



Living With Deep Brain Stimulation for Parkinson's Disease: a Systematic Review and Qualitative Synthesis of Patient Experiences

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Abstract This study examines the ethical implications of deep brain stimulation (DBS) for Parkinson's disease (PD) through a systematic review and qualitative synthesis of the literature. While DBS significantly improves motor function and quality of life for many patients, individual experiences vary widely, often involving psychosocial challenges that can mitigate the benefits of motor improvements. Psychosocial changes, including shifts in mood, self-perception, and social relationships, are central to these experiences. The findings emphasize the critical need for comprehensive pre-surgical education and informed consent processes to ensure patients and caregivers fully understand both the potential benefits and psychosocial impacts of DBS. Moreover, the variability in patient experiences suggests that existing clinical guidelines may require revision

to incorporate routine psychological assessments and standardized follow-up care. Limitations of this study, such as methodological concerns in the included research, point to the need for further longitudinal studies and rigorous adherence to quality standards to comprehensively capture the long-term ethical implications of DBS. By examining these psychosocial and ethical dimensions, this review contributes valuable insights to inform clinical practices and promote patient-centered approaches, ensuring that DBS is applied in a manner that prioritizes patient well-being and effectively addresses ethical concerns.

Keywords Parkinson's disease · Deep brain stimulation · Neuroethics · Psychosocial adjustment

Introduction

Parkinson's disease is a progressive neurological disorder that profoundly affects the motor functions and quality of life of millions of people worldwide, being the fastest growing neurological disorder at the moment [1]. Characterized by symptoms such as tremors, rigidity, and bradykinesia, the disease often becomes increasingly challenging to manage with medication alone as it progresses. Deep Brain Stimulation (DBS) has emerged as a promising surgical intervention for alleviating these symptoms, offering the possibility of improved mobility and reduced medication dependency. However, while DBS can

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significantly enhance the physical aspects of life for many persons diagnosed with PD, it also raises complex bioethical questions that need careful consideration, such as altering brain function, the potential for adverse effects, and the challenges associated with obtaining informed consent from patients who may have cognitive impairments.

DBS for PD involves the implantation of electrodes in the basal ganglia, which are then stimulated to modulate neural activity. While the physical benefits of this procedure are well-documented, its impact on the psychological, social, and ethical dimensions of patients' lives is less well understood. Patients may experience shifts in self-perception, such as changes in their sense of identity or agency, as well as mood changes, including depression, anxiety, or euphoria [2–5]. These changes can have significant ethical implications, raising questions about the patient's autonomy and well-being. Moreover, literature also indicates that despite motor improvement, patients' quality of life (QoL) does not necessarily improve [6]. In opposition, some authors demonstrate a lack of empirical evidence on DBS effects on theoretical aspects, such as personality, identity, agency, authenticity, autonomy and self [7]. These discussions highlight the need for a deeper exploration of the broader consequences of DBS, beyond its clinical efficacy, to ensure that the treatment is aligned with the overall well-being of patients.

One reason for this need is that most patients seem to expect psychosocial improvements after DBS [8]. In fact, presurgical expectations modulate perceived motor improvement, perceived autonomy, and quality of life after surgery [9, 10]. In this regard, the bioethical discussion surrounding DBS in Parkinson's disease is crucial, as it encompasses issues of informed consent, patient autonomy, and the long-term psychological and social effects of the procedure. Understanding these implications is vital for developing ethical guidelines that protect patients and support clinicians in making informed decisions, taking into account the individual perspectives and preferences of each patient. Previous research highlights this issue, suggesting the need to identify patients' individual perspectives towards the disease and treatment options, considering there is extensive variability in preferences and attitudes towards DBS [11]. In particular, systematic reviews in bioethics are still uncommon [12] but render the analysis of DBS's

ethical implications particularly valuable, as it helps bridge the gap between technological innovation and ethical practice.

This article contributes to this discussion by systematically reviewing studies that capture the lived experiences of patients undergoing DBS, offering insights into the ethical challenges and the need for a more holistic approach to patient care in the context of advanced neurotechnological interventions. It is also an update and an extension of the review conducted by Mathers et al. [8]. Following PRISMA 2020 guidelines [13], the review includes qualitative studies that explore patients' perspectives, preferences, and attitudes toward DBS. The decision to include only qualitative studies aims to identify nuances of patients' perspectives that are not properly addressed by standardized tests or quantitative measures. The study aims to provide a comprehensive understanding of how DBS impacts patients' lives beyond mere motor improvements, addressing themes such as self-perception, mood changes, social relationships, and decision-making processes. The objective is to address the ethical implications that emerge from patients' experiences with DBS for PD. By ethical implications, we mean not only ethical principles and values, such as autonomy, beneficence, and non-maleficence, but also societal issues that need careful consideration [14]. To our knowledge, this is the first systematic review aimed at ethical implications of DBS for PD.

Methods

This systematic review was registered on PROSPERO (CRD42023409016) and follows PRISMA 2020 guidelines [13].

Eligibility Criteria

The inclusion and exclusion criteria were decided before the review started. Inclusion criteria consisted of qualitative studies, published in English, that employed in-depth interviews, surveys or focus groups, in order to investigate the preferences, perspectives, and attitudes of patients concerning deep brain stimulation for Parkinson's disease. Qualitative studies were chosen because they allow for a deeper exploration of patients' experiences and perspectives,

which may not be captured by standardized quantitative measures. No restrictions of publication date were made, in order to find any relevant studies on the topic.

Studies on neurodevices other than deep brain stimulation, samples including persons other than patients diagnosed with Parkinson's disease, correspondence papers, ongoing studies, systematic reviews, conference abstracts, or papers other than empirical research were excluded. Papers in languages other than English or for which no full-text could be found were also not considered eligible.

Search Strategy

We conducted searches in five databases relevant for health and ethics research, in order to cover both fields in the search strategy. Selected databases were PubMed, PsycNet, Scopus, Web of Science, and EthicsWeb. The search was done on 04–22–2023 by one of the authors. Except for the results from Ethics Web's results, which had to be assessed manually, results were imported and processed in the Rayyan software [15].

Search strings combined synonyms for qualitative study, deep brain stimulation, Parkinson's disease and empirical ethics. Truncations were used to include all forms of the words. The full search strings for each database are available as supplementary material (details available on Open Science Foundation https://osf.io/nzj2v/?view_only=75036aaaea5a4732ad5671881798f7a1).

Screening of Articles

Duplicates from studies retrieved from the searches were first excluded. Following this initial step, titles and abstracts were screened for assessment of inclusion and exclusion criteria. This was initially done by one researcher, and a second researcher checked all the decisions to ensure consistency with inclusion criteria.

One researcher then performed a full-text screening of articles marked as "include" to double-check for inclusion and exclusion criteria. Full-text screening was also done for articles marked as "maybe." All decisions were checked by a second researcher. All studies that did not meet inclusion criteria were excluded.

For all articles, decisions were documented in a data extraction sheet, including relevant article

information such as author names, author affiliations, year of publication, country of origin, title, main goal of study, and main conclusions. Reasons for exclusion were also documented (details available on Open Science Foundation https://osf.io/nzj2v/?view_only=75036aaaea5a4732ad5671881798f7a1).

References from included studies, as well as systematic reviews retrieved in the searches, were screened in order to identify any articles matching the inclusion criteria. Reasons for inclusion and exclusion were also documented in the data extraction sheet.

Quality and Confidence Assessments

The quality of the individual studies included in this review was assessed through the Mixed Methods Appraisal Tool (MMAT; [16]) and discussed by two researchers. Unlike other critical appraisal instruments, the MMAT assesses methodological quality of studies [17]. Its latest version, published in 2018, has 25 criteria in total, including criteria related to study design, data collection, data analysis, and reporting. It may be applied to qualitative, randomized controlled, non-randomized, quantitative descriptive and mixed methods studies [16].

Similarly, the confidence in review findings was assessed through GRADE-CERQual ('Confidence in the Evidence from Reviews of Qualitative research'; [18]) and discussed by two researchers. GRADE-CERQual assesses the coherence of review findings across studies by considering factors such as the consistency of findings, the strength of evidence, and the potential for bias. Methodological limitations of individual studies assessed by GRADE-CERQual include factors such as the adequacy of sampling, the appropriateness of data collection methods, and the rigor of data analysis. As pointed out by Wainwright and colleagues [19], it is more adequate to assess the confidence of qualitative evidence as opposed to the quality of the evidence, in that qualitative research may employ different designs to collect and analyze data. The tool assesses methodological limitations of individual studies, coherence of review finding across studies, adequacy (richness) of data and relevance.

