RESEARCH

Qualitative studies involving users of clinical neurotechnology: a scoping review

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Abstract

Background The rise of a new generation of intelligent neuroprostheses, brain-computer interfaces (BCI) and adaptive closed-loop brain stimulation devices hastens the clinical deployment of neurotechnologies to treat neurological and neuropsychiatric disorders. However, it remains unclear how these nascent technologies may impact the subjective experience of their users. To inform this debate, it is crucial to have a solid understanding how more established current technologies already affect their users. In recent years, researchers have used qualitative research methods to explore the subjective experience of individuals who become users of clinical neurotechnology. Yet, a synthesis of these more recent findings focusing on qualitative methods is still lacking.

Methods To address this gap in the literature, we systematically searched five databases for original research articles that investigated subjective experiences of persons using or receiving neuroprosthetics, BCIs or neuromodulation with gualitative interviews and raised normative guestions.

Results 36 research articles were included and analysed using gualitative content analysis. Our findings synthesise the current scientific literature and reveal a pronounced focus on usability and other technical aspects of user experience. In parallel, they highlight a relative neglect of considerations regarding agency, self-perception, personal identity and subjective experience.

Conclusions Our synthesis of the existing qualitative literature on clinical neurotechnology highlights the need to expand the current methodological focus as to investigate also non-technical aspects of user experience. Given the critical role considerations of agency, self-perception and personal identity play in assessing the ethical and legal significance of these technologies, our findings reveal a critical gap in the existing literature. This review provides a comprehensive synthesis of the current qualitative research landscape on neurotechnology and the limitations thereof. These findings can inform researchers on how to study the subjective experience of neurotechnology users more holistically and build patient-centred neurotechnology.

Keywords Neurotechnology, Qualitative research, Subjective experience, Self-perception, Patient-centred technology, Ethics

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Introduction

Due to a rapid expansion in public-private investment, market size and availability of Artificial Intelligence (AI) tools for functional optimization, the clinical advancement of novel neurotechnologies is accelerating its pace [1]. Bidirectional intelligent Brain-Computer interfaces (BCI) that aim at merging both read-out and write-in devices are in active development and are expanding in functional capabilities and commercial availability. [2, 3]. Such BCIs that can decode and modulate neural activity through direct stimulation of brain tissue, promise additional avenues in the treatment of neurological diseases by adapting to the particularities of individual users' brain. Potential applications are Parkinson's disease [4] or epilepsy [5] as well as psychiatric disorders, such as major depressive disorder [6] or obsessive compulsive disorder [7]. Driven by these advances and in conjunction with progress in deep learning and generative AI software as well as higher-bandwidth hardware, clinical neurotechnology is likely to take an increasingly central role in the prevention, diagnosis and treatment of neuropsychiatric disorders.

In line with these scientific trends, the last decade has seen a consequent fast rise in the ethical attention devoted to neurotechnological systems that establish a direct connection with the human central nervous system [8], including neurostimulation devices. Yet, at times, neuroethical concerns may have outpaced real-life possibilities, particularly with view to the impact of neurotechnology on personality, identity, autonomy, authenticity, agency or self (PIAAAS) [9]. This points to the need for basing ethical assessments and personal decisions about deploying devices on solid empirical grounds. In particular, it is crucial to gain a comprehensive understanding of the lived experience of using neurotechnologies from the epistemically privileged first-person perspective of users "what it is like" to use neurotechnologies. Its examination by empirical studies have added a vital contribution to the literature [10].

Yet, few reviews have attempted to synthesize the growing body of empirical studies on user experience with clinical neurotechnology. Burwell et al. [11] reviewed literature from biomedical ethics on BCIs up to 2016, identifying key ethical, legal and societal challenges, yet noting a lack of concrete ethical recommendations for implementation. Worries about a lack of attention to ethics in BCI studies have been further corroborated by two reviews by Specker Sullivan and Illes, reviewing BCI research published up until 2015. They critically assessed the rationales of BCI research studies [12] and found a remarkable absence of ethical language in published BCI research [13]. Taking a different focus, Kögel et al. [14] have provided a scoping review summarizing empirical studies investigating ethics of BCIs

until 2017, with a strong focus on quantitative methods in the reviewed papers. Most recently, this list of reviews has been complemented by van Velthoven et al. [15], who review empirical and conceptual ethical literature on the use of visual neuroprostheses.

To the best of our knowledge, a specific review of qualitative research on the ethics of emerging neurotechnologies such as neuroprosthetics, BCIs and neuromodulation systems is outstanding. We believe that qualitative research involving actual or prospective neurotechnology users is particularly significant as it allows researchers to tap into the richness of first-person experiences as compared to standardized questionnaires without the option of free report. In the following, we synthesize published research on the subjective experience of using clinical neurotechnologies to enrich the ethical debate and provide guidance to developers and regulators.

