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ORIGINAL PAPER

A Mixed-methods Study of Deep Brain Stimulation's Temporal Impact on Parkinson's Disease Patients: Insights from Short-, Medium-, and Long-term Experiences

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Abstract

Introduction Deep brain stimulation (DBS) is a well-established neurosurgical treatment and is considered the standard of care for refractory Parkinson's disease (PD). While the evaluation of DBS outcomes is often focused on therapeutic efficacy and motor improvement, this approach overlooks patients' daily functioning and their adaptation to living with the device over time.

Objective This study aimed to explore the lived experiences of patients with varying durations of DBS treatment—short-term, medium-term, and long-term—focusing on satisfaction, concerns, and the emotional trajectory post-surgery.

Methods A mixed-methods, cross-sectional study design was adopted, combining qualitative interviews and quantitative semantic network analysis to investigate patients' journey with DBS. Patients were categorized into three groups of experience, based on the time spent with the device (short, medium, and long-term), and their narratives about surgical experiences, management preferences, and emotional adjustments were explored.

Results Regardless of the time passed with the device, patient satisfaction and motivation remained consistent, alleviating concerns about the potential negative impact of DBS on the individual. Findings demonstrated a need for timely education about the realistic expectations of DBS and the changing demands of PD management. The study revealed diverse surgical experiences and preferences for treatment strategies, emphasizing the importance of tailored support at each stage of the DBS journey.

Conclusion This study reveals that the lived experiences of patients implanted with DBS can have different nuances at different time periods. Furthermore, it highlights the value of integrating qualitative and quantitative approaches to better understand patient experiences with the treatment. Our findings suggest significant implications for health policy, personalized medicine, and enhancing the doctor-patient relationship by promoting realistic expectations and individualized patient support.

Keywords Deep brain stimulation · Parkinson's disease · Patient's experience · Long-term outcome · Qualitative secondary analysis · Natural language processing

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Introduction

Deep brain stimulation (DBS) is a neurosurgical treatment in which electrodes are implanted in specific brain regions to deliver electrical impulses; it is used for a range of neurological and psychiatric conditions but is particularly well-established as a standard of care for refractory Parkinson's disease (PD) [1]. The prevailing evaluation of long-term outcomes in DBS for PD focuses primarily on therapeutic efficacy and motor performance indices, lacking a comprehensive assessment of patients' daily functioning over time [2]. Indeed, it has been repeatedly emphasised that, in addition to monitoring motor outcomes and routine clinical follow-up, it is crucial to accompany these with systematic qualitative observations that explore how patients' experiences evolve [3]. This approach would enhance the understanding of the temporality and evolution of experiential phenomena encountered by individual patients while enabling in-depth exploration of pivotal transitions of experience within the journey with DBS [3]. On a broader scale, incorporating qualitative observations throughout the clinical follow-up may reveal gaps in extant research perspectives, affording a more comprehensive understanding of the multifaceted and complex impacts of DBS. This, in turn, may catalyse the implementation of innovative practices within clinical contexts [4, 5].

Patients experience diverse and challenging postoperative phases, with substantial variation observed among individuals, including facing unmet needs that extend beyond motor outcomes. For instance, little or no marked improvement in occupational function, interpersonal relationships, leisure activities, or patient expectations related to professional life, daily activities, marital relations, and social adjustments that often go unfulfilled [6–8]. Numerous qualitative studies on PD patients with DBS have been conducted, often retrospectively, by interviewing them and analysing their lived experiences based on their own narratives and perspectives [4, 5, 9–14]. This body of research has been crucial in highlighting under-reported effects that may not be fully captured by standard medical assessments but still significantly impact patients' daily lives. Through these narratives, researchers have uncovered subtle psychological and social changes, such as shifts in identity, alterations in interpersonal relationships, and evolving coping strategies, which are often overlooked in more quantitative or clinical evaluations. However, how these aspects develop and transform as patients continue with long-term DBS treatment remains less explored. In their systematic qualitative review, Mathers and colleagues aimed to chronologically map the experiential trajectory of PD-DBS patients by identifying significant themes linked to various stages of the overall DBS process [15]. The review demonstrated that the sense of control, lost in late-stage PD, is not immediately restored post-surgery due to a complex adjustment to the post-DBS disease state. The prolonged and challenging nature of stimulation adjustments may extend hopes for unrealized outcomes, hindering swift accommodation to DBS [9]. However, there remains a notable gap in our understanding of how patients' experiences evolve over the medium to long term. This highlights a lack of comprehensive insights into the experiential trajectory of patients' conditions beyond the immediate aftermath of surgical intervention.

The present study adopts a mixed-methods cross-sectional design to compare patient experiences at different time points following DBS. This approach examines the diversity and complexity of experiences across short-, medium-, and long-term perspectives, to provide insights into the commonalities and variations in how patients adapt to and evaluate their treatment outcomes over different periods. To clarify, the objective of this study is not to trace a temporal progression, but rather to capture thematic patterns and narratives that characterise the experiences of different patient groups. We use a previously collected dataset of interviews with individuals diagnosed with Parkinson's disease who have undergone DBS for varying durations, ranging from 1 to 10 years. This study seeks to explore the short-, medium-, and long-term experiences of DBS. Our focus is to understand the subjective perceptions, challenges, and expectations of patients at these different stages, emphasizing a cross-sectional comparison rather than a developmental trajectory.

Finally, we will also seek to integrate the use of natural language processing (NLP) tools to generate semantic maps of themes for each group. By visualising key themes and their interconnections, we want to explore the potential contributions of NLP in qualitative research. These semantic maps may reveal underlying patterns in patients' narratives, providing new insights into the experiential dimensions of DBS and illustrating how qualitative data can be enriched and systematised using computational methods [16].

Materials and Methods

Data Source

The data used in this study comes from an extensive qualitative investigation conducted in Switzerland between 2018 and 2020, in collaboration with various Swiss hospitals. The original study involved collecting and exploring the diverse experiences of 44 patients diagnosed with PD undergoing assistive device treatments, including DBS or the Duodopa pump, along with their respective caregivers (for a detailed description of the study population, ethical approval, informed consent process, and data collection, see [9]). The study is part of the International Database of Individual Patients' Experiences research initiative (DIPEx International), which uses a narrative method developed by the Health Experiences Research Group at the University of Oxford [17] and adapted to the Swiss context [18]. The overall aim of DIPEx is to provide a wide audience (patients, carers, health professionals, and students) with diverse perspectives on different diseases and health conditions [19, 20].

Data Selection Criteria

For this study, we focused specifically on a subset of the original dataset, namely PD patients with DBS. The interview subsample was categorized into three groups based on the time passed since the device implantation surgery: 1) patients receiving the treatment for 1 to 2 years (referred to as the *'short-term experience'* group; n= 6), 2) patients receiving the treatment for 3 to 6 years (referred to as the *'medium-term experience'* group; n= 6), and 3) patients receiving the treatment for 7 to 10 years (referred to as the *'long-term-experience'* group, n= 6) (see Table 1 for subsample description).

Data were originally collected and analysed in the three official languages of Switzerland (German, Italian, and French) to ensure inclusivity and cultural sensitivity. For this study, the selected data were translated into English, with translations and back translations overseen by native speakers proficient in the respective languages. The purpose of this rigorous multi-stage translation protocol was to ensure precision and faithfulness to the original content while guaranteeing homogeneity for the Natural Language Processing (NLP analyses). This process was relevant given the researcher DS's proficiency in English and Italian exclusively.

Data Analysis

Qualitative Analysis

In the original study, data analysis was performed using the DIPEx methodology as a modified grounded theory approach, requiring an iterative process between data collection and analysis [18]. For a detailed description of methods from the original study and the DIPEx methodology, see [9, 10, 18].