Data Analysis and Synthesis

To extract the findings from the studies, we performed an inductive content analysis, a qualitative research method that involves identifying and

categorizing themes within a dataset [20]. Rigorous measures implemented to mitigate reporter bias included the use of a predefined research strategy, a comprehensive search of relevant databases, standardized quality assessment tools, and a structured data analysis method. The procedure consisted in addressing a name or topic for each theme found. All findings were derived exclusively from quotations referring to patients, although a few studies also included interviews with caregivers. A list of all themes, experiences, attitudes, or preferences was then generated, and similar topics grouped into broader categories. For each category, we stated how many articles contribute to the finding, synthesized into a frequency table. Two researchers discussed the themes and sub-themes created during this step.

Results

Figure 1 shows the number of studies retrieved in the searches and included in the review.

From all 30 studies assessed for eligibility, ten were excluded after full-text screening for not

meeting inclusion criteria, including four that addressed topics or populations other than specified in the review questions, two that were quantitative despite collecting categorical data, and three that were non-research articles, such as commentaries or case reports.

Table 1 shows an overview of the included studies. Overall, 317 participants undergoing DBS were included in the sample. However, it is possible that articles [21, 22] and [23, 24] share the same sample, which would reduce the total number of participants. Few authors provide precise information on brain target and lateralization. With four exceptions being mixed methods studies, all of them were qualitative, employing one or more data collection techniques (semi-structured interview, focus groups, and surveys) in order to explore patients' experiences and perspectives about the treatment.

From the 20 studies included in this review, 19 were conducted in high-income countries. Most of them (65%) were made in Europe, and exceptions are 6 studies done in Australia and one in the United States. No studies from other locations met inclusion criteria.

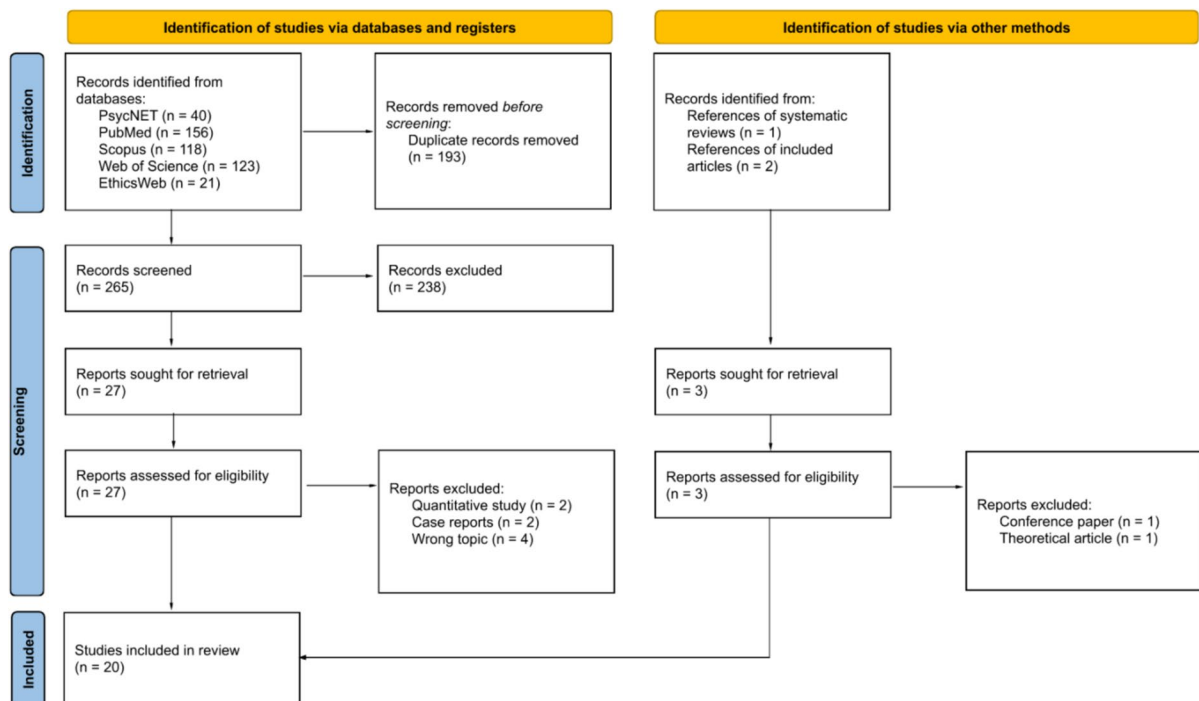


Fig. 1 Flowchart of studies retrieved, excluded, and included in the final review

Table 1 Description of studies

Authors	Study objective	Sample size (% patients with DBS)	% men	Mean age at time of interview (years)	Target (sample)	Mean time between surgery and interview (years)	Data collection method	Main findings
Ahlberg et al. (2011) [25]	To explore patients' perspectives of speech and communication changes after STN-DBS	4 (100%)	50%	71	STN	6.25	Video-recorded semi-structured interviews	Increased mobility, reduction in tremor and medication. Improved quality of life. Decision for surgery was made with a feeling of having no choice. Deterioration of speech and communication. Perceived lack of information before surgery, in particular, regarding speech and communication issues. Participants were satisfied with outcomes
Baertschi et al. (2019) [26]	To explore whether the burden of normality model could predict and describe psychosocial adjustment after DBS	19 (100%)	63.2%	*	*	24.5	Questionnaires (pre- and post-surgery) and semi-structured interview (post-surgery)	Signs of psychosocial maladjustment present in all participants. The Burden of Normality model can be applied to such phenomena. Participants perceived DBS as valuable and effective

Table 1 (continued)

Authors	Study objective	Sample size (% patients with DBS)	% men	Mean age at time of interview (years)	Target (sample)	Mean time between surgery and interview (years)	Data collection method	Main findings
Cabrera et al. (2020) [27]	To explore patients' experiences and attitudes about DBS surgery timing	20 (100%)	60%	60	*	2.5	Digitally recorded structured interview (with closed and open-ended questions)	Participants expressed different opinions on earlier use of DBS, men being more prone to accept it than women. Most participants are thankful for improvements. Earlier use would be accepted mainly because of trust in the doctor. Reasons for not undergoing DBS earlier are not considering oneself ill enough, as well as medications still working

Table 1 (continued)

Authors	Study objective	Sample size (% patients with DBS)	% men	Mean age at time of interview (years)	Target (sample)	Mean time between surgery and interview (years)	Data collection method	Main findings
Chacón Gámez et al. (2021) [28]	To collect and analyze patients' and caregivers' experiences with DBS	36 (53%)	68%	67.2	*	4.7	Narrative semi-structured interviews (transcribed verbatim) and drawings	Participants report different symptoms, disease progression, and DBS effects. They also describe using different coping strategies, with some of them working for one participant, but not for the other. The one strategy that helps most patients, however, is physical activity or concentrating on something enjoyable. In this case, participants report fewer symptoms
Eatough et al. (2016) [29]	To understand the paradox of motor improvement not matching with improved psychosocial adjustment in DBS for PD	1 (100%)	0	72	GPI	.16	Recorded semi-structured interview	Decision for surgery was propelled by the feeling of being at a dead end with the disease. Fear of surgical outcomes, of personality changes and visibility of the device were mentioned as core aspects of DBS. The participant also expected more emotional support from her family and more attention from the medical team

Table 1 (continued)

Authors	Study objective	Sample size (% patients with DBS)	% men	Mean age at time of interview (years)	Target (sample)	Mean time between surgery and interview (years)	Data collection method	Main findings
Gilbert (2018) [21]	To explore perceived self-change by patients with DBS, in particular feelings of self-estrangement	17 (100%)	*	*	*	3.1	In-depth, semi-structured interviews	Participants report self-perceived changes after DBS, either at some point, intermittently, or persistently. Changes were mentioned despite motor improvements. Such self-estrangement might be placed within a continuum, from sameness to otherness
Gilbert et al. (2017) [22]	To address the lack of phenomenological evidence on effects of deep brain stimulation (DBS) on the self of the patient	17 (100%)	59%	*	*	3.1	In-depth, semistructured interviews with open-ended questions	Both destructive and restorative self-estrangement is reported by participants, being directly proportional to their preoperative state. The self-estrangement is associated with loss of control and distorted perception of capacities. In general, the treatment seems to increase an autonomous power over one's self

Table 1 (continued)

Authors	Study objective	Sample size (% patients with DBS)	% men	Mean age at time of interview (years)	Target (sample)	Mean time between surgery and interview (years)	Data collection method	Main findings
Gilbert et al. (2018) [30]	To address the experience of mania and hypersexuality after DBS from a patient perspective; to demonstrate the patient's thoughts and feelings when symptoms arise	1 (100%)	0%	*	STN	*	Case study with in-depth, semi-structured interview	Severity of side effects require long-term narrative studies in DBS patients, in particular, to understand how mood changes affect patients' quality of life. Depressed patients might deem DBS unsatisfactory, despite having motor improvements
Gisquet (2008) [31]	To show how DBS can be a disruptive experience, in particular, through loss of control over the illness; loss of control over one's life; and how these are compounded by the difficulties medical teams have in recognising such problems	20 (50%)	57%	*	*	*	Interview	Participants express loss of control over the illness and personality changes despite motor improvements. Dependence of the medical team remains both for parameter adjustments and due to new side effects