Methods

On January 13, 2022 we conducted a search of relevant scientific literature across 5 databases, namely Pubmed (89 results), Scopus (178 results), Web of Science (79 results), PsycInfo (134 results) and IEEE Xplore (4 results). The search was performed for title, abstract and keywords, using a search string to identify articles employing qualitative methods that engaged with users of neurotechnology, and covered normative issues: ["qualitative" OR "interview" OR "focus group" OR "ethnography" OR "grounded theory" OR "discourse analysis" OR "interpretative phenomenological analysis" OR "thematic analysis"] AND ["user" OR "patient" OR "people" OR "person" OR "participant" OR "subject"] AND ["Brain-Computer" OR "BCI" OR "Brain-Machine" OR "neurostimulation" OR "neuromodulation" OR "TMS" OR "transcranial" OR "neuroprosthetic*" OR "neuroprosthesis" OR "DBS"] AND ["ethic*" OR "bioethic*" OR "normative" OR "value" OR "evaluation"].

Across databases, search syntax was adapted to reflect the respective logic of each library. Our search yielded a total of 484 articles. Of these, 133 duplicates were removed. 52 further results were marked as ineligible by automation tools, due to either not being written in English or not representing original research in a peerreviewed journal. The remaining 299 were screened manually, with screening tasks being shared equally among the authors GS, TBA, AC, MV, CB, JC, and MI. Articles were included if they were written in English, published in a peer-reviewed journal, and reported original research of empirical qualitative findings among human users of a neurotechnological system that establishes a direct connection with the human central nervous system (including neurostimulation devices). Other types of articles such as perspectives, letters to the editor, or review articles were not included. Potential methods

included individual interviews, focus groups, stakeholder consultations but excluded studies that did not use any direct verbal input from the users. Each abstract was screened individually by two reviewers. Unclear cases were resolved by discussion among reviewers. This process resulted in the exclusion of 247 articles, leaving 52 publications for inclusion into the final synthesis.

Full texts of these 52 articles were retrieved and assessed for eligibility. Again, this task was shared equally across the 7 authors who made independent recommendations whether an article was included for further analysis, and disagreement was resolved by discussion. 20 articles were excluded at this stage, due to not meeting the inclusion criteria. This resulted in a body of 32 articles plus 4 additional papers identified through citation chaining, as customary in scoping reviews.

In the data analysis phase, we compiled a descriptive summary of the findings and conducted a thematic analysis. When compiling the descriptive summary, we followed the recommendations by Arksey and O'Malley [16] and included comprehensive information beyond authors, year, and title of the study, extracting also study location, methodology, study population, type of neurotechnology, and more. For the thematic analysis, the full text was read and coded by the authors through annotations in pdf files, with papers evenly distributed among the group. Coding was based on a previously agreed coding structure of four thematic families, covering (1) subjective experience with BCIs, (2) aspects concerning usability and technology, (3) ethical questions, (4) impact on social relations, and a fifth miscellaneous category for future resolution. In accordance with the suggestions by Braun and Clarke [17], codes that were not clearly covered by the coding tree were grouped into a category "miscellaneous", and after discussion used to develop new themes or subsumed under the existing thematic families. The results were compiled and unified by the first author and imported into the Atlas.ti software (version 22.2), with adaptations to the coding tree being discussed between first and last author.

In line with the framework suggested by Pham, Rajić [18], we adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) in conducting and presenting our results [19]. A flow diagram representing the entire process is depicted in Fig. 1.

Results

Descriptive findings

Our study included 36 papers reporting original qualitative research among users of BCIs, neuroprosthetics and neuromodulation. We found a pronounced increase in the number of publications employing qualitative methods in the investigation of such neurotechnology users over time, with the earliest study dating back to 2012. However, contrary to what one may expect as reflection of the growing number of neurotechnology users, we did not find an increase in the average sample size of participants enrolled in qualitative studies nor a correlation between year of publication and number of participants (see Fig. 2).

The included studies were exclusively conducted in Western countries, with 11 studies from the US, 9 from Australia and the remaining 16 distributed across Europe (UK: 6, Germany: 4, Sweden, Netherlands and Switzerland 2 each). The majority of studies investigated the effects of invasive neurotechnology in the form of Deep Brain Stimulators (DBS) (26/36), especially in patients with Parkinson's Disease (PD) (19/36). Many papers also investigated users' experiences with non-invasive EEGbased BCIs (7/36), whereas all other technologies such as TMS, ECT, FES, intracortical microelectrode arrays, or spinal cord stimulation were only covered by one or two papers each.¹ Due to the large focus on PD patients, other potential fields for clinical neurotechnological applications were much less present in the analysed research, with only 4 papers each investigating the effects of DBS on patients with major depressive disorder (4/36) or obsessive-compulsive disorder (OCD) (4/36). Across all technologies and patient groups, studies most frequently relied on semi-structured interviews with individual participants (28/36), with much fewer studies using focus groups (3/36) or other qualitative methods.