For this study, a secondary data analysis was conducted on the original dataset from the primary study [9, 10]. In the primary study, researchers proficient in

Table 1 Descriptive statistics of the three groups of DBS patients

Group	Average Age at Diagnosis (range, mean, and median)	Size	Average Age at the Interview (range, mean, and median)	Gender (F;M)	Average Years with DBS (range, mean, and median)	Average Interview duration (min.) (range, mean, and median)
Short-term experience group	41–55; 48.3; 50.5	6	54–75; 65.5; 68.5	1;5	1–2; 1.7; 2	27–107; 60.7; 66
Medium-term experience group	49–55; 51.2; 51	6	59–73; 67.8; 69.5	2;4	3–6; 4.8; 5	31–150; 84.8; 101.5
Long-term experience group	41–55; 48.3; 50.5	6	58–75; 67.3; 68	3;3	7–10; 7.8; 7.5	31–68; 53.7; 56.5

the languages employed during the interviews undertook the coding process, thereby ensuring linguistic accuracy and contextual comprehension. The secondary analysis entailed a systematic re-examination of the original dataset, intending to investigate the differences and commonalities in the lived experiences of DBS patients across three distinct temporal groups: short-term, medium-term, and long-term DBS experiences. This analysis was conducted using the method of constant comparison [21–25]. Through this approach, we conducted comparative assessments between the three subgroups, identifying patterns that reflect how participants' experiences may vary depending on the duration of their exposure to DBS. This facilitated the recognition of themes across groups, ensuring that emerging patterns were meaningful and allowing for an assessment of saturation across the three temporal categories. This approach strengthened the reliability of our findings by providing a structured means of comparing experiences while maintaining consistency with the original coding framework. It is important to elucidate that the present analysis does not employ a longitudinal cohort of patients but instead refers to a set of cross-sectional groups of patients, divided into three temporal categories. This cross-sectional approach allowed the comparison and contrast of in-group experiences, without any assumption of longitudinal tracking.

Data Selection and Import

We selected a subset of data relevant to our specific research questions from the original Parkinson's DBS dataset. The selection process focused on categorising interviews by time since DBS intervention. Participants were grouped into three distinct categories based on this variable: 1–2 years post-intervention (short-term experience), 3–6 years post-intervention (medium-term experience), and 7–10 years post-intervention (long-term experience). Each group consisted of six individuals to ensure homogeneity within categories. The data subset included transcripts, field notes, the original coding file, and other relevant materials, which were imported into MAXQDA 2022 [26] for analysis. Based on the original coding tree, we used MAXQDA's data query and retrieval tools to identify, extract, and compare relevant segments across groups. This facilitated a systematic examination of patterns and variations within and between groups. Thematic analysis was carried out iteratively, starting with themes from the original study. These themes were refined to suit the specific aims of this research, ensuring a comprehensive exploration of participants' experiences. Our approach highlighted key themes that characterize each group, providing valuable insights into how DBS patients' experiences can change over different post-intervention periods. Ethical considerations were strictly adhered to. All transcripts were originally anonymised to protect participants' privacy, and MAXQDA's file security features were used to protect project data.

Quantitative Analysis

Semantic Network Analysis

We employed semantic network analysis as a systematic approach to complement and triangulate the findings from the qualitative analysis, an approach that allows to the overcome the intrinsic limitations of both approaches when taken alone, and that provides "great potential for exploring phenomena that matter in our mediatized society" [27]. In this method, which we successfully employed on other health-related topics [28], we look at how the base forms of words—called *lemmas* (for example, "running" becomes "run")—appear together in the text. Instead of fitting the text into preset categories, we let themes naturally emerge based on these word associations, or co-occurrences, offering a more fluid, continuous map of relationships between clusters of lemmas, rather than from a classification of the content into categories. This approach allows to explore how emerging clusters relate and overlap within the overall discourse, offering a nuanced understanding of the relative position and interconnection of themes. While semantic network analysis is useful for identifying common themes and their interrelationships, it does not capture more subtle aspects like tone or deeper, abstract meanings [29], which are better captured by the qualitative approaches described above. Qualitative approaches provide deep insights into the meanings and subtleties of the text, yet they might overlook the broader structural patterns. In contrast, the method described here offers a comprehensive overview of how themes interconnect across the entire discourse, though it may miss some of the finer nuances. By combining both methods, we can achieve a richer, more holistic understanding of the data [16].

The objectives of this analysis were threefold: to identify recurring themes concerning treatment outcomes and patient perspectives at different phases of DBS utilization; to cross-validate findings from qualitative analysis; and to investigate the utility of semantic network analysis and NLP methods, both for visualizing qualitative data and uncovering nuanced patterns or associations within the text.

To ensure scrutinizability and replicability, the code we developed for these analyses is available via a Zenodo repository [30].

Data Preprocessing

The textual data belonging to themes identified in the qualitative analysis were exported from MAXQDA as".csv"files. Three distinct files were generated for each thematic topic, each representing a different time-based subgroup.

For the preprocessing we used Python 3.11.5 and several libraries, including pandas, glob, os, regex, spacy, textblob, numpy, and word2vec (detailed information is available in the code) [30]. Data were imported and organized into structured DataFrames for systematic processing. Each text segment underwent a lemmatization process, transforming texts into lists of lemmas while preserving the context within sentences using both a “flat” and “convoluted” lemmatization approach – in flat lemmatization, the entire text becomes a single list of lemmas, whereas in convoluted lemmatization the text becomes a list of sub-lists of lemmas, where each sub-list represents a sentence. This structure facilitated both general and granular linguistic analysis. Lemma frequencies were computed (based on flat lemmatizations) and visualized through word clouds. To examine the relationships between lemmas, a co-occurrence matrix was calculated, based on convoluted lemmatizations. This matrix quantified the frequency of lemma pairs appearing within the same sentences and formed the basis for constructing **nodes** and **edges** tables, later used in Gephi for visualization.

Co-occurrence Analysis and Network Visualization

The co-occurrence matrix served as input for Gephi, an open-source tool for visualizing networks. Two tables were created: **a nodes table,** containing lemmas, their absolute frequency, and normalized frequency (proportional to the total lemmas); and an edges table, representing lemma co-occurrences, detailing the source and target nodes and their co-occurrence frequencies.

These data were visualized by importing them into Gephi, treating connections as non-directed. **Modularity class** was calculated with a resolution of 0.5 to detect clusters within the network, generating meaningful thematic groupings based on lemma co-occurrence [31, 32]. Node colors and topology reflect the modularity class, while their sizes, rescaled from 10 to 40, are determined by the normalized frequency of lemmas. Edges (i.e. the lines connecting the nodes) represent co-occurrences between lemmas, with line thickness indicating the frequency of co-occurrence. Layout adjustments, including Circle Pack layouts and edge pruning, were applied to represent the cluster topology based on the modularity class, and to improve the clarity of visualizations. The overall interplay of the different components in this analysis pipeline are schematically represented in Supplementary Fig. 1.

Integration of Data Sets

The quantitative and qualitative data sets were first examined independently before comparing the analyses to identify similarities and differences. This integration process facilitated the triangulation of participants’ experiences and outcomes across the different groups [16]. Triangulation entailed the comparison of themes emerging from qualitative coding with central nodes and clusters in the semantic maps, ensuring consistency and alignment between the methods. Pattern discovery focused on leveraging the semantic maps to identify connections, clusters, or gaps that complemented and expanded upon the qualitative insights, particularly in uncovering experiential patterns across the short-, medium-, and long-term DBS groups. Semantic maps were used to visualize the relationships and structures among themes, enriching our understanding of how patients’ lived experiences were interconnected. We employed several foundational mixed methods research techniques, including the use of visual displays, triangulation across data types, and tracing connections from one type of data to another [16].

Results

The findings are presented in a mixed-methods format, aligning with the methodological framework employed in this study, elucidating qualitative analysis with a visual representation of the semantic network map derived from the quantitative analysis of texts.

The qualitative analysis reveals that certain thematic domains had consistent resonance regardless of the duration of patients' experience with DBS, particularly aspects related to treatment decision-making and narratives surrounding the surgical procedure. Conversely, distinct disparities emerge across several themes among individuals who had undergone DBS for short-, medium-, or long-term periods, such as the descriptions of treatment benefits and side effects, as well as outlooks regarding future expectations.