Table 1 (continued)

Authors	Study objective	Sample size (% patients with DBS)	% men	Mean age at time of interview (years)	Target (sample)	Mean time between surgery and interview (years)	Data collection method	Main findings
Haahr et al. (2010) [32]	To explore and describe patients' experience with DBS	9 (100%)	*	*	*	*	Qualitative in-depth interviews in three time points during the first year of treatment	Participants experience a major impact on their bodies after DBS and report an adjustment process in three steps: the feeling of being liberated, having challenges with treatment outcomes and reconciling with the fact they still have PD. Despite heterogeneity in participant experiences, difficulties with adjusting stimulation and medication were dominant
Hariz et al. (2014) [23]	To explore patients' perspectives on living with DBS	42 (100%)	74%	64.1	STN (19), Zi (18), GPi (1)	2.8	Semi-structured interview, with open-ended questions, sociodemographic questionnaire	90.5% of participants report at least some degree of improvement after DBS, whereas 10% report deterioration. Device is not seen as a big issue, but carefulness, professional support and coping strategies for side-effects are mentioned as important

Table 1 (continued)

Authors	Study objective	Sample size (% patients with DBS)	% men	Mean age at time of interview (years)	Target (sample)	Mean time between surgery and interview (years)	Data collection method	Main findings
Hariz et al. (2016) [24]	To collect and analyze patients' narratives about their everyday experiences with DBS	42 (100%)	74%	64.1	STN (19), Zi (22), GPi (1)	2.8	Semi-structured interviews with open-ended questions and sociodemographic questionnaire	Participants report great relief from tremor, cramps and pain. DBS also allows for easier movement and living. Side effects are acknowledged as difficult, but bearable. Participants also recognize the progression of PD despite improvement with stimulation. In general, relief from symptoms, especially tremor and cramps, outweigh side effects of the stimulation
İbrahimoglu et al. (2020) [33]	To determine the challenges, expectations and accomplishments of patients with DBS	7 (100%)	86%	56.9	*	6.1	Focus group with semi-structured interviews	DBS improves daily activities and promotes feelings of hope and reattachment, despite initially provoking fear. Biopsychosocial adaptation is required from patients after implantation

Table 1 (continued)

Authors	Study objective	Sample size (% patients with DBS)	% men	Mean age at time of interview (years)	Target (sample)	Mean time between surgery and interview (years)	Data collection method	Main findings
Lewis et al. (2015) [34]	To examine patients' perceptions of personality and mood changes; to characterize patients perceiving personality changes, by relating neurological and psychiatric questionnaire data to subjectively perceived outcomes of STN-DBS	54 (50%)	*	*	STN	*	Semi-structured interviews at three months and one year after surgery, sociodemographic questionnaire, and neurological and psychiatric assessments (PDQ-39, UPDRS-III, BDI-II, AES, STAI-state, BIS-11, HPS, MMSE, MDRS)	Most participants perceive personality changes after STN-DBS. Mood changes are reported as being both positive and negative
Liddle et al. (2018) [35]	To explore the occupational experience of the DBS journey	35 (40%)	71%	64.3	*	1.7	Prospective mixed-methods study with semi-structured interviews	Participants highlight occupational changes after DBS that help better understand PD. Shift in familial roles, changes in interpersonal relationships and behavior changes were experienced by them during the treatment. A change in priorities was also reported after DBS

Table 1 (continued)

Authors	Study objective	Sample size (% patients with DBS)	% men	Mean age at time of interview (years)	Target (sample)	Mean time between surgery and interview (years)	Data collection method	Main findings
Mosley et al. (2021) [36]	To explore the meaning and significance of stimulation-related neuropsychiatric symptoms amongst a sample of persons with PD and their spousal caregivers	20 (50%)	90%	59.4	STN	*	Semi-structured interviews	Neuropsychiatric symptoms after DBS affected participants' quality of life and were a burden to some of their caregivers. Such symptoms are reported to be unexpected, with different degrees of loss of control experienced. However, no participant expressed a fear of change in their fundamental identities
Schupbach et al. (2006) [37]	To evaluate the impact of STN-DBS on patients' social adjustment	29 (100%)	48%	52.4	STN	*	Clinical assessment, in-depth semi-structured psychiatric interview, open unstructured interview	Participants mentioned improvements in movement, activities of daily living and quality of life, but poor social adjustment. The surgery had detrimental and positive effects on their self-perception, marital relationships and professional life. Authors are unsure whether this experience emerges from a response to a changing body, from stimulation itself, or both

Table 1 (continued)

Authors	Study objective	Sample size (% patients with DBS)	% men	Mean age at time of interview (years)	Target (sample)	Mean time between surgery and interview (years)	Data collection method	Main findings
Shahmoon et al. (2019) [38]	To explore how 10 male people with PD experienced life after STN-DBS surgery	10 (100%)	100%	58.3	STN	*	Semi-structured interview	Participants report feeling rebirth after implantation and being extremely grateful for the surgery. DBS and its manual control are seen as power over symptoms. Reality, however, is experienced as disappointing, in particular, due to side effects of the stimulation. Having less predictability regarding symptoms is also mentioned by participants as a constant source of worry. On the other hand, social support is perceived as a buffer that allows for facing such effects

Table 1 (continued)

Authors	Study objective	Sample size (% patients with DBS)	% men	Mean age at time of interview (years)	Target (sample)	Mean time between surgery and interview (years)	Data collection method	Main findings
Thomson et al. (2020) [39]	To examine the significance and meaning of DBS-related changes in personality and self for patients and caregivers	22 (50%)	64%	*	STN (10), GPi (1)	.75	In depth semi-structured interviews, pre and post surgery	Personality changes were mentioned by participants as part of the post-DBS life. Such changes are attributed not only to the stimulation but also to other factors. In particular, when related to disease progression, personality changes seemed to escalate suffering for patients and caregivers. On the other hand, some participants also mention a feeling of restoration of their premorbid self
Voigt (2021) [40]	To demonstrate the positive aspects of the application of STN-DBS for PD, from the perspective of the patients	8 (100%)	88%	*	STN	*	Narrative or partly-structured interviews	Participants express feelings of euphoria and joy due to a reestablished freedom of movement

DBS deep brain stimulation, PD Parkinson's disease, STN subthalamic nucleus, Zi zona incerta; GPi *globus pallidus*, * = not disclosed

Risk of Bias Assessment

Table 2 shows the results from the MMAT quality assessment (Hong et al., 2018).

In all cases, clear research questions were presented and the qualitative methodology was appropriately employed. Three studies did not specify sampling strategies, data collection methods or data analysis methods (criteria 1.2 and 4.1), although present results in a clear fashion. In such cases, the analysis of coherence between data sources, collection, analysis and interpretation (criteria 1.5) was not possible. The same issue emerged in cases where authors did not present sufficient data (e.g. quotes or examples) to support the evidence (criteria 1.3 and 1.4). For mixed-methods studies, only one of them did not integrate qualitative and quantitative data, presenting the results independently (criteria 5.2 and 5.3).

Confidence in the Evidence

During the data analysis and confidence in the evidence assessment, eight main themes were identified: 1) experience with DBS; 2) self-perception; 3) mood; 4) social relationships; 5) decision for surgery; 6) behavior; 7) handheld controller; and 8) cognition. Each of these themes is explored in one or more articles included in the final review, and their frequencies are described below (Table 3).

The themes outlined above also serve as a categorization of the 34 individual findings identified in this review. These encompass areas such as movement, mood, behavior, self-perception, and social relationships, as well as challenges faced during the adaptation period. Table 4 presents the complete GRADECERQual assessment of the quality of each review finding, previously referred to as evidence.