We found that a large number of papers (14/36) incorporated longitudinal aspects in their study design. With view to non-invasive BCIs, this comprised involving users in the development and testing of BCIs for acquired brain injury [20, 21], assessing subjective reports across sessions for experimental BCI training [22], or having a 2-month follow-up interview for users of a BCI for pain management after spinal cord injury [23]. Studies of invasive devices often included interviews pre- and postimplantation, with a potential third follow-up. In studies with two interviews, the first interview after implantation took place a few weeks after implantation [24, 25], after 3 months [26], after 9 months [27, 28] or after a year [29]. In studies with 3 interviews, post-implantation interviews were either conducted after surgery and again after 3 months in a study on spinal cord stimulation [30] or, in the case of DBS for PD, after 3 and 6 months [31, 32] or after 3–6 and 9–12 months respectively [33]. Table 1 provides a full overview over the included studies.

¹ As many publications included patients with different diagnoses or investigated the effects of different neurotechnologies, the numbers indicated here do not add up.



Fig. 1 PRISMA flow diagram: search and screening strategy. Based on Page et al [19]



Number of participants and publications

Fig. 2 Average number of participants and number of publications over time

Thematic findings

Our findings from the thematic analysis can be grouped into four overlapping thematic families, namely (1) ethical challenges of neurotechnology use, (2) subjective experience with clinical neurotechnologies, (3) impact on social relations, and (4) usability and technological aspects. The raw data of our findings are accessible in the supplementary file.

Ethical concerns

With respect to users' experiences of neurotechnology that touch on classical ethical topics, we found that autonomy played a central role in slightly more than half of all papers (20/36), yet in four different ways. Many papers noted the positive impact neurotechnology has on users' autonomy. Users often perceive the technology as enabler of greater control over their own life, allowing

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|-------|--|---|---------------------------------|----|--|---------|--|--|-----|
| Year | Authors | Title | Patient group | 2 | Method | Country | Neurotechnology | Quality measure | ≥ Z |
| 2012 | Blain- Moraes et al. | Barriers to and mediators of brain-computer interface user acceptance: Focus group findings | ALS | œ | Focus group | N | EEG-based BCI | 1 | z |
| 2012 | Mulvenna et al. | Realistic expectations with brain computer interfaces | Acquired brain injury | 1 | Interviews | Х | EEG-based BCI | | Z |
| 2013 | Maier et al. | Patients' expectations of deep brain stimulation, and subjective perceived outcome related to clinical measures in Parkinson's disease: a mixed-method approach | Q | 30 | Semi-structured interview | Ω | DBS | I | _ |
| 2014 | Grubler et al. | Psychosocial and Ethical Aspects in Non-Invasive EEG-Based BCI Research-A Survey Among BCI Users and BCI Professionals | Stroke | 6 | Semi-structured interview | D/CH | EEG-based BCI | two coding done & checked by two researchers | Z |
| 2014 | Hariz, G., & Hamberg, K. | Perceptions of living with a device-based treatment: An account of patients treated with deep brain stimulation for parkinson's disease | Q | 39 | Semi-structured interview | SE | DBS | No COREQ but rigorous description of grounded theory approach | _ |
| 2015 | de Haan et al. | Effects of deep brain stimulation on the lived experience of obsessive-compulsive disorder patients: In-depth interviews with 18 patients | OCD | 20 | Semi-structured interview | NL | DBS | COREQ | _ |
| 2015 | Lewis et al. | Subjectively perceived personality and mood changes associated with subtha- lamic stimulation in patients with Parkinson's disease | DD | 27 | Semi-structured interview | | DBS | I | _ |
| 2016 | Hariz, G.M., Limousin, P, & Hamberg, K. | "DBS means everything-For some time". Patients' perspectives on daily life with deep brain stimulation for Parkinson's disease | Q | 42 | Semi-structured interview | SE | DBS | No COREQ but rigorous description of grounded theory approach | _ |
| 2016 | Klein et al. | Brain-computer interface-based control of closed-loop brain stimulation: at- titudes and ethical considerations | OCD / Depression | 15 | Focus group (8), semi-structured interview (7) | N | DBS | . 1 | _ |
| 2016 | Maier et al. | Subjective perceived outcome of subthalamic deep brain stimulation in Parkin- son's disease one year after surgery | PD | 28 | Semi-structured interview | | DBS | I | _ |
| 2017 | de Haan et al. | Becoming more oneself? Changes in personality following DBS treatment for psychiatric disorders: Experiences of OCD patients and general considerations | OCD | 18 | Semi-structured interview | NL | DBS | I | _ |
| 2017 | Kryger et al. | Flight simulation using a Brain-Computer Interface: A pilot, pilot study | Spinocerebellar degeneration | - | Participant's description of experience during experiment | N | invasive BCI (intra- cortical microelec- trode arrays) | I | _ |