DBS Intervention

Duration of the Surgery

For individuals in all three groups, the experience of surgery stands out as a particularly daunting moment. The length of the procedure, often several hours, leaves patients feeling mentally and physically exhausted. This duration not only increases stress, but also heightens feelings of anxiety and fatigue, shaping their overall experience of surgery.

One participant in the short experience group described the emotional toll of the procedure: "*The tears came to my eyes, and then my surgeon told the neurologist to stop because it was no longer possible. But really, every time, he'd ask me, 'How's it going?' I could feel my teeth clenching. Then other symptoms came up, and I started crying because I couldn't take it anymore. After six or seven hours of surgery, I was drained. Then they gave me something to help me sleep, and it helped a lot*" (Patient 40). This quote sums up the profound psychological stress that occurs during surgery. Repeated questioning by the medical team to assess the patient's condition becomes a source of stress rather than reassurance, increasing feelings of vulnerability. The expression of tears and the physical manifestation of clenched teeth underline the raw emotional experience of being under such duress for a prolonged period.

However, one participant from the long-term group had a slightly different perspective on the operation: "*Yes, it was actually good because they explained everything. You have to participate so they can see where the electrode is going. You count with your fingers, and once the electrode is in place, they put the battery in and you go to sleep. You don't experience that part. But yes, I didn't sleep the night before, and they couldn't give me any medication, so I almost fell asleep during the operation*" (Patient 21). Here, the patient's involvement in the process seems to provide a sense of agency, reducing anxiety. However, the admission of fatigue due to lack of sleep highlights a contradiction; while active participation can foster empowerment, it can also lead to overwhelming exhaustion at such a critical moment.

Unsettling Memories of being Awake

Despite some positive reflections, unsettling memories of the surgery remain, particularly in relation to the skull drilling required for screw insertion. Many participants described discomfort during this part of the procedure, illustrating the physical and psychological challenges they faced. One patient recalled, "*I think I was partly awake when I shouldn't have been. At one point, I felt they were stapling my head like a Bostitch. It was only later I realized that was when they closed the wound. I was probably more awake than they thought I was*" (Patient 5). This experience of being partially conscious during a traumatic medical procedure raises significant concerns about patient comfort and consent. The metaphor of being 'stapled' emphasises a dehumanising experience, reducing a complex medical procedure to an act of construction that can evoke feelings of helplessness and anxiety. Another participant expressed their discomfort more vividly: "*With the crown of thorns. That was the most unpleasant part of the whole thing. They screw this metal frame into your bones with sharp screws*" (Patient 27).

The phrase ‘crown of thorns’ illustrates the physical pain and psychological distress associated with this experience. This imagery evokes a sense of suffering akin to biblical aspects, deepening the emotional resonance of the surgical experience.

One long-term patient explained the physical aspects of the procedure: “*They have to cut, remove the hair, cut the skin, and then make a hole—eight millimeters is still not nothing. We had a setup to know where it is in the brain, so we have like a king’s crown on the skull*” (Patient 38). This detailed description highlights not only the invasiveness of the surgery, but also the complexity of navigating the brain’s anatomy. The comparison to a ‘king’s crown’ suggests a duality: while it represents a position of authority and importance, it also symbolises the burden of pain and the high stakes involved in such a procedure.

Interestingly, another long-term participant attempted to contextualise the fear: *“If you think about it, you are too scared of the operation, especially when they drill into your brain, but it’s like when the dentist drills, it’s so quick and then it’s over*” (Patient 21). This comparison seeks to reduce the fear associated with brain surgery by comparing it to a more common, though still anxious, experience. This juxtaposition reflects a coping mechanism and illustrates how patients may attempt to rationalise their anxiety through relatable analogies.

A Journey Worth Enduring

Despite these challenges, undergoing such an operation often leaves patients with a sense of empowerment and amazement at their resilience. One participant expressed: “*I’m still amazed today that I survived it*” (Patient 23). This statement reveals a transformative realisation; surviving the ordeal becomes a point of pride and a testament to their strength, underlying the journey from vulnerability to empowerment, reflecting a shift in perspective as they navigate their recovery.

Another participant reflected on the surreal nature of the experience: “*Somewhere, I theoretically still have photos, you know, with the wreath, where you feel like Christ. Then you wake up, and you’re actually healthy and still alive, and everyone is amazed*” (Patient 27). This evocative imagery encapsulates not only survival, but a spiritual or existential rebirth, placing the experience in a context that transcends the medical intervention.

This mix of fear, discomfort and eventual triumph highlights the complex emotional landscape surrounding DBS surgery. While the surgical experience is fraught with anxiety and physical challenges, it also becomes a pivotal journey that empowers patients, fostering a sense of agency and hope as they embrace the possibilities that lie ahead.

Semantic Networks for ‘DBS Intervention’ Experiences

The semantic network maps align closely with the qualitative analysis of patients’ surgical experiences, highlighting consistent and stable themes across all three maps. The nodes representing the most common themes, such as the surgical procedure, the duration of surgery and the unpleasant nature of the experience, are clearly identifiable throughout. In particular, the description of the DBS procedure consistently includes these themes, regardless of how long a patient has had DBS. However, as time passes after the procedure, the emphasis on the procedure diminishes and becomes less interconnected with other themes.

In Fig. 1, which captures narratives from patients with recent DBS experience, the map is dense, which may reflect vivid memories of the operation. The central node ‘operation’ is highly connected to clusters related to the emotional and physical aspects of the procedure, with terms such as ‘long’, ‘awake’, ‘unpleasant’, ‘pain’, ‘feel’, ‘frame’ and ‘injection’ featuring prominently.

Figure 2 illustrates themes from patients with medium-term experience of DBS. Here, while ‘surgery’ remains a central node, it is less connected to other clusters. The ‘time’ node becomes more prominent, linked to terms such as ‘remember’, ‘sound’ and ‘screw’, suggesting that patients recall specific moments, such as the unpleasant experience of drilling into the skull, rather than focusing solely on the procedure itself.

In Fig. 3, representing long-term DBS experiences, the ‘operation’ cluster is still central, but is now more associated with words such as ‘experience’, ‘place’, ‘therapy’, ‘month’ and ‘sleep’. It is less associated with words like ‘long’, ‘stressful’ and ‘exhausting’, although such feelings are still reported. This shift

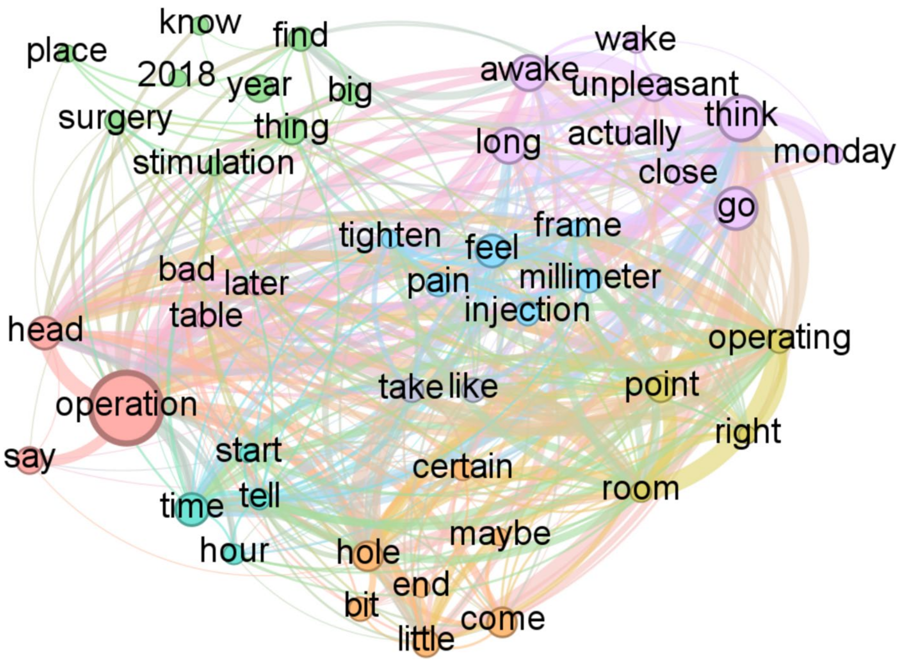

Fig. 1 A semantic network map illustrates the theme 'DBS intervention' for the DBS **short-term** experience group. In this group, patients have a relatively recent experience with DBS (1–2 years). The map visually represents the interconnectedness and clustering of concepts within participants' narratives when asked about the surgery experience. Nodes represent lemma frequencies; color and topology represent the cluster, based on modularity class; edges represent frequency of co-occurrence (see: Methods)