Table 2 Quality appraisal of studies

Authors	Methodological quality criteria																
	Screening questions		Qualitative study					Quantitative descriptive					Mixed methods				
	S1	S2	1.1	1.2	1.3	1.4	1.5	4.1	4.2	4.3	4.4	4.5	5.1	5.2	5.3	5.4	5.5
Ahlberg et al. (2011) [25]	Y	Y	Y	Y	Y	Y	Y										
Baertschi et al. (2019) [26]	Y	Y	Y	Y	Y	CT	Y	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y
Cabrera et al. (2020) [27]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Chacón Gámez et al. (2021) [28]	Y	Y	Y	Y	Y	Y	Y										
Eatough et al. (2016) [29]	Y	Y	Y	Y	Y	Y	Y										
Gilbert (2018) [21]	Y	Y	Y	Y	Y	Y	CT										
Gilbert et al. (2017) [22]	Y	Y	Y	Y	Y	Y	CT										
Gilbert et al. (2018) [30]	Y	Y	Y	Y	Y	Y	CT										
Gisquet (2008) [31]	Y	Y	Y	CT	Y	Y	CT										
Haahr et al. (2010) [32]	Y	Y	Y	Y	Y	Y	Y										
Hariz et al. (2014) [23]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	Y
Hariz et al. (2016) [24]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
İbrahimoglu et al. (2020) [33]	Y	Y	Y	Y	Y	Y	Y										
Lewis et al. (2015) [34]	Y	Y	Y	Y	Y	CT	Y										
Liddle et al. (2018) [35]	Y	Y	Y	Y	Y	Y	Y										
Mosley et al. (2021) [36]	Y	Y	Y	Y	Y	Y	Y										
Schupbach et al. (2006) [37]	Y	Y	Y	Y	CT	Y	Y										
Shahmoon et al. (2019) [38]	Y	Y	Y	Y	Y	Y	Y										
Thomson et al. (2020) [39]	Y	Y	Y	Y	Y	Y	Y										
Voigt (2021) [40]	Y	Y	Y	CT	CT	Y	CT										

N no, Y yes, CT can't tell

Table 3 Frequency of themes

Themes (% of studies)	Sub-themes	Number of studies
Experience with DBS (28%)	Satisfaction with results	11
	Challenges with adaptation	10
	Perception of the disease	9
	Medication needs	8
	Feeling rebirth	8
	Perception of the device	7
	Frustration with medical appointments and stimulation adjustments	6
	Recommendation of surgery	3
	Gratitude for DBS	2
	Self-estrangement	14
Self-perception (18%)	Freedom and independence	9
	Self-confidence	8
	Loss of control	7
	Shift in priorities	3
	Depression	11
Mood (17%)	Impulsivity, aggressiveness and mania	10
	Anxiety and irritability	8
	Emotional lability	6
	Relaxation and good humor	4
	Marital and familial conflicts	10
Social relationships (12%)	Improvements in social life	8
	Speech and communication issues	8
	Sexual activity	2
	Expectations other than motor improvement	9
	Not enough information	9
Decision for surgery (11%)	Fears and concerns	4
	Drastic decision	3
	Timing for surgery	1
	Reengagement in activities	7
	Stubborn, excessive behaviors	7
Behavior (7%)	Work life	3
	Controller as a tool	4
	Confusion and anxiety around controller use	2
Handheld controller (3%)	Memory issues and mental fatigue	8
Cognition (3%)		

From all 34 review findings, most of them are of moderate confidence (19 or 56%), presenting no to moderate concerns in one or more elements of GRADE-CERQual. Similarly, 12 review findings (35%) are considered of low confidence, whereas only one is of very low confidence. A high confidence in the evidence is seen in only two review findings (6%), since these are the ones coherently supported by high quality studies. The detailed

results of each overarching theme are available below.

Theme 1: Experience with DBS

The first category emerging from 17 different studies highlights patients' overall experiences with the treatment. Six out of eight review findings under this theme are of moderate confidence. They are

Table 4 Qualitative evidence synthesis table

Summary of review finding	Studies contributing to the review finding	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Patients do not have enough information regarding what to expect after surgery or fail to fully believe, rationally and emotionally, the information that was given	[21, 25, 26, 30, 31, 33–35, 38]	Moderate confidence	Minor concerns regarding methodological limitations and coherence (participants present different opinions on the amount of information provided). Moderate concerns regarding adequacy, since most studies provide few quotes or statistics to support the review finding. Minor concerns regarding relevance, since studies were conducted in six countries in three different continents (one in America, four in Europe, four in Australia); however, all in high-income countries
Fears before surgery include the surgical procedure itself, possible malfunctions of the device after implantation, as well as the concern with personality changes due to the treatment	[24, 27, 38, 40]	Low confidence	Minor to no concerns regarding methodological limitations, coherence, adequacy, and relevance. Studies were conducted in four different countries of different continents (three in high-income countries, one in a middle-income country). Although most participants of mentioned studies report review finding, most studies of this review did not explore pre-operative fears and concerns
The decision for surgery is seen as unavoidable, driven by PD symptoms, concern with others, and inability to function in daily life	[25, 34, 40]	Low confidence	No to minor concerns regarding methodological limitations, coherence, and adequacy. Moderate concerns regarding relevance, since studies were conducted in different locations, however, all three from high-income countries (one in Australia, one in Sweden, one in the UK). It is worth noting that, while most participants report the research finding, evidence is supported by only three studies
Many patients expect more than motor improvement from DBS, including improvements in mood and social relationships, the cure of the disease itself, the elimination of all PD symptoms, or a restored life after surgery	[24–26, 28, 30, 31, 36–38]	High confidence	High confidence in the evidence, since studies contributing the most data to the review finding have minor concerns regarding methodological limitations, coherence, and relevance. No concerns regarding adequacy. Studies were conducted in seven different countries (eight in Europe, one in Australia), however, mostly in high-income countries

Table 4 (continued)

Summary of review finding	Studies contributing to the review finding	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Patients overall recommend the surgery	[26, 35, 37]	Moderate confidence	Minor to no concerns regarding methodological limitations, coherence, and adequacy. Moderate concerns regarding relevance, since review finding emerged from three studies, two presenting samples purposefully restricted to males or persons with neuropsychiatric symptoms. Studies were all conducted in three different high-income countries (two in Europe, one in Australia)
Patients are unsure whether they would have undergone DBS earlier, for they consider it an option only when medication is no longer effective	[27]	Low confidence	No concerns regarding methodological limitations, coherence, and adequacy. No concerns regarding relevance, however, finding emerged from only one study, conducted in the US, which provides low confidence in the evidence
DBS promotes a sensation of rebirth or miracle, usually experienced by patients as a new chance in life	[23, 24, 26, 28, 31, 36, 37, 39]	Moderate confidence	Minor concerns regarding methodological limitations and relevance, since studies with no to minor concerns contribute the largest quantity of data to the review finding. Moderate concerns regarding adequacy, since most studies provide few quotes or context to support the evidence. Minor concerns regarding coherence and relevance, however, all studies were conducted in seven different European countries, mainly in high-income countries
Medical appointments and adjustments of DBS parameters are a source of frustration and challenge	[26, 27, 31, 32, 38, 40]	Moderate confidence	Minor to no concerns regarding methodological limitations, coherence, adequacy, and relevance. One of the studies has an inconsistent fit to the review finding. Studies were conducted in four high-income countries in three different continents (four in Europe, one in America, one in Australia)
Patients experience challenges while adapting to DBS, in a journey of ups and downs in physical capacities and mood, which poses a struggle to comprehend their changing body	[21, 23, 26–28, 30, 31, 34, 38, 40]	Low confidence	Moderate concerns regarding methodological limitations and coherence, since review finding is not entirely supported by all studies. No concerns regarding adequacy or relevance, however, studies were conducted in seven countries of three different continents, all of them in high-income countries

Table 4 (continued)

Summary of review finding	Studies contributing to the review finding	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Patients perceive the reduction of medication needs after surgery as positive, although they acknowledge the central role of medication in PD and in balancing side effects of stimulation	[23–25, 28, 30–32, 39]	Moderate confidence	Moderate concerns regarding methodological limitations, since most evidence comes from studies with minor to moderate methodological concerns. Moderate concerns regarding adequacy, once studies provide little to no evidence of finding, except general affirmations. Minor concerns regarding coherence and relevance, however, all studies were conducted in five European countries, most of them high-income countries
Patients tend to have a positive view of DBS and feel satisfied with treatment outcomes when improvements outweigh side effects. When the positive effects of DBS become invisible, motor swings continue despite stimulation or they feel their initial expectations were not met, they report feeling dissatisfied or frustrated	[23, 25–27, 31, 32, 35–38, 40]	Low confidence	Minor concerns regarding methodological limitations and relevance. Studies were conducted in seven different countries (seven in Europe, one in America, two in Australia). Moderate concerns regarding coherence and adequacy, since most studies partially support review finding and provide thin data to support the evidence
While most patients do not think about having an electronic device implanted on their brains, some report finding this idea disturbing. Concerns, however, arise mostly in relation to the possibility of impairing the device with daily activities (e.g.: when exercising or at the airport security control) or regarding the visibility of the device to other people	[24, 26, 28, 32, 36, 38, 40]	Moderate confidence	Minor concerns regarding methodological limitations, coherence, adequacy, and relevance. Studies were conducted in six different countries (six in Europe, one in Australia), most in high-income countries and one in a middle-income country. Most studies with minor to no concerns regarding each GRADE dimension provide the most data to support review finding
Patients recognize PD is still progressing despite treatment. However, DBS may provoke a shift in patients' perception of the disease; some of them report they did not notice, before surgery, how sick they were, some express bitterness towards PD and towards how their identities are merged with it, and some of them also lament for the time they lost struggling with symptoms	[23–26, 28, 30, 31, 36, 37]	Moderate confidence	Minor concerns regarding adequacy and relevance. Moderate concerns regarding methodological limitations and coherence. Review finding seems to emerge for many participants, but not all of them. Studies were conducted in seven different locations (nine in Europe, one in America), most of them in high-income countries
Patients express gratitude towards the surgery	[31, 37]	Low confidence	No concerns regarding coherence and adequacy, and most participants report the review finding. Minor concerns regarding methodological limitations and relevance. However, it is worth noting the finding is supported by evidence from few studies, both from high-income European countries