| continued) | |
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| Table 1 | |

| Year Authors 2017 LaHue et a 2017 Gilbert et a | Titlo | | | | | | | |
|--|---|---|----|---|---------|--|---|-----|
| 2017 LaHue et a 2017 Gilbert et a | 95 2 | Patient group | 2 | Method | Country | Neurotechnology | Quality measure | ≥ Z |
| 2017 Gilbert et a | . Parkinson's disease patient preference and experience with various methods of DBS lead placement | DA | 89 | Structured interview | US | DBS | 1 | _ |
| | l. I Miss Being Me: Phenomenological Effects of Deep Brain Stimulation | D | 17 | Semi-structured interview | AUS | DBS | I | _ |
| 2018 Bosanac et al. | Identity challenges and 'burden of normality' after DBS for severe OCD: a narrative case study | OCD | - | Narrative analysis | AUS | DBS | COREQ | _ |
| 2018 Gilbert, F., 8 Viaña, J. N. | A Personal Narrative on Living and Dealing with Psychiatric Symptoms after DBS Surgery | D | - | Personal narrative | AUS | DBS | I | _ |
| 2018 Kubu et al. | Patients' shifting goals for deep brain stimulation and informed consent | Q | 52 | Semi-structured interview | SU | DBS | No COREQ but rigorous description of grounded theory approach | _ |
| 2018 Martin et a | A qualitative study adopting a user-centered approach to design and validate a brain computer interface for cognitive rehabilitation for people with brain injury | Traumatic brain injury | Ś | Oral feedback at the end of experiment | ЛК | EEG-based BCI | | Z |
| 2019 Al-Taleb et al. | Home used, patient self-managed, brain-computer interface for the management of central neuropathic pain post spinal cord injury: Usability study | Central neu- ropathic pain in people with spinal cord injury. | 15 | Semi-structured interview | Х | EEG-based neurofeedback | 1 | Z |
| 2019 Gilbert et a | Embodiment and Estrangement: Results from a First-in-Human "Intelligent BCI" Trial | Epilepsy | 9 | Semi-structured interview | AUS | Intelligent implant- able BCI (predictive & advisory function); intracranial elec- trodes on cortical surface | I | _ |
| 2019 Liddle et a | . Impact of deep brain stimulation on people with Parkinson's disease: A mixed methods feasibility study exploring lifespace and community outcomes | Q | 00 | Semi-structured interview | AUS | DBS | No COREQ but mixed methods qual- ity checks such as triangulation or following themes from one data type to the | _ |

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| Year | Authors | Title | Patient group | 2 | Method | Country | Neurotechnology | Quality measure | <u> </u> |
| 2019 | Liddle et al. | Mapping the experiences and needs of deep brain stimulation for people with Parkinson's disease and their family members | Qd | 4 | Semi-structured nterview | AUS | DBS | No Coreq but lengthy description of coding process | _ |
| 2019 | Ryan et al. | An Exploration of the Experiences and Educational Needs of Patients With Failed Back Surgery Syndrome Receiving Spinal Cord Stimulation | Failed back sur- | 12 | Semi-structured nterview | Х | Spinal Cord Stimulation | - 1 | _ |
| 2019 | Shahmoon, S.; Smith, J. A.; Jahan- shahi, M. | The Lived Experiences of Deep Brain Stimulation in Parkinson's Disease: An Inter- pretative Phenomenological Analysis | Q | 10 | Semi-structured nterview | Х | DBS | | _ |
| 2020 | Cabrera, L. Y; Kelly- Blake, K; Sidiropou- los, C. | Perspectives on Deep Brain Stimulation and Its Earlier Use for Parkinson's Disease: A Qualitative Study of US Patients | Q | 20 i | (semi-)structured nterview | SU | DBS | I | _ |
| 2020 | Kögel, J.; Jox, R. J.; Friedrich, O. | What is it like to use a BCI? - insights from an interview study with brain-computer interface users | different muscular conditions | о О | Semi-structured nterview | ۵ | invasive & non-inva- sive (EEG-based) BCIs (active or reactive; no passive such as DBS) | Compre- hensive description of grounded theory approach | Z∞_ |
| 2020 | Thomson et al. | "He's back so I'm not alone": The impact of deep brain stimulation on personality, self, and relationships in Parkinson's disease | Dd | = | Semi-structured nterview | AUS | DBS | crosscoding; no COREQ | _ |
| 2021 | Chacón Gámez, Y. M.; Brugger, F.; Biller- Andorno, N. | Parkinson's Disease and Deep Brain Stimulation Have an Impact on My Life: A Multimodal Study on the Experiences of Patients and Family Caregivers | Q | 44 2011 | Semi-structured nterview | G | DBS | report on researchers' reflexivity; double-cod- ing; coding tree checked with further team members | _ |
| 2021 | Merner et al. | Changes in Patients' Desired Control of Their Deep Brain Stimulation and Subjec- tive Global Control Over the Course of Deep Brain Stimulation | DA | 52 | Semi-structured nterview | US | DBS | I | _ |
| 2021 | Mosley et al. | 'Woe Betides Anybody Who Tries to Turn me Down'. A Qualitative Analysis of Neuropsychiatric Symptoms Following Subthalamic Deep Brain Stimulation for Parkinson's Disease | CL | 0 | Semi-structured nterview | AUS | DBS | COREQ | _ |
| 2021 | Bluhm et al. | They Affect the Person, but for Better or Worse? Perceptions of Electroceutical Interventions for Depression Among Psychiatrists. Patients, and the Public | Depression | 48 | Semi-structured nterview | US | ECT; TMS; DBS | I | ∞ z |

