to address some of the barriers identified. Based on comments from our study population a successful TMS education program would include the following information:

1. *How many studies have been conducted about TMS and how many people were involved in these studies?*
2. *What percent of people respond to TMS?*
3. *If I respond to treatment, how long does the response typically last?*
4. *Do people need to get TMS multiple times in their life? If so, how long do people go between treatment series?*
5. *How often do side effects happen? How quickly do they go away?*
6. *What other treatment options are there if TMS doesn't work for me or if I don't go forward with TMS?*

This approach is familiar, broadly accomplishing the same goal of question prompt lists (QPL). A QPL is a tool to help patients ask questions to encourage engaged healthcare decision making between patient and provider. QPLs are disease specific and have been successfully implemented in oncology, gastrology, and cardiology [32–34]. Existing literature has begun to explore the use of QPLs in the context of neuromodulation research [35], further strengthening the argument for bolstering patient education within the neuromodulation field.

Successful education is not just about the content, it must also be delivered at the right time by the right person. A central feature of the focus groups was the desire for information to be delivered from someone they trust. For some racialized groups, community plays a key role in making decisions about whether to

Table 4 Actions to address barriers to treatment

	Immediate actions	Structural actions
Transportation	<ul style="list-style-type: none"> • If TMS clinics are easily accessible by bus lines or other public transit highlight this • For prospective patients explain parking situation clearly (paid or free parking ramp, surface level parking, paid or free street parking, etc.) • Provide script for contacting insurance about potential medical transport 	<ul style="list-style-type: none"> • Locate new TMS clinics in areas that are easily accessible by multiple modes of transportation • Consult travel patterns within an area (ex. Downtown Minneapolis, people come in via bus/train, locate a TMS treatment facility in the skyway that is easily accessible and walkable by the 200,000+ people who work in downtown) • Partner with BIPOC serving institutions who already provide mental health care to BIPOC populations to set up new TMS clinics • Create a mobile TMS clinic that is accessible to those with insurance as current models are based off private pay models [39] • Extend TMS clinic day to allow for “off hour” TMS visits • Research and development of new TMS treatment types that focus on minimizing time commitment (specifically in quantity of visits or length of visits). The SAINT protocol [40], which lumps together 10 treatments a day for 5 days a week significantly shortens the number of days spent getting TMS but requires full day availability which may or may not be feasible for all patients
Time commitment	<ul style="list-style-type: none"> • Have a clear policy for missed appointments with options for rescheduling—how many days in a row can be missed before treatment effects are lost • Have discussions early on about how to plan for time off needed for TMS (starting work later in day or earlier to be at edge of clinic day or over lunch hour. Use of PTO or vacation time) • For hourly workers, potential for short term accommodation for not allowing work to start before or after a certain time to allow for treatment during the 7 weeks • Highlight need for childcare during treatment time so this can be planned proactively. Additionally outline a clinical policy for childcare (what age of child can wait in the waiting area and for how long, etc.) 	
Costs	<ul style="list-style-type: none"> • Transparent pricing for whole treatment, laying out cost of copays per individual • Prioritize finishing treatments by the end of the year so deductibles don't reset mid-series 	<ul style="list-style-type: none"> • Provide financial education for prospective patients including information about getting on public insurance or accessing FSA's through their employer • Work with local and state government to provide sliding scale support
Provider support	<ul style="list-style-type: none"> • Treatment decisions are a personal topic for patients. Providers should keep this in mind when walking through the decision making process with patients and pull in support from other trusted sources of the patient during this process. [41, 42] • Create an outreach program for clinicians not in own system that do not have TMS in their facility to create a referral pipeline 	<ul style="list-style-type: none"> • Updated curriculum and/or continuing education for all levels of doctors who treat MDD. This includes psychiatrists, primary care, and anyone prescribing antidepressant medications so they are up to date on insurance coverage and FDA approval of TMS • Utilize strategies known to increase uptake of medical care such as implementing treatments that are responsive to patient needs and preferences, building in flexibility to evidence-based practices, and intervening earlier in the disease trajectory

undergo treatment for mental illness [36, 37]. However, many medical decisions often happen alone in clinical spaces. It is important that the provider introducing TMS is utilizing effective education tools when discussing TMS with prospective patients [38]. This improved education would serve two purposes, (1) informing the prospective patient of key pieces of information needed to make an informed treatment decision and (2) opening the door for providers to proactively discuss the need for support in overcoming common treatment barriers within TMS (need for transportation, insurance coverage and copays, work and childcare considerations, etc.). This new education program could be paired with a resource play-book that can be maintained by clinics offering TMS to connect individuals with resources commonly utilized by other TMS patients to help overcome these common barriers.

Table 4 lays out the barriers reported in the focus groups as well as immediate actions and structural level actions that can be taken to address these barriers.

In addition to the actions TMS clinics can take to address the barriers and concerns expressed by our BIPOC community members in Table 4, more research is needed to further address the concerns of this patient population as a whole. This may involve large-scale epidemiological studies, as well as qualitative research with underrepresented communities to further document neuromodulation treatment disparities.

Secondly, research is required to address structural barriers to treatment, such as availability, affordability, and transportation. This involves a range of approaches, including policy research, evaluation of health insurance models, development of community-based resources and support. Work to address structural barriers takes the onus from the individual and puts it back on the institution of healthcare to come up with solutions. There should be a sense of urgency to address the structural level changes. Structural interventions often require large sample sizes across regions over a multi-year period of time [43]. The nature of this type of research means if we want to see meaningful change enacted, it needs to start now.

Finally, research into tailored education and outreach programs is vital to bridge knowledge and information gaps to increase awareness about various treatment options for MDD such as TMS. Efforts to improve education should be informed by practices known to increase uptake of medical care within

racialized communities broadly. Additionally, studies should focus on optimizing the delivery of these programs, addressing when and by whom the information is provided to ensure the information is shared in a trustworthy and effective manner. This research should incorporate ways to make treatments more responsive to real life where treatment adherence is not perfect. Together, these diverse paths of research can combine to foster a more equitable TMS practice, which from a neuroethics point of view is key to address social justice considerations related to mental health treatments. If successful, this could herald a paradigm shift in how we educate and engage patients about TMS.

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Declarations

Financial Interests The authors declare they have no financial interests.

Non-financial Interests S. Wilson is on the board of directors of the Clinical TMS Society and receives no compensation as member of the board of directors. L. Cabrera is on the board of directors of the International Neuroethics Society and receives no compensation as member of the board of directors.

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

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Data Availability The data that support the findings of this study are available in the supplementary information section of this article.

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