Table 4 (continued)

Summary of review finding	Studies contributing to the review finding	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
The manual controller of the stimulator is seen as a tool to have more control over one's bodies and symptoms	[28, 32, 37, 38]	Low confidence	Minor concerns regarding methodological limitations, adequacy and relevance. Moderate concerns regarding coherence. As the finding is supported by evidence from few participants or authors who did not provide enough context to the findings, it provides low confidence in the evidence. Studies were conducted in four different European countries, all in high-income locations
Many patients express confusion or anxiety around controller use	[32, 37]	Low confidence	No to minor concerns regarding methodological limitations, coherence, and adequacy, and most participants report review finding. Moderate concerns regarding relevance, since both studies were conducted in high-income European countries
Patients report difficulties with emotion regulation after DBS, describing it as sensitiveness, loss of control or emotional incontinence	[26, 28, 29, 31, 38, 40]	Moderate confidence	Minor concerns regarding methodological limitations and adequacy. Moderate concerns regarding coherence, since review finding applies to few participants. No concerns regarding relevance, but it is worth noting all studies were conducted in four different high-income countries (four in Europe, one in Australia)
Impulsivity, aggressiveness and mania are reported by patients after DBS	[21, 22, 26, 28, 29] [33–35, 38, 39]	Moderate confidence	Moderate concerns regarding methodological limitations and relevance. Studies were conducted in three different high-income countries (four in Europe, six in Australia). Minor concerns regarding coherence and adequacy, and the number of patients reporting review findings varies according to the study, which allows for moderate confidence in the evidence
There is great variability regarding depressive symptoms after DBS, but several patients report apathy, bitterness, lack of initiative and loss of vitality as distressing issues	[21, 25, 26, 28–31, 33, 35, 36, 38]	Moderate confidence	Minor concerns regarding adequacy and relevance. Studies were conducted in six different high-income countries (seven in Europe, five in Australia). Moderate concerns regarding methodological limitations and coherence. Both improvements and worsening in mood are reported, however, most studies mention an increase in depressive symptoms after DBS, which provides moderate confidence in the evidence

Table 4 (continued)

Summary of review finding	Studies contributing to the review finding	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Most patients report feeling more anxious, impatient or irritated after DBS	[26, 28, 33–36, 38, 39]	Moderate confidence	Minor concerns regarding coherence and adequacy. Most studies report an increase in anxiety and irritability, but also present moderate concerns regarding methodological limitations and relevance. Studies were conducted in four different high-income countries (five in Europe, three in Australia)
Patients report feeling more relaxed and light-humored after DSB	[21, 28, 33, 38]	Moderate confidence	Minor concerns regarding methodological limitations and adequacy. Moderate concerns regarding coherence and relevance. Studies mention both improvements and worsening in mood. All of them were conducted in high-income countries (two in Europe, two in Australia)
Improvement in symptoms after DBS implantations leads to better social connection	[23, 28, 34, 36–39]	Moderate confidence	Minor concerns regarding methodological limitations, coherence, and adequacy. Moderate concerns regarding relevance, since all studies were conducted in seven different high-income countries (six in Europe, two in Australia)
Changes in patients' role, behavior or attitudes after the treatment may stir marital and familial conflicts	[22, 26, 28, 29, 31, 34–38]	Moderate confidence	No concerns regarding adequacy (rich data provided). Minor concerns regarding methodological limitations and relevance. Studies were conducted in five different high-income countries (five in Europe, five in Australia). Moderate concerns regarding coherence, with marital conflicts emerging from other aspects or participants reporting also improvement in marriage
Patients report an improvement in sexual life, including degrees of hypersexuality	[29, 36]	Low confidence	Minor to no concerns regarding coherence, adequacy, and relevance. Since finding emerged from only two studies, both with relevant methodological limitations (one from France, one from Australia), it provides low confidence in the evidence
Patients experience memory issues and mental fatigue after DBS surgery	[23, 25, 26, 28, 31, 36, 38, 39]	Very low confidence	Minor concerns regarding relevance. Studies were conducted in five different countries (six in Europe, one in Australia). Moderate to serious concerns regarding methodological limitations, coherence, and adequacy. Decline in cognition seems limited to a few patients, and some studies report improvements in cognition, which provides very low confidence in the evidence

Table 4 (continued)

Summary of review finding	Studies contributing to the review finding	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
While patients with marked motor improvement experience greater self-confidence with the treatment, those who encounter side effects refrain from being physically and socially active	[23–25, 28, 31, 34, 36, 38]	Moderate confidence	Minor to no concerns regarding methodological limitations, coherence, and relevance. Studies were conducted in six different countries (six in Europe, two in Australia), most of them in high-income countries. Moderate concerns regarding adequacy. Although many participants described improvement or worsening in self-confidence in the absence or presence of side effects respectively, the direction of such relation is not entirely clear from data, which supports moderate confidence in the evidence
The sense of self might be affected after DBS by a feeling of return to oneself after improvement or by a feeling of self-estrangement, the latter usually related to the presence of unexpected or unwanted effects	[25–29] [21, 22, 30, 35–40]	Moderate confidence	Minor concerns regarding coherence, adequacy, and relevance. Studies were conducted in seven different countries (eight in Europe, one in America, five in Australia). Moderate concerns regarding methodological limitations. Most of the studies provide evidence of some degree of self-estrangement after DBS in the presence of undesired effects, otherwise, the feeling of returning to oneself is consistently reported
Patients experience a sense of freedom and independence that emerges from motor improvement	[22–25, 27, 30, 31, 34, 39]	Moderate confidence	Minor to no concerns regarding coherence, adequacy, and relevance. Studies were conducted in various locations and income profiles (six in Europe, one in America, two in Australia). Moderate concerns regarding methodological limitations. Most studies mention independence as a positive aspect of DBS, providing moderate confidence in the evidence
Although motor improvement is mentioned as a driver of feeling of control over one's body, some patients experience a feeling of loss of control when facing side effects, intense euphoria after improvement, or unexpected challenges during the stimulation adjustment	[21, 25, 29, 31, 35, 37, 39]	Low confidence	Minor concerns regarding coherence and adequacy. Moderate concerns regarding methodological limitations and relevance, specially in studies that provide the most data to the review finding. All studies were conducted in five high-income countries (four in Europe, three in Australia)

Table 4 (continued)

Summary of review finding	Studies contributing to the review finding	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Some patients experience a shift in priorities after general improvement with DBS	[31, 34, 37]	Moderate confidence	Minor concerns regarding methodological limitations, coherence, adequacy, and relevance. Data allows us to infer that some patients experience a shift in priorities, but since review finding emerged from only three studies, it allows for moderate confidence in the evidence, and should be interpreted with caution. All three studies were conducted in high-income countries (two in Europe, one in Australia)
Patients reengaged in daily activities, as well as in new projects or hobbies after motor improvement	[21, 23, 26, 28, 31, 34, 36]	Low confidence	Studies providing the largest amount of data to the review finding present no to minor methodological concerns. Minor concerns regarding adequacy and relevance. Studies were conducted in five different high-income countries (four in Europe, two in Australia). Moderate concerns regarding coherence, since review finding is supported by most of the data, however, contradictory evidence is also found, which provides low confidence in the evidence
Some patients present more stubborn, excessive behaviors after treatment, some of them attributing behavior change to DBS	[22, 26, 34–36, 38, 39]	Moderate confidence	No concerns regarding coherence. Minor concerns regarding adequacy and relevance. Studies were conducted in four different high-income countries (three in Europe, four in Australia). Minor to moderate concerns regarding methodological limitations in most studies. Stubborn, excessive behaviors or behavior change in general is perceived by most participants, but many studies do not present sufficient details of such behaviors
Patients did not resume professional life after DBS. Reasons include symptoms still present due to higher levels of stress or because they actively wanted to pursue activities other than work after motor improvement	[23, 30, 36]	Low confidence	No concerns regarding coherence and relevance, and minor concerns regarding adequacy. All three studies were conducted in high-income countries (two in Europe, one in Australia). Two out of three studies provided little to thin data to support the evidence. Review finding emerged from only three studies with moderate methodological concerns, which provides low confidence in the evidence

Table 4 (continued)

Summary of review finding	Studies contributing to the review finding	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Impaired speech after surgery poses a challenge for interpersonal communication and social interaction not only to patients but also to their families and friends. In a few cases, reading and writing difficulties also emerged	[23, 25, 28, 31, 32, 34, 37, 38]	High confidence	Minor concerns regarding methodological limitations, coherence, adequacy, and relevance. Studies were conducted in five different countries, most of them in Europe. Although one study reports both improvement and worsening in speech and communication, most of the data supports review finding, high provides high confidence in the evidence

expressed in terms of a changing perception of the disease (example 1), a positive view of the medication reduction after surgery (example 2), as well as a feeling of being reborn (example 3). Other findings of moderate confidence revolve around challenges with post-surgical medical appointments or with the fact they are now implanted with an electronic device (example 4). None of these sub-themes were supported by all 17 studies equally. They also did not apply to all participants in the samples.