| Tabl | e 1 (continu | ed) | | | | | | | |
|------|---|---|-------------------------------------|-------------|-----------------------------|---------|--|--|------------|
| Year | Authors | Title | atient group <i>n</i> | - | Method | Country | Neurotechnology C | Quality neasure | ⊳ z |
| 2021 | Sankary et al. | Exit from Brain Device Research: A Modified Grounded Theory Study of Researcher Obligations and Participant Experiences | troke, Depres- 1 ion, Epilepsy | 9 | semi-structured nterview | SU | Investigational brain implants (DBS, responsive neurostimulation) | Discussion of data saturation (Corbin & Strauss) | _ |
| 2021 | Thomson et al. | "Nothing to Lose, Absolutely Everything to Gain": Patient and Caregiver Expecta- tions and Subjective Outcomes of Deep Brain Stimulation for Treatment-Resistant Depression | Jepression 6 | | iemi-structured nterview | AUS | DBS | COREQ | _ |
| 2021 | Zulauf-Czaja et al. | On the way home: a BCI-FES hand therapy self-managed by sub-acute SCI partici- pants and their caregivers: a usability study | pinal ord injury tetraplegic) | ш. <u> </u> | ocus group & nterview | NK | EEG & functional electrical stimulation | I | Z |
| 2021 | Wexler et al. | Ethical Issues in Intraoperative Neuroscience Research: Assessing Subjects' Recall of Informed Consent and Motivations for Participation | D 2 | 22 | iemi-structured nterview | US | DBS | T | _ |
| 2021 | Goering, S., Wexler, A. and Klein, E. | Trading Vulnerabilities: Living with Parkinson's Disease before and after Deep Brain Stimulation | 2 م | 22 i | iemi-structured nterview | US | DBS | 1 | - |

them "to become who they wanted to be" [2], providing them with agency and greater independence, restoring their ability to help others, or allowing them to be more spontaneous in their everyday life [2, 10, 28, 31, 32, 34-37]. Some studies reported how neurotechnology may impact users' autonomy negatively, especially by making them more dependent on technological and medical support [25, 28, 35, 38, 39]. When balancing these positive and negative impacts, some users seem to prefer such dependency and to leave control over the devices to healthcare professionals, to ensure its safe and appropriate working [2, 32, 39, 40]. Also related to autonomy were concerns about consent, especially with a view to the level of information patients received before the implantation of an invasive device, which was deemed inadequate by some patients [2, 24, 31, 34, 38-46]. Several papers called to include patients during the technology design process [2, 31, 39]. In addition, questions of responsibility and accountability in case of malfunctioning were repeatedly named as key concern [10, 25, 37, 38, 45, 47].

Concerns about beneficence and about harming patients also featured prominently in most of the analysed papers (24/36), yet with substantive differences on a more granular level. While symptom improvement and restorative changes were widely reported [2, 10, 23, 26, 29, 31, 33-35, 38-40, 43, 44, 46], some users reported experiencing physical or psychological side effects, such as postoperative complications, new worries - for instance about magnetic fields or about changing batteries -, stigma, or becoming more aware of their past suffering [23, 25, 26, 28, 34-40, 42, 46, 48, 49]. Less frequently we found concerns about patient-doctor-relationships [2, 24, 32, 40, 42, 43], which seem to mediate the acceptance of clinical neurotechnologies but are also themselves impacted by technology use. For instance, while some research points to the importance of patients' trust in healthcare professionals for the acceptance of neurotechnology [24], a personal narrative described a breakdown of patient-physician relationship following a distressful DBS implantation for treating PD [42].

Impact on subjective experiences

Since the subjective lived experiences of neurotechnology users commonly constituted the central element of the reviewed qualitative papers, we found a rich field of reports in the vast majority of paper (31/36), describing experiences that were perceived as positive, negative or neutral. Neurotechnology-induced behavioural changes [28, 36, 37, 40, 42, 46, 47, 49], as well as changes in feelings [27, 41, 42], (self-) perception [10, 23, 34, 36, 40–42, 44, 48, 50], personality [27, 29, 34–37, 42–44, 47, 49], preferences [49, 50] or thinking [10, 41] were also reported, particularly in users receiving continuous, nonadaptive deep brain stimulation (DBS).

