

“Retraining your brain”: An Empirical Assessment of Ethical Concerns and Attitudes of Users of Electroencephalography Neurofeedback



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Introduction

Electroencephalography (EEG) neurofeedback is a type of biofeedback that purportedly teaches users how to self-regulate their brainwaves.¹ Although neurofeedback is currently offered by thousands of providers worldwide,² its provision is contested, as its effectiveness beyond a placebo effect is unproven.^{1,3} Scholars have expressed concerns that exaggerated marketing claims by providers³ could mislead consumers regarding the potential of such services and result in opportunity cost from foregoing standard-of-care treatments.⁴ To-date, however, concerns regarding the risk-benefit trade-offs have largely remained theoretical, as there is a lack of data regarding the characteristics of users and their views on these services.

Objective

The present study aimed to empirically examine the demographic characteristics, experiences, and attitudes of those who use neurofeedback services and/or purchase neurofeedback devices for home use.

Methods

Neurofeedback users were recruited via social media (Facebook and Twitter) and snowball sampling between August 2020 and February 2021.

Upon completing an eligibility questionnaire, individuals were invited to participate in a 30-minute semi-structured telephone interview.

Eligibility criteria:

- 1) Used neurofeedback services at least once, for themselves or for a child
 - 2) Over the age of 18
 - 3) Capable of providing consent
- Neurofeedback providers were excluded from participating in the study.

Participants were offered a \$20 Amazon e-gift card as compensation for completing the interview.

All interviews were transcribed and analyzed thematically by two coders according to the principles of grounded theory.⁵

The interview guide was informed by a scoping review of relevant literature and included open- and closed-ended questions, drawing on both qualitative and quantitative methodologies.

Results

Demographic Characteristics & purpose of use

A total of 36 subjects were recruited. Most respondents were white, female and living in the U.S. The majority of participants were highly educated, and 81% of subjects reported earning over \$50k as an annual household income. The top four indications among adults participating in our study were anxiety (51.5%), post-traumatic stress disorder (24.2%), attention deficit hyperactivity disorder (24.2%), and depression (12.1%).

Demographic Characteristics	Total N=36 (%)
Gender, n (%)	
Male	8 (22.2)
Female	27 (75.0)
Non-binary	1 (2.8)
Age (mean years ± SD)	44.9 ± 11.5
Race/Ethnicity, n (%)	
White	33 (91.7)
Other	3 (8.3)
Education, n (%)	
High school or less	1 (2.8)
Some college	9 (25.0)
Associate's degree	2 (5.6)
Bachelor's degree	8 (22.2)
Master's degree	11 (30.6)
Professional or doctoral degree	5 (13.9)
Household Income, n (%)	
Less than \$50,000	6 (16.7)
\$50,000-100,000	13 (36.1)
\$100,000-\$150,000	8 (22.2)
\$150,000+	8 (22.2)
Country of Residence, n (%)	
United States	31 (86.1)
Other	5 (13.9)

Perceived Unwanted Effects

The majority of respondents reported experiencing various (mostly minor) unwanted effects:

Unwanted Effects	N=31* (%)	Examples
Physical Unwanted Effects	20 (60.6%)	Headaches, nausea, tics, vertigo
Emotional & Interpersonal Unwanted Effects	11 (33.3%)	Irritability, feeling re-traumatized, feeling stressed

*Number of respondents who used neurofeedback for themselves

Perceived Benefits

Most participants (81.8%) reported being overall satisfied with the therapy.

Participants reported experiencing a wide range of perceived benefits:

Benefits	N=31* (%)	Examples
Symptom Improvement	25 (75.8%)	Improved focus, reduced stress, feeling less depressed
Emotional & Interpersonal Benefits	24 (72.7%)	Feeling more in touch with themselves and others
Performance Improvement	7 (21.2%)	Memory improvement

*Number of respondents who used neurofeedback for themselves

Opportunity Cost

Most (87.9%) stated that they considered other treatments or therapies before starting neurofeedback (e.g., medication, cognitive behavior therapy and complementary and alternative medicine). Of those, 89.7% reported actually using these therapies before trying neurofeedback. Most (53.8%) of those participants considered the therapies to be effective, and 57.7% of them reported that they are still using them in parallel with neurofeedback. Common reasons for stopping the use of other therapies were perceived lack of effectiveness (26.9%), side effects (11.5%) and high cost (3.8%).

Informed Consent

The majority of participants (58.1%) who had contact with a neurofeedback provider reported having a discussion about both risks and benefits of neurofeedback before starting the treatments. However, 19.4% reported that their provider only talked about the benefits of neurofeedback and 16.1% did not remember having a discussion with their provider before the beginning of their sessions.

Most (71.4%) participants remembered signing an informed consent form, but of those, 80% stated that they cannot recall what was in that form.

The majority (61.1%) considered neurofeedback to be a scientifically well-established therapy. However, of those, 77.3% were using neurofeedback for indications not supported by scientific evidence.

Discussion

This is the first empirical study evaluating the characteristics and experiences of neurofeedback users. Most respondents reported several benefits, but also unwanted effects, which in most cases were deemed to be minor. However, considering that most participants suffered from complex conditions, and many reported using other therapeutic options in conjunction with neurofeedback, it is not possible to determine to what extent these effects (both positive and negative) can be attributed to neurofeedback.

Given that the vast majority of participants considered—and in most cases tried—other treatments before resorting to neurofeedback, our findings do not support theoretical concerns regarding opportunity cost.

The high overall satisfaction with neurofeedback indicates that most participants may consider the benefits of treatment to outweighed the risks. At the same time however, a substantial number of participants did not have or did not remember having a discussion with their provider about potential risks of neurofeedback. Furthermore, most respondents overestimated the scientific evidence supporting neurofeedback. This indicates that there needs to be clearer communication from neurofeedback providers about the limitations of the therapy.

There is a need for further empirical research in this field, including representative quantitative studies, in order to better understand how the insights gained from this research apply to the general population of neurofeedback users.

References

1. Marzbani, H., Marateb, H. R. & Mansourian, M. Neurofeedback: A Comprehensive Review on System Design, Methodology and Clinical Applications. *Basic Clin Neurosci* 7, 143–158 (2016).
2. ISNR. In Defense of Neurofeedback. *ISNR* <https://isnr.org/in-defense-of-neurofeedback> (2017).
3. Thibault, R. T. & Raz, A. The psychology of neurofeedback: Clinical intervention even if applied placebo. *American Psychologist* 72, 679–688 (2017).
4. Nagappan, A., Kalokairinou, L. & Wexler, A. Ethical and Legal Considerations of Alternative Neurotherapies. *American Journal of Bioethics-Neuroscience* (2021).
5. Tie, Y. C., Birks, M. & Francis, K. Grounded theory research: A design framework for novice researchers. *Sage Open Medicine* 7, 2050312118822927 (2019).

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