- (1) “Barry: “I feel more confident and then also at the same time we are still on a downhill slope so that confidence is still being taken away from me everyday”. [38]
- (2) “DBS liberates patients from their medication: “we don’t have to live by the clock any more”. [31]
- (3) “When describing the comprehensive significance of DBS, patients often used strong, positive and decisive descriptions of DBS such as, ‘life changing’.” [24]
- (4) “The hassle seeking to find the right stimulation settings and medicine dosage affected participants’ sense of success in a more negative way than those participants where adjusting to the stimulation went easier.” [32]

Three review findings, on the other hand, are of low confidence. They highlight the ups and downs of the treatment (example 5) and overall satisfaction and gratitude for surgery (example 6). Although emerging from most of the 17 studies, data is not entirely consistent and varies greatly among participants.

- (5) “The course of the post-DBS life was perceived with great heterogeneity among patients. [...] Four patients reported the three distinct periods of euphoria, adjustment and acceptance observed in previous work. However, such a pattern did not clearly emerge in most patients. Six of them pictured a continuous line and three underscored feelings of discontinuity mainly characterized by “ups and downs”. In addition, not all individuals described distinct phases.” [26]
- (6) “81% of the patients considered the impact of DBS on life as a whole as markedly or moderately positive, while 10% perceived a negative impact from DBS” [23]

Theme 2: Self-perception

The second most cited aspect of post-DBS life is a shifting self-perception. Feelings of self-estrangement (example 7), freedom and independence (example 8), and self-confidence (example 9) are highlighted by 18 different studies included in this review. Accordingly, a shift in priorities was also mentioned as an effect (example 10). Although most patients report similar experiences, which provide moderate confidence in the evidence, such findings do not apply to the entire sample. Similarly, the experience of loss of control (example 11), although highlighted in seven studies, is inconsistent, and presents the lowest confidence of the category.

(7) “Six patients (out of 19) testified of difficulties to deal with their personal identity after DBS.” [26]

(8) “Shortly after the DBS surgery, there is an intensive feeling of freedom based on freedom of movement.” [40]

(9) “They also described fear about starting new projects because they were uncertain whether they would be able to follow them through.” [25]

(10) “Ed: “What’s important now is totally different to what it used to be. Re-evaluation I put it down to, I think, reevaluate what’s important in life.” [38]

(11) “On the one hand, the struggle and decline was related to failing expectations. It was a time of uncertainty and loss of control.” [32]

Theme 3: Mood

Mood changes after DBS were reported by at least half of studies included in this review. However, although supported with moderate confidence, there is great heterogeneity in manifestation, with a range of different emotional experiences reported by patients, including both positive and negative emotions. Depressive symptoms, for example, vary depending on the patient (example 12). Anxiety (example 13), irritability (example 14), impulsivity (example 15) and sensitiveness (example 16) are reportedly increased after surgery. On the other hand, a few participants also mentioned being perceived as more relaxed with the treatment (example 17).

(12) “In the nine patients followed up after DBS, personality changes experienced varied from positive mood changes ($n = 4$, e.g., being happier, more lighthearted, more euphoric) to negative mood changes (e.g., more depressed [$n = 2$]; angry, frustrated, grumpy, irritable [$n = 5$]).” [39]

(13) “I don’t have the feeling that I’ve become a different person. I haven’t but at the same time I’m not the same. I’m much more anxious. [...] (P12)” [28]

(14) “I’m probably more angry than I used to... I get a bit agro towards [spouse]... just suddenly started—when I can’t move—bang! I get cranky quick, agro. (P)” [39]

(15) “For instance, Patient 09 self-reported, saying: “I felt so good I tried to move the pool table and I ruptured the disc in my back [...] I blame DBS for that because I felt so good.” [21]

(16) “I have become much more sensitive. I cry over nothing and I also feel I have lost my drive. I have been through so much that I am emotionally....[Pause].... I find it hard hiding emotions” (Participant 8).” [32]

(17) “Some perceived changes, such as finding themselves or their loved ones more relaxed, positive, disinhibited, or with a cheekier sense of humor were positively valued by a few participants.” [28]

Theme 4: Social Relationships

Changes in social dynamics are highlighted by 12 studies. Both improvements and conflicts emerged from research data. Better social connections are attributed to greater motor capacities, when the latter improves patients’ self-confidence (example 18). On the other hand, the direct impact of patients’ attitude or personality change may stir familial and marital conflicts, especially when perceived negatively by caregivers and spouses (example 19). Except for sexual activity, which was mentioned in only two studies with low confidence (example 20), there is moderate confidence in the evidence regarding social relationships, exemplified as below:

(18) “Several participants experienced that they were able to take part in social gatherings that they had not been able to for a very long time. Participant 1 said: “Before the operation I was

always the first one to go home. Now I can stay out longer.” [32]

(19) “Patient 06: I think I have been causing a bit of problems in my relationships by being just so full on. [...] It’s a realisation I have to slow down that activity and make it more manageable for myself and my wife.” [21]

(20) “Patient 11: My sex drive has increased because I can control my body now.” [21]

One of the review findings, however, states how speech impairments created communication issues in the post-DBS life. It is one of the two review findings of high level of confidence, supported by a large number of studies conducted in different settings. Although such side effects are not necessarily prevalent in the samples, participants who mentioned struggles with communication attribute social difficulties or isolation to it (example 21). As seen in Thomson et al. [39]:

(21) “I’ve never had a stutter in my entire life, ever. It was only post-operation... Basically, my self-confidence has gone out the window and a lot of it is due to the bloody Parkinson’s, the—this, having the stammer. (P)”

Theme 5: Decision for Surgery

Regarding the decision process for surgery, different degrees of confidence in the evidence were raised. One of the two pieces of evidence with high confidence in this review relates to the existence of expectations other than motor improvement that patients recognize prior to DBS (example 22), of which the elimination of all symptoms and improvements in mood and relationships are examples. Nine studies support this finding:

(22): “With these concerns came hopes for desirable personality change with DBS, specifically a restoration of qualities lost through the disease or to simply go “back to normal.” Some hoped DBS would give them the “freedom and energy” to express their true self and act in the world in a way they value. Particular areas participants hoped to see change were mood (be a “happy person” not “miserable”), demeanor (“fun-loving” not “easily frustrated”), and social engagement and connection with others

(take “more of the world in” not just focus on illness).” [39]

On the other hand, other aspects of decision making are supported with low to moderate degrees of confidence. Moderate confidence supports the finding that patients do not have or do not adequately process information on the surgical procedure and expected outcomes (example 23), found in nine different studies. Fears and concerns with the procedure (example 24), optimal time for undergoing DBS (example 25), and final decision for surgery (example 26) are mentioned in six individual studies, deemed as of low confidence:

(24) “They stated that they were afraid of losing their good and nice side with DBS. Additionally, two participants stated that they were concerned that the battery would not function properly after the surgery.” [33]

(25) “Many regarded DBS as a serious surgical procedure done on the brain and considered it a last resort only when medications were no longer effective.” [27]

(26) “The decision to go ahead with the surgery was described as dramatic and unavoidable, because of increased disease symptoms and less levodopa effect.” [25]

Theme 6: Behavior

Seven different studies mention stubborn, excessive behaviors, such as becoming more rigid, inflexible, or impulsive, prevalent in at least part of the samples after DBS (example 27). A moderate degree of confidence in the evidence is allowed by minor to no concerns regarding methodological limitations, adequacy, coherence and relevance. In such cases, patients and caregivers attribute changes to the stimulation.