Behavioural changes often concerned desired outcomes such as fewer obsessive thoughts and compulsive behaviours after successful OCD treatment [49], acting with less impediment due to seizure predictions [36], or acting more boldly with more energy and increased confidence due to symptom improvement in PD [37, 47]. Nevertheless, it was necessary for patients and for their environment to adapt and get used to new patterns of behaviour. Some patients also reported undesirable behavioural changes after subthalamic DBS implantation, "bordering on mania" [42], such as being excessively talkative [46] or shopping compulsions that were later described by the patient as "ridiculous" [28].

These outwardly observable changes were often related to psychological changes that users reported. Some DBS users experienced mood changes, ranging from elevated to depressed [27, 41, 42, 44], while others reported changed preferences. Sometimes this affected what users valued as important in life [50], sometimes it related to very particular preferences, such as taste in music, with one patient attributing a transition from The Rolling Stones and The Beatles to Johnny Cash to their DBS implantation [49]. In patients treated for OCD or motor disorders, two studies also found positive impact on users' thinking, whether by freeing them from obsessive thoughts [41] or improving their concentration skill [10]. In line with the large neuroethical debate on the subject, changes at times amounted to what neurotechnology users described as personality changes. Such changes included negative impacts such as being more irritable, anxious or less patient [34, 35] or overly increased libido [49], neutral changes, such as (re-)taking an interest in politics or movies [49], and positive changes linked to improvement of psychiatric symptoms, such as being more easy-going and daring, being more expressive and assertive, or simply being more confident [35, 49].

In line with the diversity of these changes, patients reported a vast spectrum of different attitudes towards and relations with the neurotechnology. Some users embraced the BCI explicitly as part of themselves [14, 37, 39, 49] and described how "DBS becomes a part of who you are rather than changing you" [37]. Others felt estranged using the BCI [28, 36, 37, 42, 49] and even expressed desires to remove the alien device in forceful terms: "I hate it! I wish I could pull it out!" [37]. Aside from changes brought about by the device, the patients' state before using neurotechnology and especially their relation to their illness seemed to play a crucial role [28, 51]. An overview over the different thematic findings is provided in Fig. 3.

The overwhelming majority of studies (23/36) reported improvements of the treated symptoms [2, 26, 28, 31, 33–35, 37, 40–43, 46–50, 52], making patients' lives easier [48, 49] or – as some put it – even saving their lives [34, 45, 48]. Patients felt that the neurotechnology allowed them an increase in activity [33, 34, 40] and a return to previous forms of behaviour [33, 40, 48, 49], strengthening their sense of freedom and independence [2, 10, 22, 33–36, 40, 43, 49, 50, 53]. Emotionally, users reported feeling more daring [29, 35], self-confident [28, 35–37, 44] or more stable [34, 50] as well as feelings of hope or joy [10, 22, 35, 50]. For better or worse, such changes were sometimes perceived as providing a "new start" [34, 48] or even a "new identity" [34, 41, 42, 49], while others perceived their changes as a reversion to their "former" [28, 29, 47, 49, 50] or their "real" self [36, 42, 49].

Among the negative subjective impacts of clinical neurotechnology mentioned in the literature (16/36), users commonly reported issues of estrangement, caused by self-perceived changes to behaviour, feelings, personality traits, or patients' relation to their disease or disorder [28, 36, 37, 42, 49]. The negative impact differed largely depending on the type of neurotechnology used as well as on the disorders and symptoms treated with the technology. While ALS patients as users of non-invasive BCIs for spelling interfaces reported increased anxiety in interaction with the devices [53], PD patients with invasive DBS reported presurgical fears of pain and of the invasive procedure as well as fear of outward manipulation within their brain through the DBS implantation [40, 43, 54]. Frequently, it was not entirely clear whether adverse developments such as further cognitive decline were attributable to the implanted device or to the persisting disease and its natural trajectory [31, 33, 34, 40, 43, 48, 50]. However, occasionally very severe psychiatric consequences of treatment were reported, notably by one PD patient who experienced mania and depressive symptoms through DBS treatment, resulting in a suicide attempt [42]. For DBS patients with OCD, negative impacts seem more related to difficulties of adapting to the new situation [35, 49], for instance to their suddenly increased libido as a side-effect of DBS use that may be perceived as "too much" [49], or to a perceived lack of preparation for their new (OCD-free) identity [41]. In two studies on patients with OCD, the sudden improvement of symptoms also led to moments of existential crisis, given that the symptoms had shaped a great part of their previous daily activities [41, 49].