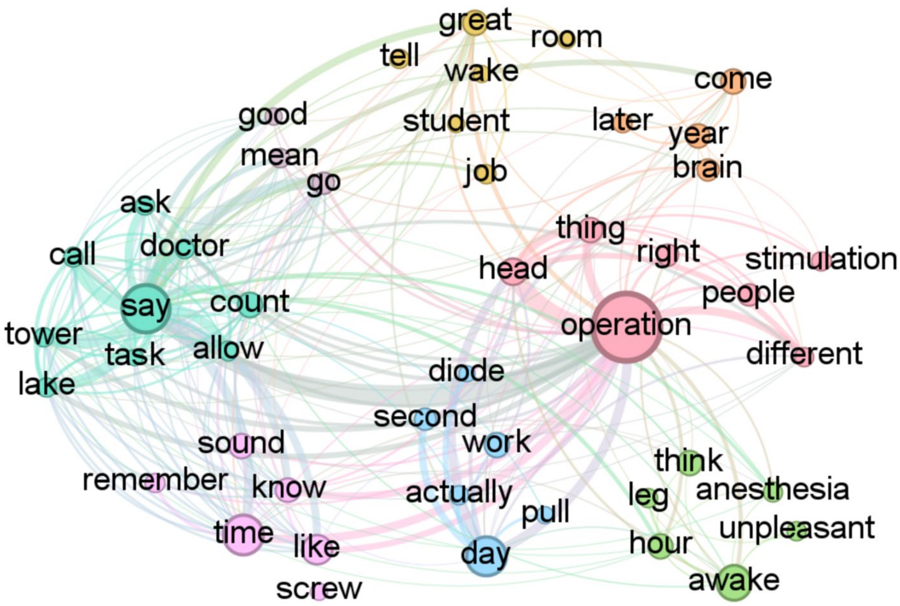

Fig. 2 A semantic network map illustrates the theme 'DBS intervention' for the DBS **medium-term** experience group. In this group, patients have a medium-term experience with DBS (3–6 years). The map visually represents the interconnectedness and clustering of concepts within participants' narratives when asked about surgery experience. Nodes represent lemma frequencies; color and topology represent the cluster, based on modularity class; edges represent frequency of co-occurrence (see: Methods)

suggests that memories of the surgery become less prominent over time, with patients now focusing more on the broader experience of living with DBS. Notably, a new theme related to 'batteries' emerges in this map, highlighting an aspect not addressed in the qualitative analysis. This may indicate that with longer-term use, battery management and recharging become an integral part of the overall DBS experience.

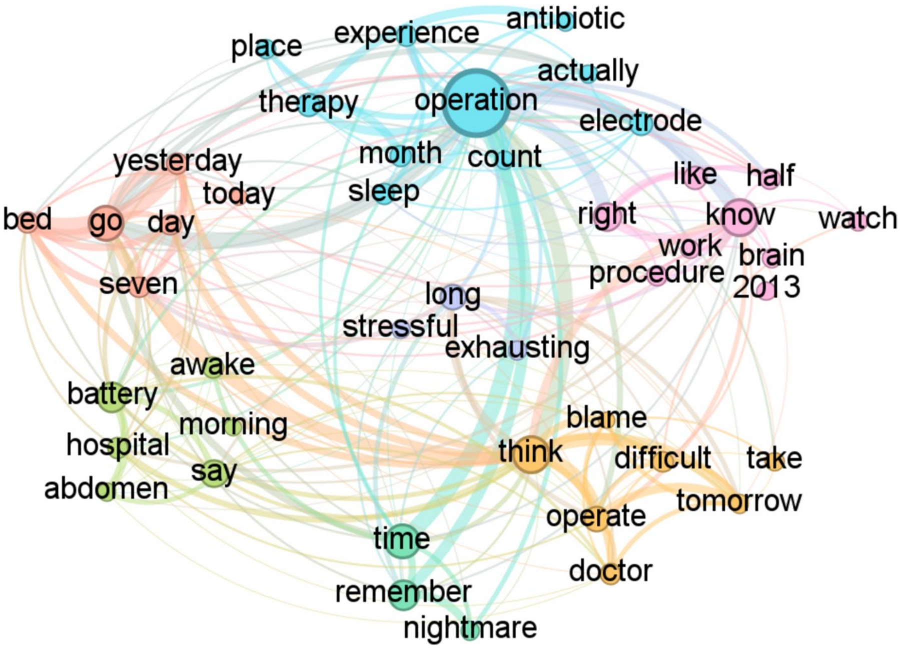

Fig. 3 A semantic network map illustrates the theme 'DBS intervention' for the DBS **long-term** experience group. In this group, patients have a long-term experience with DBS (7–10 years). The map visually represents the interconnectedness and clustering of concepts within participants' narratives when asked about the surgery experience. Nodes represent lemma frequencies; color and topology represent the cluster, based on modularity class; edges represent frequency of co-occurrence (see: Methods)

Life with DBS and Stimulation Effects

Individuals in all three groups express general satisfaction with DBS, noting a significant reduction in medication use and less fluctuation in their symptoms. Many report improvements in tremor, rigidity, and mobility, although some mention a decline in gait and speech. Contrary to previous literature suggesting that DBS could threaten one's sense of identity and personality, participants in this study attributed any perceived changes to their condition rather than to the treatment itself. Their narratives about the DBS experience and its effects show a nuanced evolution over time, reflecting their adaptation to the treatment and the changing nature of their experiences.

Short-term Experience with DBS

In the short-term experience group, patients are generally enthusiastic about their treatment results, with two distinct patterns in their responses: immediate appreciation and gradual adaptation.

Immediate Appreciation

For some patients, the benefits of DBS were felt almost immediately, extending beyond motor improvements to a restoration of a sense of purpose in life. One patient captured this feeling beautifully: "*I can do practically everything again. I have a perspective again, at least for the next ten years. A positive perspective*" (Patient 5, DBS short-term experience group). This renewed sense of agency reflects a profound shift; patients who previously felt constrained by their illness now feel liberated. Another participant echoed this sentiment: "*Now I can walk and do things again. Before, you were just tied up, dependent on others if you wanted to do anything*" (Patient 12, DBS short-term experience group). These quotes illustrate a powerful reclaiming of autonomy and highlight the emotional and psychological benefits of regaining control over one's life.

Gradual Adaptation

However, not all patients experienced immediate benefits. Some needed more time to adapt or reported minimal improvements: "*There are people who realise the effect very quickly, but there are people who need more time*" (Patient 27, DBS short-term experience group). For others, there was disappointment, as articulated by patient 23: "*Just that it doesn't work. Not the medication. Not the surgery*". This sense of futility was compounded by feelings of irritability and frustration after surgery, leading to a disturbing realisation of their altered emotional state:

"*After the surgery… I was irritable, belligerent and freaked out*" (Patient 23). This participant's struggle to reconcile their pre- and post-operative selves highlights the complex emotional landscape that can accompany DBS and illustrates the challenges some face in adjusting to their new reality.

Adaptation and Acceptance of Limitations

Despite these challenges, some patients emphasised the need to adapt to new limitations and adjust their expectations of treatment outcomes. "*I got used to a lot of things*,"explained one patient. "*After the operation, it suddenly became clear what was no longer possible and what was now possible again*" (Patient 15, DBS short-term experience group). This acceptance marks a crucial step in their journey and illustrates how patients navigate the psychological landscape of living with a chronic illness, coping with evolving realities.