(27) “The inhibited manner appears as uncontrolled, aggressive or childish behaviour. They experience eruptions, stick their tongue out at other people, giggle uninhibitedly and make frivolous jokes. These patients described extreme states of being pumped up, and they developed different addictions (sexual addiction, shopping addiction, compulsive gambling, compulsive car racing). For all patients,

euphoria decreased after a certain period, e.g. by adjusting the patient's devices and the regulating mechanisms of the organism itself (as the patients claim)." [40]

On the other hand, reengagement in daily and professional activities, although mentioned by eight different studies, provide evidence of low confidence, mainly due to varying experiences reported by participants. While some participants embrace new chores or projects after motor improvement (example 28), others face diminished abilities, diminished self-confidence or lack of motivation to do so (example 29):

(28) "DBS increased the possibilities for patients to plan for and perform daily chores and hobbies, and for some the improvement of dyskinesia was the major gain after DBS." [24]

(29) "A few participants found their everyday life changed dramatically due to malfunction in stimulation or medication keeping them from engaging in new activities, or leaving usual activities on hold." [32]

Theme 7: Handheld Controller

The use of remote control is mentioned by patients in 4 different studies. However, both review findings in this category are of low confidence, since they are supported by few studies and present some degree of concern regarding relevance and methodological limitations. Although it is seen as "a tool to have more control over one's body" (example 30), there is also "anxiety around control use", which describes concerns about unintended effects of using the remote control to adjust their DBS settings (example 31).

(30) "A few patients mentioned the ability to modulate the amplitude of the stimulation with a remote control to better control certain symptoms as an advantage; however, most of the patients did not use it." [28]

(31) "[...] the setting of the DBS parameters was not considered as within their domain, and it was not something for them to deal

with, even if they knew how to adjust it. The tuning of the DBS device was described as vulnerable and sensitive, and in order "to be in charge of it," the patients deemed that it had to be done by a professional." [23]

Theme 8: Cognition

At last, the evidence of post-operatively cognitive issues presents the lowest level of confidence in this review, although cognition is mentioned by nine studies. In fact, some studies report improvements in memory and attention (example 32), whereas reports of decline appear in specific cases (example 33). Methodological concerns also emerged in many of the studies that supported this review finding, including limitations in the assessment of cognitive function and the potential for confounding factors to influence the results. Examples of this dual phenomenon appear in quotes such as:

(32) "For a few, increased self-confidence emerged from an internal experience of improved cognitive clarity and alertness, facilitating better engagement and connection with others." [39]

(33) "Mr. 22 said that less than two months after DBS, the negative impact on his balance and speech had totally prevailed over resolved tremor and now, one year after surgery, his memory also faltered." [24]

Discussion

This systematic review and qualitative synthesis aimed at understanding the experience of patients with DBS for Parkinson's disease from their own perspectives. To our knowledge, this is the first systematic review to provide a nuanced understanding of the ethical implications of DBS in individuals diagnosed with PD. The evidence largely suggests that the experience is highly individualized, with varying degrees of success and challenges. More importantly, psychosocial alterations, such as changes in mood, self-perception, or social relationships, are at the core of this experience, even in cases where motor improvement was significant.

In our study, we updated Mathers et al. [8] systematic review. In their work, although patients report

significant improvements in motor symptoms and activities of daily living, negative changes (or no changes at all) were found regarding social relationships, emotional wellbeing and cognition. In fact, while the outcomes of surgery were seen as positive, DBS still requires patients to transition from an old disease state to a new form of life, which includes trade-offs between stimulation parameters, medications, and symptoms [8]. For instance, the experience of DBS, while generally positive in reducing medication dependence and improving quality of life, also brings about challenges, particularly in adjusting to the implanted device and post-surgical care.

In this context, the findings highlight how the decision-making process for surgery involves ethical concerns, particularly regarding informed consent and patient autonomy. Many patients affirm feeling overwhelmed by this process, often due to inadequate information or unrealistic expectations. The evidence supporting these findings varies, with some themes showing low confidence due to methodological limitations, primarily associated with small sample sizes, undisclosed sample characteristics, and unclear data collection and analysis methods. These observations are consistent with Weaver et al. [41], who also noted variability in patient outcomes and highlighted the complexity of DBS's impact on different aspects of patients' lives.

Evidence from our review also points to the feeling of loss of control experienced by patients during treatment. While feelings of euphoria and freedom may instantly follow surgery, encounters with unpredicted effects or remnants of the disease might undermine patients' sense of self and autonomy. Mathers et al. [8] attribute the sense of normality to the ability to experience a certain level of control after DBS, which is crucial to an adequate adaptation process. This phenomenon is illustrated by Gisquet [31], indicating that patients want to control both the treatment and its effects. Similarly, the mixed feelings about the handheld controller reflect concerns regarding patients' ability to manage their own treatment effectively.

This issue gains relevance when accounting for the fact that most patients seem to expect psychosocial changes from the treatment. Our study maintains the conclusions of Mathers et al. [8], in that despite having enough information on the procedure, patients still hope to return to a state of premorbid normality.

Presurgical expectations, however, may influence treatment outcomes. Mameli et al. [9] found that when patients formulate overly optimistic expectations before surgery, QoL, perception of autonomy, and perceived motor outcomes are lower, even when motor improvement is objectively significant. This is supported by Maier et al. [10], which found that dissatisfied patients expected more improvements in mental state, social life or romantic relationships than patients who felt satisfied with DBS. On the other hand, while formulating unrealistic expectations may affect perceived outcomes, adjusting expectations before surgery increases satisfaction, even when symptoms do not improve or when psychosocial adjustment is absent or worsened [9].

Self-perception shifts, mood alterations, and social relationship dynamics further illustrate the profound psychological and social impact of DBS. In relation to mood changes, a recent systematic review found depression, mania/hypomania, psychosis, anxiety, suicidal ideation, and hypersexuality as the most common psychiatric disorders reported after DBS [2]. However, data remains controversial. Results from a meta-analysis focused on depression and anxiety after DBS are heterogeneous, with reports of improvements shortly after the surgery but becoming weaker with time [42], which was also found by Perestelo-Pérez et al. [43] with a smaller effect. Suicide rates were also considered unlikely [42].

In general, mood changes seem to emerge depending on electrode position, besides psychosocial factors. GPi-DBS, for instance, seems more favorable for depressive mood, when compared to STN-DBS; the opposite seems to apply for anxiety symptoms [42, 44]. However, more recent data points to an increase in apathy after STN-DBS, compared with pre-surgical and medication-only groups, despite dopaminergic treatment, disease progression or pre-existent psychiatric conditions [45]. Such differences in electrode placement are identified as a possible cause for different outcomes [2, 44]—which makes the lack of transparency and information regarding electrode position an important bias in qualitative studies.

While changes in humor are recognized both by patients and caregivers, it is possible to say they do not perceive changes in the same way, which may contribute to interpersonal challenges and difficulties in communication. These changes are supported by

moderate confidence, reflecting a consistent but not universally applicable pattern across the studies. This aligns with findings from Mathers et al. [8], which similarly emphasize the varied and deeply personal nature of patients' experiences with DBS. Similarly, Lewis et al. [46] found that patients and caregivers perceive postoperative quality of life (QoL) differently. In particular, while patient QoL scores improve significantly after surgery, caregivers report lower QoL scores at the same time point.

Regarding social relationships, in a meta-analysis of 13 studies by Zapf et al. [4], both improvements and deteriorations were found. With few exceptions, studies support changes in different directions, depending on the quality of the relationship, communication levels and pre-existent conflicts. Hypersexuality is also mentioned as a core cause of strain in marital relationships, decreasing social adjustment post-surgery. The same issue is reported by Mathers et al. [8], in that spouses must renegotiate roles after surgery, which might cause struggles within marriages. However, Zapf et al. [4] point to the lack of data that allows for clear conclusions about social maladjustment after DBS.

Similarly, varying effects on behavior and attitude also emerged from the findings. While some patients experience increased freedom and reengagement in daily activities, others struggle with behavior changes. A meta-analysis by Razmkon et al. [47] found that impulse control seems to improve after surgery. In a more recent meta-analysis by Zapf et al. [4], irritability, aggressiveness, and impulsivity are mentioned as causes of maladjustment following DBS. Moreover, loss of initiative and decreased interest in activities is also mentioned in studies that point to behavior change after DBS, with Mathers et al. [8] as an example. The evidence raised by our review also varied, in that some findings show low confidence due to methodological limitations.

Finally, issues related to cognition underscore the need for further research and ethical consideration. The cognitive effects of DBS are particularly contentious, with reports of both improvement and decline, leading to the lowest confidence in this area. Wang et al. [3], in a recent meta-analysis, point to a general improvement in cognition, except for a decrease in phonetic and semantic fluency.

The same finding is reported in Perestelo-Pérez et al. [43]. Here again, patients and caregivers may not perceive these changes in the same way, highlighting the importance of personalized care and the need for continued ethical scrutiny in the application of DBS in Parkinson's disease.