Impact on social relations

Using a neurotechnology not only impacts users but can also affect social relations with others (23/36), particularly primary caregivers. While some neurotechnologies such as non-invasive BCIs for communication may create additional workload for caregivers if the BCI needs to be



Fig. 3 Impact of clinical neurotechnology on subjective experience. The colours represent the valence of the impact, with orange dots representing negative, green dots representing positive, and blue dots representing ambivalent changes

set up, neurotechnologies can also reduce their burden by rendering patients more independent [10, 34, 40, 53]. Beyond workload, neurotechnologies were also reported to enrich social relations by facilitating communication [10, 34, 53], though in some cases, they led to potential tension between informal caregivers and patients, e.g. due to personality changes [28, 35, 37, 40, 42, 47, 49, 55] or if the device was blamed for a patient's behaviour or suggested as a solution to interpersonal problems [2]. Whether positive or negative, family and social support were reportedly playing a vital role in the treatment [2, 28, 40, 50].

Similarly important was support by clinicians [39, 40] and the wish for support groups with fellow neurotechnology users [27, 30, 40, 41]. Inclusion in research activities was also reported as a positive effect of (experimental) BCIs [10, 38]. More importantly though, in a large number of studies, neurotechnology users reported positive effects on their social relations [2, 29, 35, 43, 46, 48, 50], with some users reporting an increased wish to help others [35, 50]. A negative social consequence in public was perceived stigma [25, 35, 48], even though some patients chose to actively show their device in

public, "to spread information and knowledge about this treatment" [39].

Usability concerns

Concerns with technical questions and usability issues comprising efficiency, effectiveness and satisfaction [52] were also raised by almost half of the research papers (17/36), yet differed greatly between neurotechnologies, owing to large differences in hardware (e.g., between EEG caps and implanted electrodes) and handling (e.g., between passive neurostimulation or training-intensive active BCIs). Across all applications, invasive as much as non-invasive, the most frequent concerns (8/36 each) related to hardware issues [2, 22, 23, 38, 39, 46, 52, 53] as well as to the required fine-tuning of devices to find optimal settings, associated with time-burden for their users [20, 23, 27, 32, 39, 46, 50, 56]. Similarly, the training of patients required for the successful use of non-invasive, active BCIs was reported as being perceived as cumbersome or complicated, providing a potential obstacle to their implementation in everyday contexts [38, 52]. Several studies reported that the use of such active BCIs required considerable concentration, leading to fatigue after prolonged use [10, 38, 53]. Mediating factors to address such obstacles were the availability of technical support [33, 53], general attitudes towards technology [53], ease of integrating the technology into everyday life [10, 38, 53] and realistic expectations regarding the neurotechnology's effects [30, 38, 40, 46].

Discussion

The identified publications highlight that qualitative research through interviews and focus groups offers a useful way to gain access to the subjective experience of users of a diverse range of neurotechnologies. Such investigation of users' privileged knowledge about novel devices in turn is crucial to improve future neurotechnological developments and align them with ethical considerations already at an early stage [57]. Here, we discuss our findings by comparing different clinical neurotechnologies, identify gaps in the literature and point to the limitations of our scoping review.

One finding of our scoping review is that qualitative research on neurotechnologies has so far primarily focused on users of DBS treated for PD. In part, this may reflect that DBS is an established, effective treatment for controlling motor symptoms in PD, improving patients' quality of life, resulting in its wide-spread adoption in many different healthcare systems worldwide [58–61]. Still, it would be highly beneficial to extend qualitative research to different patient groups and other clinical neurotechnologies that directly target mental states or processes, where more pronounced effects of subjective experiences may be expected. A potential obstacle to involving more neurotechnology users beyond PD patients treated with DBS is that, for many other technologies, users are still likely to receive their treatment as part of an experimental trial. Qualitative research with such patients may face the additional practical barrier of convincing the other researchers to facilitate access to their patients. Better communication across disciplines and research fields may facilitate such access, providing much-needed insights into user experiences of experimental neurotechnologies.

Some of the articles reviewed here already offer such perspectives, e.g. the ones investigating DBS used for major depressive disorder or OCD. Such research may also help to further clarify which differences in subjective outcome are owed to technology and which are owed to differences in the treated disorders. As different patient groups are likely to have different needs and views, further research is needed to explore those needs and views and develop implementation strategies designed to address them in a patient-tailored manner. Furthermore, different neurotechnologies (and applications thereof) are likely to impact the mind of their users in a different way. Therefore, future research should investigate whether the type and modality of stimulation exert differential impacts on the subjective experience of the end users.

Our findings reveal differential effects among patients using DBS for the treatment of PD and patients using DBS for the treatment of OCD, respectively. For example, some reported effects of invasive neurotechnology such as the induction of more assertive behaviour may be a reason for concern in PD [28], while being considered a successful treatment outcome in OCD [35, 49]. More comparative research among DBS users treated for OCD or other neuropsychiatric disorders, such as depression, are needed [62] and may help to better understand which experiences are directly attributable to the stimulation of specific brain areas such as the subthalamic nucleus for PD and the nucleus accumbens for OCD, and which result from other factors, e.g., related to undergoing surgery or to different treatment settings in neurological and psychiatric care [63, 64].