Psychological Symptoms

In addition, some people in this group reported new or worsening psychological symptoms after DBS, which raised new concerns: "I have some kind of psychological situations, something depressive that I haven't experienced before… but it's just a change that I've noticed" (Patient 5, DBS short-term experience group). This acknowledgement of psychological changes, including hallucinations, suggests that while DBS may provide physical relief, it may also introduce new emotional complexities that require careful management. "Did you have these hallucinations before the deep stimulation?" the interviewer asked. "Not so much," replied Patient 19, highlighting how the treatment can amplify certain experiences rather than alleviate them.

Nevertheless, patients shared an overwhelming sense of euphoria in the first days and weeks after the procedure. One patient described the experience vividly: "*When I woke up from the anaesthetic and my wife and son came in, I was completely there. Just like before! Just like before the illness… It was really like a new life*" (Patient 5, short-term DBS experience group). This initial euphoria, often referred to in the literature as the 'honeymoon period', reflects a strong emotional response to recovery, although it may be tempered by the subsequent realisation of the need for ongoing adjustments to stimulation settings.

As they progressed through the first few years post-DBS, patients maintained a sense of anticipation about their improvements, often feeling that more could be achieved with further adjustments to their stimulation parameters.

Semantic Network Map for 'Life with DBS' in the Short-Term Experience Group

In Fig. 4, patients report positive effects associated with DBS, as shown by the 'life' cluster, which is associated with words such as 'give', 'new' and 'experience', while the 'stimulation' cluster is associated with 'effect' and 'positive'. In addition, the 'feeling' cluster, associated with words such as 'change' and 'different', emphasises the transformative effect of treatment. Although medication is still mentioned, in line with our qualitative analysis, it is mentioned in the context of the need for adaptation alongside stimulation.

Interestingly, the two tendencies identified in our qualitative analysis—immediate appreciation and gradual adaptation—are not as evident in this map. Similarly, the emergence of psychological symptoms is not reflected here. This highlights the importance of combining qualitative and quantitative data to capture the subtle nuances of patients' experiences of DBS.

A new theme emerges around the 'walk' cluster, linking terms such as 'problem', 'difficult' and 'good'. This suggests a complex, varied impact of DBS on motor functions such as walking, an aspect we did not address in our qualitative analysis. This highlights how semantic maps can uncover other relevant topics, in this case showing how DBS can have different effects on movement at this stage, working well for some patients but presenting challenges for others.

Medium-term experience with DBS

For those in the medium-term group (3–6 years post-DBS), the narratives reveal significant improvements in symptoms and overall well-being. The initial euphoria still lingers, but patients now express gratitude for the improvements in their quality of life, particularly in terms of mobility and motor symptoms.

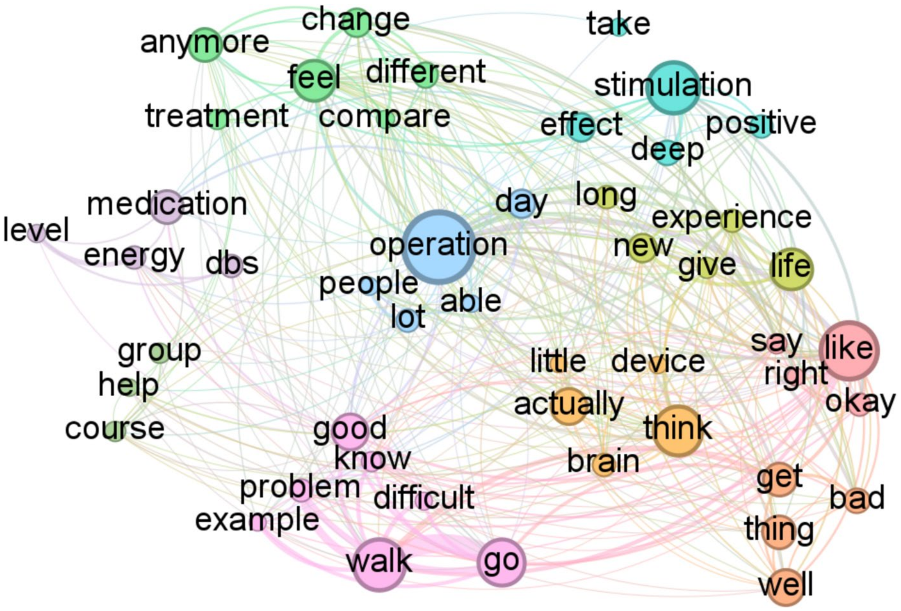

Fig. 4 Semantic network maps illustrating the theme 'Life with DBS' for the DBS **short-term** experience group. In this group, patients have a short-term experience with DBS (1–2 years). These maps visually represent the interconnectedness and clustering of concepts within participants ' narratives when asked to describe their life after DBS, changes in their daily routines, benefits, and potential side effects of stimulation. Nodes represent lemma frequencies; color and topology represent the cluster, based on modularity class; edges represent frequency of co-occurrence (see: Methods)

Decreased Efficacy Over Time

While many patients reported lasting benefits from DBS, some experienced a gradual decline in its effectiveness. "*I was better on my feet and everything. Everything was much better. But unfortunately it doesn't last… Now it's slowly getting worse again*" (Patient 27, DBS medium-term experience group). This variability in outcomes suggests that individual responses to treatment can vary widely, highlighting the importance of personalised care and monitoring.

Disease is still there, but more Manageable

Despite these challenges, many patients reported a greater sense of control with DBS than with medication alone. "*Of course it doesn't always go as well. But as long as I have the potential to turn up the power, it works*" (Patient 27, DBS medium-term experience group). This acknowledgement of disease progression, together with the ability to adjust stimulation parameters, illustrates a proactive approach to symptom management that allows patients to see their treatment as a tool for greater agency.

Furthermore, many narratives reflect a growing recognition of the ongoing impact of the disease, yet patients articulated that DBS made the journey more bearable: "*I think deep brain stimulation has made the whole thing more manageable*" (Patient 9, DBS medium-term experience group). This shift in perspective reinforces the idea that while the disease persists, DBS offers a means of coping with its challenges more effectively.

Semantic Network Map for 'Life with DBS' in the Medium-Term Experience Group

Figure 5 shows the thematic clusters identified in the narratives of patients with a medium-term experience of DBS. We can see that the 'good' and 'stimulation' clusters are interrelated and consistent with the qualitative analysis reporting satisfaction with DBS across all groups.

Consistent with our qualitative analysis showing that there is a recognition of the impact of the disease, the 'Parkinson' cluster reappears as a topic of discussion along with 'mood', 'swing' and linked to the 'operation' and 'medication' nodes, demonstrating that patients in this group are beginning to recognise how DBS, medication and the progression of the disease may interact and also reflect an ongoing adaptation.

Long-term experience with DBS

Interviews with the long-term experience group (7–10 years post-DBS) reveal a nuanced understanding of

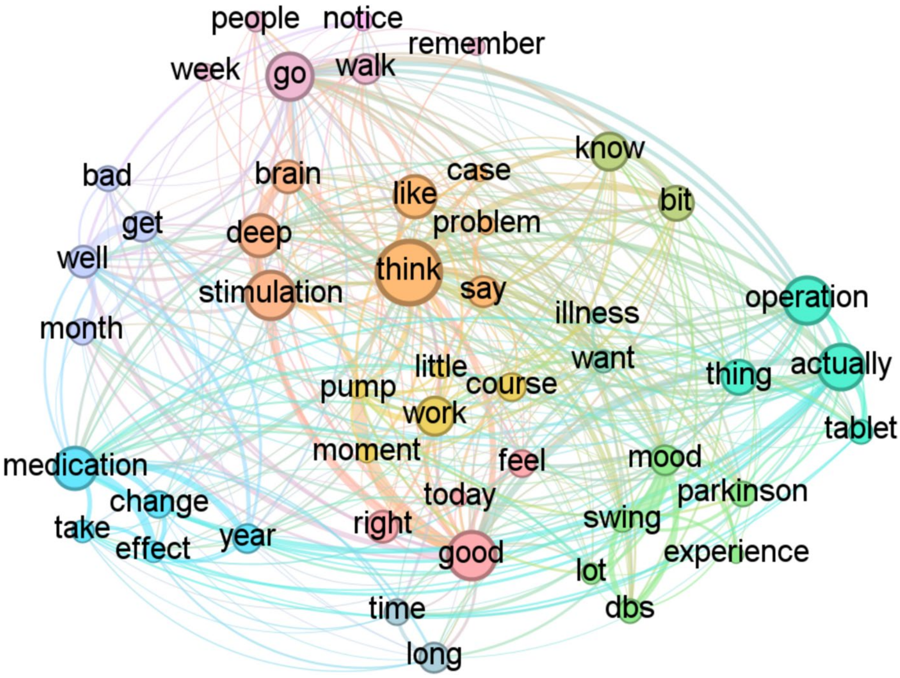

Fig. 5 Semantic network maps illustrating the theme 'Life with DBS' for the DBS **medium-term** experience group. In this group, patients have a medium-term experience with DBS (3–6 years). These maps visually represent the interconnectedness and clustering of concepts within participants' narratives when asked to describe their life after DBS, changes in their daily routines, benefits, and potential side effects of stimulation. Nodes represent lemma frequencies; color and topology represent the cluster, based on modularity class; edges represent frequency of co-occurrence (see: Methods)