Ethical Implications of DBS

Deep brain stimulation (DBS) for Parkinson's disease is uniquely significant due to the specific motor symptoms it targets, such as tremors, rigidity, and bradykinesia, which are not as prevalent in other disorders. The focus on Parkinson's disease stems from the established success of DBS in improving these motor symptoms, which are often refractory to medication. This specificity underscores the necessity of evaluating DBS within the context of Parkinson's disease, independent from its application in other neurological or psychiatric disorders. The unique risks, benefits, and patient experiences associated with DBS for PD demand tailored ethical considerations and regulatory frameworks, distinct from those required for other applications of DBS or different neurotechnologies. As noted by van Velthoven et al. [14], "though we can indeed learn from the ethical implications of the other neurotechnologies included in our review, it is equally important to acknowledge that relevant differences between these technologies may also exist". Given that different neurotechnologies have specific implications, there is a need to analyze each one of them to assess the conditions for acceptability and to develop further regulation and ethical guidance for the translation of these technologies into society [14].

Additionally, the ethical implications of DBS in PD, such as changes in self-perception, mood, and social relationships, are deeply tied to the nature of the disease and the particularities of its treatment. As seen in the results, the experiences of Parkinson's patients with DBS highlight issues of identity, autonomy, and quality of life that may not be as prominent in other contexts. Thus, while lessons can be drawn from the use of DBS in other disorders or from other neurotechnologies, the specific ethical challenges in Parkinson's disease necessitate a focused and context-specific analysis. This approach ensures that the ethical guidance and regulations developed are appropriately aligned with the unique needs and experiences of individuals with Parkinson's disease.

In this direction, empirical ethics offers a vital approach to understanding the ethical implications of medical interventions like DBS by integrating empirical research with normative ethical analysis [48, 49]. This approach is particularly relevant in the context of DBS for PD, where the experiences of patients and their caregivers reveal a complex interplay of benefits and challenges. Empirical data drawn from patient experiences helps to contextualize ethical principles, ensuring that ethical analyses are grounded in the lived realities of those affected by the intervention.

The variability in patients' experiences with DBS, as highlighted in the review, also underscores the importance of context-sensitivity in ethical evaluations. Musschenga [49] notes that "all conceptions of empirical ethics have in common a concern with the context-sensitivity of ethical principles, guidelines, and recommendations as an essential part of the job of ethics. Care for context-sensitivity requires that ethics cooperate with the empirical sciences" (p. 485). By engaging with disciplines such as sociology and psychology, empirical ethics can more accurately reflect the diverse ways in which patients and caregivers experience and interpret the impacts of DBS, thereby refining ethical guidelines to be more attuned to these nuanced realities.

Moreover, empirical ethics is crucial when considering DBS, as the moral implications of the treatment may vary significantly depending on the personal, social, and cultural contexts of the individuals involved. By uncovering the "moral sources" embedded in the everyday experiences of those undergoing DBS, it provides a more nuanced and contextually informed ethical analysis, contributing to the responsible development and application of such medical technologies.

The ethical implications for practice, based on these findings, underscore the need for comprehensive patient education and informed consent processes that go beyond the technical aspects of DBS. The evidence suggests that while patients often experience significant motor improvements, the psychosocial alterations—such as shifts in self-perception, mood changes, and social relationship dynamics—are equally critical and may not be sufficiently explored by clinicians during pre-surgical assessments. The variability in patient experiences, particularly in areas of mood and self-perception, indicates that these aspects need to be explicitly addressed with patients

and their caregivers prior to surgery to set realistic expectations and prepare them for the potential challenges.

Moreover, the review highlights the importance of integrating psychological support, such as psychotherapy, into the treatment plan for patients undergoing DBS. The psychosocial stressors and emotional fluctuations reported by patients suggest that ongoing psychological care is crucial to help them navigate the complexities of post-surgical life. This approach calls for necessary caution in identifying and managing these stressors during pre-surgical assessments, ensuring that patients are not only physically but also mentally prepared for the outcomes of DBS. Addressing these ethical considerations in practice can lead to more holistic care, ultimately improving the overall quality of life for patients receiving DBS.

In this context, studying the ethical implications of DBS is crucial for promoting the responsible development of new interventions. As Kanter et al. [50] emphasize, such studies can serve as valuable resources and educational tools for scientists, engineers, and clinicians by providing an overview of the ethical considerations relevant to their work. By systematically examining the psychosocial and ethical dimensions of DBS, we can offer insights that inform clinical practices and guide the development of patient-centered approaches. This ensures that technological advancements like DBS are implemented in ways that respect and prioritize patient well-being.

Moreover, as Davies et al. [12] point out, "systematic reviews in the field of bioethics are relatively rare". This makes the analysis of DBS's ethical implications particularly valuable, as it helps bridge the gap between technological innovation and ethical practice. By conducting these reviews, we contribute to a growing body of knowledge that supports ethical decision-making in healthcare, fostering a more reflective and responsible approach to the use of neurotechnologies like DBS. This, in turn, can help clinicians anticipate and mitigate potential ethical challenges, ultimately leading to more informed and compassionate care for patients.

Implications for Practice, Policy, and Future Research

The results of this review have several important implications for clinical practice, policy development, and future research related to DBS in persons

diagnosed with Parkinson's disease. In practice, these findings highlight the need for a more comprehensive and individualized approach to patient care, particularly in the pre-surgical phase [51]. Clinicians should ensure that patients and their caregivers receive thorough and realistic information about both the potential benefits and the challenges associated with DBS, including the psychological and social impacts. This approach would help manage expectations and improve the informed consent process [52, 53], addressing ethical concerns about patient autonomy and the quality of decision-making.

From a policy perspective, the variability in patient experiences and the moderate to low confidence in many findings suggest that existing guidelines for DBS may need to be revisited and refined. Policy-makers should consider incorporating recommendations for routine psychological assessments and support, both before and after DBS surgery, to better address the psychosocial and cognitive challenges that patients and caregivers may face [52–54]. Additionally, policies could be developed to standardize the follow-up care and support provided to patients, ensuring that issues such as mood changes, self-perception shifts, and social relationship dynamics are adequately managed.

Future research should focus on addressing the gaps and limitations identified in this review. There is a need for more high-quality, longitudinal studies that explore the long-term psychosocial and cognitive effects of DBS in diverse patient populations [54]. Cross-cultural research is also needed to address the lack of diversity in current DBS research. Furthermore, research should aim to develop better tools for assessing the broader impacts of DBS on patients' lives, including their relationships and social functioning. By advancing our understanding of these complex issues, future studies can contribute to the development of more effective and ethically sound interventions for patients undergoing DBS.

Limitations

The review presents valuable insights into the ethical implications of DBS for PD, but several limitations should be acknowledged to provide a more balanced understanding of the evidence. One significant limitation is the exclusion of articles written in

languages other than English. This exclusion potentially biases the results by omitting studies that capture cultural differences in patient experiences, perceptions, and ethical considerations. As DBS is used globally, the lack of non-English studies means that important perspectives, particularly from non-Western contexts, might be underrepresented, leading to a less comprehensive understanding of the global ethical landscape surrounding DBS.

Another limitation is the heterogeneity of the included studies, particularly regarding study design, sample size, and methodological rigor. The review findings often have only moderate to low confidence, partly due to these variations, which can affect the consistency and reliability of the conclusions drawn. The differing methodologies across studies may lead to varying interpretations of similar phenomena, complicating the synthesis of results and potentially obscuring important nuances in patient experiences and ethical implications.

Finally, the review might be limited by the underrepresentation of long-term outcomes. Many studies focus on short- to medium-term effects of DBS [54], but the ethical implications of DBS might evolve over time as patients adapt to the treatment and as the disease progresses. Longitudinal studies that follow patients over extended periods are essential for capturing the full spectrum of ethical concerns, including changes in self-perception, mood, and social relationships that may develop years after the initial treatment [54]. Without such data, the review may not fully reflect the long-term ethical challenges associated with DBS, leaving an important gap in the literature.

Conclusion

Deep brain stimulation for Parkinson's disease can offer significant improvements in motor function and quality of life, although the patient experience is highly individualized, with varying degrees of success and challenges. Psychosocial changes, such as shifts in mood, self-perception, and social relationships, are at the center of this experience, even in cases where motor improvement was significant. The confidence in the evidence supporting these findings varies, mostly showing significant methodological limitations. By systematically examining the psychosocial and ethical dimensions of DBS, we offer

insights that inform clinical practices and guide the development of patient-centered approaches. This ensures that technological advancements like DBS are implemented in ways that respect and prioritize patient well-being.

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Data Availability Additional files (such as search strategy) are available at Open Science Foundation through the following link: https://osf.io/nzj2v/?view_only=75036aaaea5a4732ad5671881798f7a1

Declarations

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Consent Not applicable, since this is a systematic review study.

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