Research on such differences may also imply practical consequences. For instance, one may wonder whether different preparation stages and possibly different degrees of information for obtaining consent may be called for between invasive clinical neurotechnologies used in psychiatry and neurology—or whether, on the contrary, similarities in the use of neurotechnologies ultimately point towards ending the distinction between mental and neurological illnesses [63]. In either case, our findings highlight that psychological impacts of clinical neurotechnologies are complex and multi-faceted phenomena—mediated by many factors—calling for more qualitative research to better grasp the lived experiences of those using novel neurotechnologies.

Our scoping review identified several gaps in the literature related to research methodology, investigated topics and investigated neurotechnologies. First, while a large number of studies embrace a longitudinal approach to investigating users' experiences, none of the included studies looked at impacts beyond a timeframe of one year. However, as is known from DBS studies in major depressive disorder, it is important to investigate and evaluate long-term effects of neurotechnologies such as DBS [6]. Future qualitative research should therefore address this gap. Connected to this are, second, research questions that have not yet been investigated in full, such as long-term impacts of clinical neurotechnologies on memory or belief continuity. Third, empirical findings on closed-loop neurotechnologies that integrate artificial intelligence are so far nascent [2, 36]. As there are important conceptual and ethical questions that arise specifically from the integration of human and artificial intelligence, e.g. questions of control and responsibility, further qualitative research should be conducted on users of such devices.

Finally, our findings reveal a complex and multifaceted landscape of ethical considerations. While considerations regarding personal autonomy appear largely prevalent among users, the perceived or expected impacts of neurotechnology use on personal autonomy differ significantly. Some studies suggest that neurotechnology use may enhance personal autonomy by allowing users to be more autonomous and independent in their daily lives and even restore part of the autonomous control that was disrupted by their disorders. Other studies suggest that some neurotechnologies, especially neural implants relying on autonomous components, may diminish autonomy as they may override some users' intentions. Sometimes this ambivalent effect is observed within the same study. This is consistent with previous theoretical reflections on this topic [65] and urges scientists to develop fine-grained and patient-centred models for assessing the impact of neurotechnology on personal autonomy. These models should distinguish on-target and off-target effects and elucidate which subcomponents of personal autonomy (e.g., volition, behavioural control, authenticity etc.) are impacted by the use of neurotechnology.

Our scoping review has several limitations. Owing to the nature of a scoping review and to our inclusion criteria, there may be relevant literature that we missed to identify and analyse. For instance, since we only included English publications, we may have missed relevant research published in other languages, which may explain why we only found qualitative studies conducted in Western countries. Furthermore, our narrow search strategy excluded other relevant research, for instance qualitative studies conducted with potential users of clinical neurotechnology or with caregivers. Yet, a scoping reviews can provide a useful tool to map existing literature [16, 18], and given recent advances in technology and accompanying qualitative research, an update of earlier reviews such as the one by Kögel et al. [14], provides an important addition to the existing literature. By looking at qualitative studies only we further import general limitations of qualitative studies, such as a lack of generalizability and a dependency on the skills and experience of the involved researchers. More standardized instruments to complement the investigation of subjective experiences of neurotechnology users therefore seem highly desirable. Recent quantitative approaches such as online surveys assessing the subjective preferences of DBS users concerning the timing of implantation [66] or studies combining qualitative data with quantitative assessments [67] point in this direction. Additionally, experimental approaches to the monitoring and evaluation of the effects of neurotechnology on the user's experience are currently absent. Therefore, future research should complement qualitative and quantitative user evaluations based on social science methods (e.g., interviews, focus groups and questionnaires) with experimental models.

Conclusion

The findings of our review emphasize the diversity of individual experiences with neurotechnology across individuals and different technologies. They underscore the need to conduct qualitative research among diverse groups at different time-points to better assess the impact of such technologies on their users, which are important to inform requirements of efficacy and safety for clinical neurotechnologies. In addition, qualitative research offers one way to implement user-centred ethical considerations into product development through user-centred design and to accompany the development of novel neurotechnologies with ethical considerations as they mature and become clinical standard.

Supplementary Information

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Supplementary Material 1

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Author contributions

GS, TBA, AC, MV, SS, CB, JC and MI contributed to the design and planning of the review, conducted the literature searches and organized and analyzed collected references. GS and MI wrote different sections of the article. All

authors provided review of analysis results and suggested revisions for the write-up. All authors reviewed and approved the manuscript before submission.

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Data availability

The availability of the full data supporting the findings of this study is subject to restrictions due to the copyright of the included papers. The quotes analysed during this study are included in this published article and its supplementary information files. Further data are available from the authors upon request.

Declarations

Ethics approval and consent to participate Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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