their treatment outcomes. Patients' narratives shift from assessing the benefits of DBS solely in terms of symptom relief, to acknowledging the potential severity of their symptoms had they not undergone the procedure. Their reflections highlight the importance of considering the wider context of living with a chronic condition.

Bodily Transformations

"*I haven't changed, but my body has; it's been able to do more again*" (Patient 35, DBS long-term experience group). This statement emphasises the distinction between their sense of self and their physical abilities, suggesting that while personal identity may remain intact, the body has benefited from the intervention. Another patient remarked, "*When you have DBS, you have to reinvent your body*" (Patient 21, DBS long-term experience group). This metaphor highlights the transformative journey patients go through as they learn to navigate their bodies and identities in new ways.

A New Lease on Life

Many participants described their experience in existential terms, reflecting on the new lease of life that DBS has given them: "*It's a new life. I have a new life. And that's a tremendous experience. Even if it gets worse now, I can't say what it would be like without the operation*" (Patient 12, DBS long-term experience group). This sentiment reinforces the idea that although symptoms may persist or evolve, the initial intervention has opened doors to a better quality of life and new ways of managing their condition.

Conversely, some patients recognised the need for ongoing medication alongside DBS: "*If you do the stimulation, it's not like you get off your medication soon. You have to go back on medication soon*" (Patient 1, long-term DBS experience group). This acknowledgement represents a realistic approach to treatment, understanding that while DBS offers significant benefits, it is not a panacea.

Through these evolving narratives, the complexity of living with DBS unfolds, revealing a delicate balance between improvement and ongoing challenges, identity and transformation, agency and adaptation. Each patient's journey with DBS is uniquely their own, marked by triumphs and trials that shape their understanding of living with a chronic condition.

Semantic Network Maps for 'Life with DBS' in the Long-Term Experience Group

Figure 6 illustrates the semantic network for the narratives of patients with long-term DBS experience.

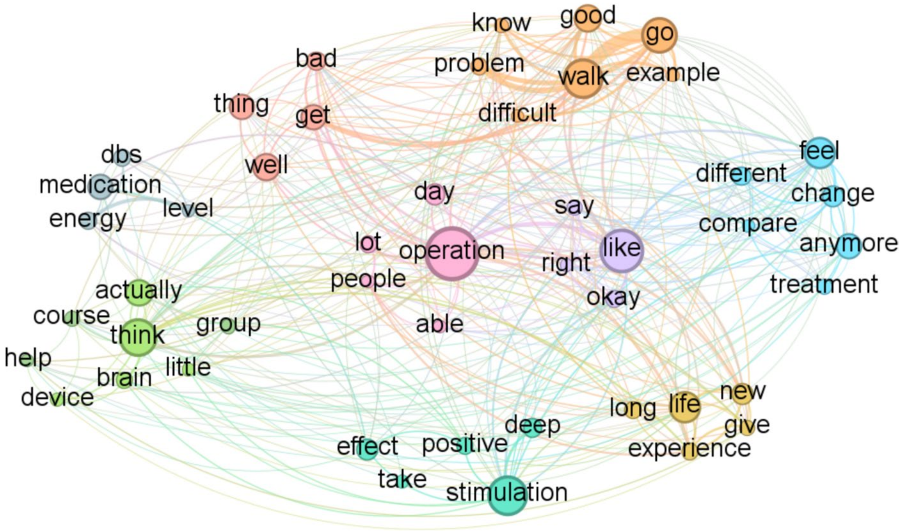

Fig. 6 Semantic network maps illustrating the theme 'Life with DBS' for the DBS **long-term** experience group. In this group, patients have a long-term experience with DBS (7–10 years). These maps visually represent the interconnectedness and clustering of concepts within participants' narratives when asked to describe their life after DBS, changes in their daily routines, benefits, and potential side effects of stimulation. Nodes represent lemma frequencies; color and topology represent the cluster, based on modularity class; edges represent frequency of co-occurrence (see: Methods)

Our qualitative analysis identified that issues related to gait and walking ability become more prominent over time, which is reflected in the corresponding semantic network map for long-term DBS patients, particularly in the 'walk' cluster.

The theme of having a "new lease on life", reported in our qualitative findings for this group, is also represented in the semantic network by the 'life' node, associated with terms like 'new,' 'give,' 'long,' and 'experience.' Interestingly, nodes such as 'medication' and 'feel' appear in both the short-term and long-term DBS experience maps. This may suggest that while patients with short-term DBS experience encounter similar challenges to those with long-term experience, they do so in different contexts.

For example, patients in the short-term group often report feelings of change or concerns about medication as they navigate the process of finding the right balance between medication and DBS stimulation. In contrast, long-term DBS patients report similar themes, but their narratives reflect how the stimulation itself may reach its limitations over time, leading them to rely more heavily on medication as their disease progresses.

However, the semantic maps do not capture the bodily transformation themes we identified in our qualitative analysis, underscoring the need to combine both qualitative and quantitative data to provide a comprehensive understanding of the narratives and the broader themes they encompass.

Technical Issues

The technical aspects of the DBS device are essential in creating personalised care plans that meet each patient's unique needs and preferences. Throughout their journey with DBS, patients consistently turn to healthcare professionals for guidance on device management, including battery checks, replacement and monitoring practices. Interestingly, the themes around the technical aspects of DBS remained largely consistent, whether patients were at the beginning of their treatment or years into it. However, subtle differences emerged in patients' perspectives on remote control use, battery preferences, and experiences with device programming. These differences often reflected personal preferences rather than technical concerns.

For many patients, the most valuable feature of their DBS device is the ability to remotely monitor battery levels. However, the ability to adjust stimulation settings remotely tended to be seen as less important. Patients often express that this feature is of limited benefit for symptom management, indicating a general feeling of ambivalence towards it.

One patient ironically described their approach to remote control usage: *"Interviewer: Who's got the remote control? Do you have a remote control? Patient: Fortunately not. <laughing> Interviewer: <laughing> Why fortunately not? Patient: Because it could fall into the wrong hands." (Patient 40, DBS short-term experience group)*

Another shared a more practical perspective, noting that they primarily use the remote to comply with travel regulations: *"Yes, for example, I use remote control to switch off when I'm on the plane. I don't fly much, but when I get on the plane, I have to switch it off. And yes, mainly like that. But I don't do much else. Sometimes it has worked—a very small transparency where I can raise or lower something. Sometimes that helped me afterward in the idea that it could be a bit more or more stimulating. But this thing, this distance, is relatively small. You can't do very much there." (Patient 9, DBS medium-term experience group).*

Long-term patients appreciate the ability to check their settings, but also recognise the limitations of this control: *"Yes. I lowered it a bit a week ago. I use it occasionally, just to check. But I don't change it every day or much. I think I'm actually not badly adjusted. What I might do, maybe this week, is to lower it a bit on the other side because I'm getting more and more cramps in this upper arm, which are very painful. Yes, that can help." (Patient 12, DBS long-term experience group).*

These stories illustrate the delicate balance patients maintain with their DBS devices, navigating the technical aspects while recognising the human element in their care and treatment.

Semantic Networks for 'Technical Issues with DBS'

The semantic maps reveal smaller clusters due to the limited corpus size for this theme. Yet it is possible to discern those discussions about the technical aspects of the device, including battery energy checks and stimulation programs, as well as the use of remote control, are consistently present across different durations of DBS experience. Nevertheless, semantic network maps become more informative with larger text corpora. In this context, while the maps do capture the overarching topics, they may not fully capture the nuanced narratives across different groups (Figs. 7, 8, and 9).

Wishes for the Future

A thematic gradient is revealed when analysing patients' hopes for their future in relation to DBS treatment, with distinct emphases observed across the three experience groups. Across all cohorts, patients consistently express a desire for stability and the preservation of treatment effects. Conversely, those with short- to medium-term experiences with DBS articulate more pragmatic hopes, focusing on specific disease aspects such as fatigue and mobility. Conversely, as individuals progress from medium to long-term experiences, their aspirations evolve into more expansive, abstract wishes centred on the ability to live life without significant challenges. This progression reflects a shift from immediate, tangible concerns to overarching goals as patients navigate their paths with DBS over time.

Short-term Wishes

In the early stages of the DBS experience, patients disclose a complex array of interconnected aspirations, all of which remain firmly anchored in the practicalities of their condition. Their aspirations encompass diverse aspects of life, ranging from the management of symptoms to the enhancement of overall quality of life.

Reduced Fatigue and Improved Mobility

Fatigue is a major concern for patients, with profound implications for their mobility and quality of life. One patient articulated that a reduction in fatigue would naturally result in enhanced mobility: *"Ah, to be able to not have this fatigue. I think if I don't have this fatigue, it will automatically improve my walking. Because my walking depends on fatigue too."* (Patient 44 – short-term experience group), underlining the intricate relationship between fatigue and mobility.

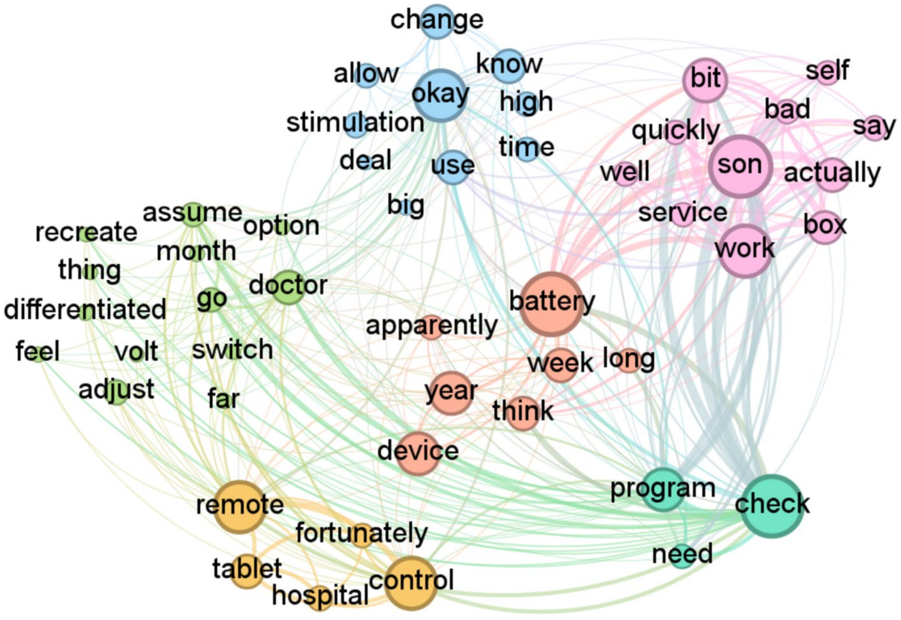

Fig. 7 Semantic network maps illustrating the theme 'Technical issues with DBS' for the DBS **short-term** group. In this group, patients have a short-term experience with DBS (1–2 years). These maps visually represent the interconnectedness and clustering of concepts within participants' narratives when asked to describe the technical aspects of DBS. Nodes represent lemma frequencies; color and topology represent the cluster, based on modularity class; edges represent frequency of co-occurrence (see: Methods)

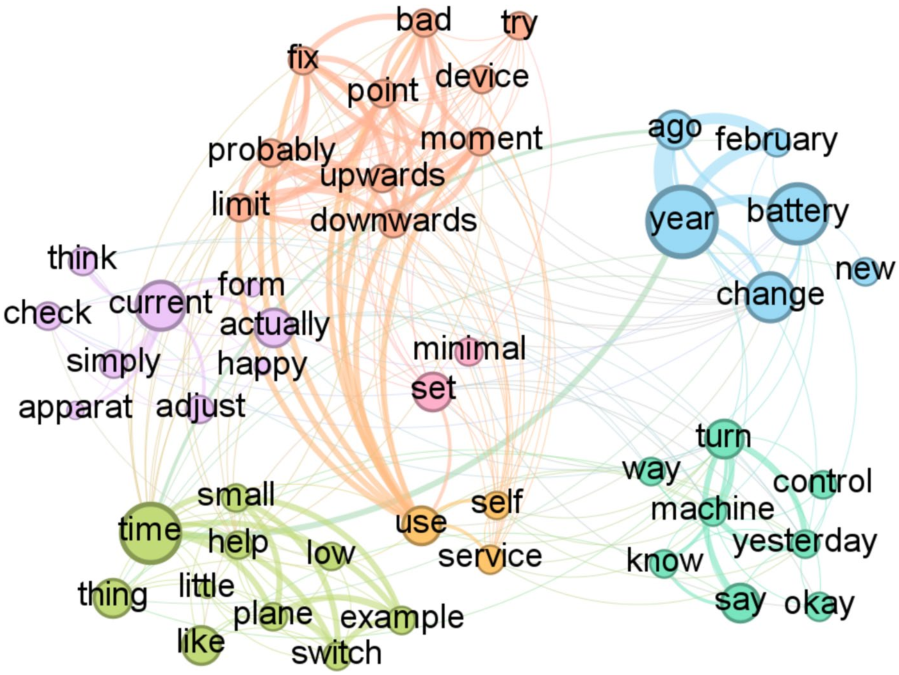

Fig. 8 Semantic network maps illustrating the theme 'Technical issues with DBS' for the DBS **medium-term** group. In this group, patients have a medium-term experience with DBS (3–6 years). These maps visually represent the interconnectedness and clustering of concepts within participants' narratives when asked to describe the technical aspects of DBS. Nodes represent lemma frequencies; color and topology represent the cluster, based on modularity class; edges represent frequency of co-occurrence (see: Methods)

Long-Lasting Effects of DBS

Many patients place a high value on the sustained benefits of DBS, regarding long-term efficacy as being of paramount importance for the maintenance of independence and functionality. One patient articulated this hope with the following statement:. *"That it stays as long as possible as it is now. That's actually the great hope—that I can maintain the level I've reached for as long as possible."* (Patient 05 – short-term experience group). This underscores the importance of ensuring the durability of DBS, reflecting a shared

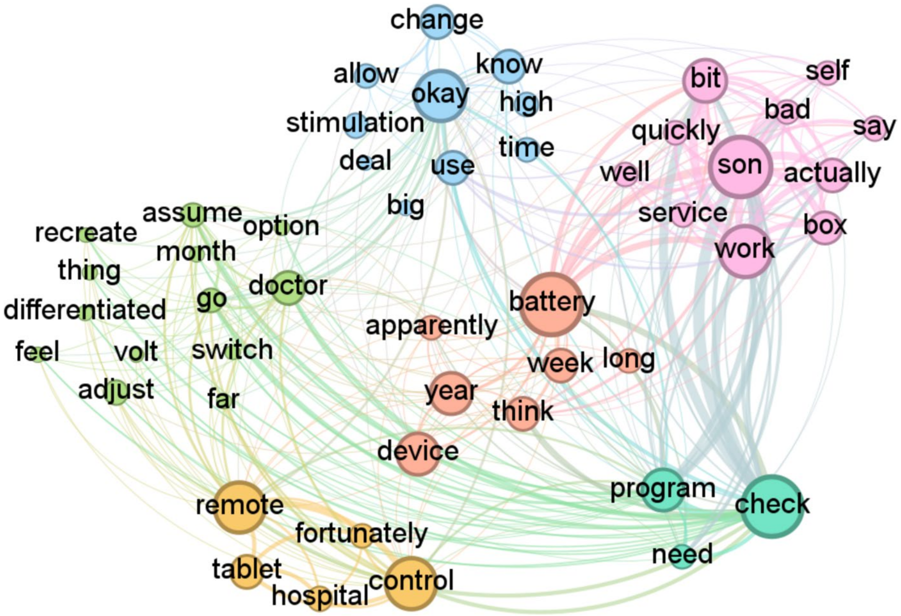

Fig. 9 Semantic network maps illustrating the theme ‘Technical issues with DBS’ for the DBS **long-term** group. In this group, patients have a long-term experience with DBS (7–10 years). These maps visually represent the interconnectedness and clustering of concepts within participants’ narratives when asked to describe the technical aspects of DBS. Nodes represent lemma frequencies; color and topology represent the cluster, based on modularity class; edges represent frequency of co-occurrence (see: Methods)

aspiration for long-lasting improvements in managing a chronic condition.

Minimizing Reliance on Medication

A common objective among patients is to minimise their reliance on medications and the adverse effects that can accompany them. One patient expressed the view that DBS could be a potential solution to this problem:

“That it lasts as long as possible, that the effects last as long as possible, and that I can live like this for years to come. Without having to medicate too much.” (Patient 40 – short-term experience group). This sentiment underscores the need for treatments that not only effectively manage symptoms but also minimise the burden of pharmaceutical interventions.

Consistency in Daily Functioning

For some patients, attaining stability within their daily routines represents a primary aspiration, with the objective being to mitigate the unpredictable nature of PD symptoms. One participant articulated this aspiration as follows: *“A homogeneous course of the day and fewer downward fluctuations.”* (Patient 19, DBS short-term experience group).

Semantic Network Maps for ‘Wishes for the Future’ in the Short-Term Experience Group

The results of the qualitative analysis, in which patients express desires for reduced fatigue and improved mobility, indicate the presence of a ‘fatigue’ cluster (see Fig. 10). This cluster features recurring terms such as ‘improve’, ‘walking’ and ‘able’. Conversely, a ‘dyskinesia’ cluster is evident, comprising words associated with the symptomatology.

A notable observation is the presence of a ‘long’ thematic cluster, which encompasses terms such as “possible,” “reach,” “stay,” and “maintain,” all connected to the ‘future’ node. This observation is in line with the concept of patients hoping to prolong the beneficial effects of stimulation while minimising medication-related side effects.

Medium-term Wishes

Patients with a medium-term experience with DBS, express wishes that reflect a deeper understanding of their condition.

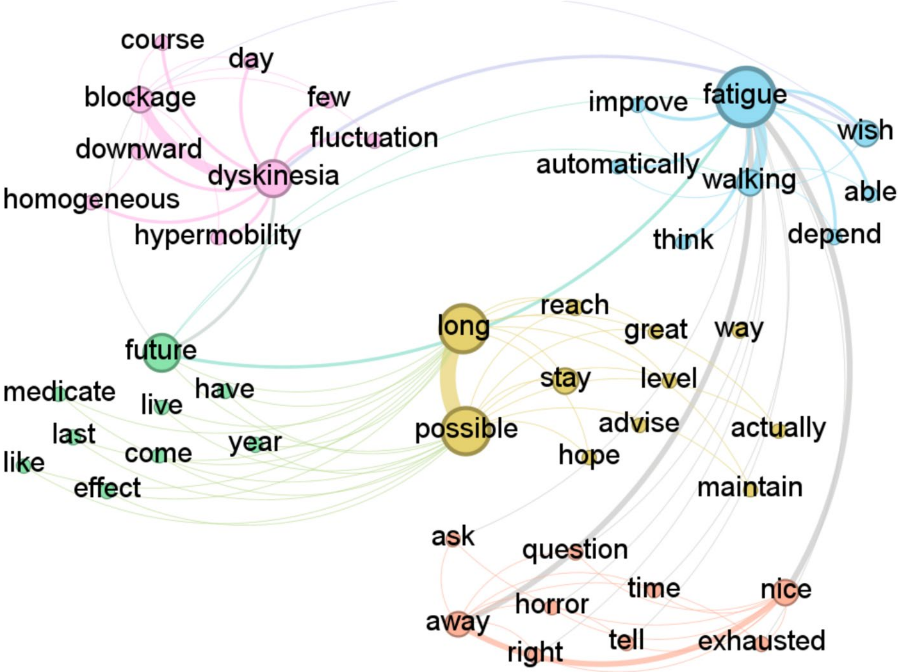

Fig. 10 Semantic network maps illustrating the theme 'Wishes for the future' for the DBS **short-term** experience group. In this group, patients have a short-term experience with DBS (1–2 years). These maps visually represent the interconnectedness and clustering of concepts within participants' narratives when asked about their aspirations and desires for the future across different time horizons post-DBS treatment. Nodes represent lemma frequencies; color and topology represent the cluster, based on modularity class; edges represent frequency of co-occurrence (see: Methods)

Stability and Maintenance

Patients with medium-term DBS experience frequently emphasise the significance of stability, expressing the hope that their health remains steady without significant deterioration. This aspiration for stability is indicative of a need for predictability in the management of their condition. As one patient articulated: *"I would be happy today if the whole thing is curable—apparently not, right? I'd be happy if it remained stable. At least the way it is now, right? That would be my greatest wish, yes. That it can be managed and that it doesn't get worse." (Patient 09 – medium-term experience group).*

Another patient highlighted the continuous effort required to maintain stability, using the metaphor of a fight: "That this effect still lasts, but on the other hand you have to keep fighting it, so the word 'fight' is right." (Patient 07 – medium-term experience group). These reflections underscore the resilience and determination of patients striving to preserve their quality of life, despite the challenges posed by PD.

Proactive Steps and Self-Improvement

It is noteworthy that some participants place significant emphasis on the significance of adopting a proactive stance in the management of their condition, thereby evidencing a profound commitment to personal enhancement. Through personal endeavours such as regular exercise and cultivating a positive mindset, they seek to more effectively navigate the challenges posed by PD and DBS treatment. One patient illustrated this proactive and self-empowering approach: *"I will work on it, with myself. Training and always telling myself that I should enjoy the beautiful things and also enjoy other people."* (Patient 28 – medium-term experience group).

Acknowledging Limitations and Setting Realistic Goals

A salient theme that emerges from this study is the acknowledgement of the limitations imposed by their condition, coupled with realistic expectations for the future. Patients recognise that PD is a progressive condition and that DBS does not represent a cure, but they express a hope for stability and manageability of their symptoms. One patient articulated this sentiment eloquently: *"[I wish] that this effect still lasts, but on the other hand, you have to keep fighting against it, so the word 'fight' is right."* (Patient 07, DBS medium-term experience group).

Semantic Network Maps for 'Wishes for the Future' in the Medium-Term Experience Group

In Fig. 11, an intriguing 'fight' cluster emerges, which was not addressed in our qualitative analysis. This cluster is linked to terms like "want", "reach", and "effect", suggesting that, at this specific time point, patients are expressing a determination to continue striving for further benefits from the device. This may also reflect their attitudes toward maintaining a positive, proactive approach.

Additionally, the 'happy' and 'right' clusters, associated with words such as "remain", "stable", and "manage", further emphasize the patients' focus on maintaining stability and managing their condition, reinforcing their desire to preserve a sense of well-being.

Long-term Wishes

In the long-term experience group, patients show a more reflective perspective on their hopes and aspirations, characterised by a broader view of their condition and the future of treatment.

Prevention and Hopes for New Scientific Discoveries

Patients' wishes at this stage were connected with a strong hope for medical progress and breakthroughs in the treatment of PD. One patient articulated hopes for advancements in the prevention and understanding of the condition: *"It is imperative that we make significant strides towards the identification of new techniques, whether these be wholly novel or at least divergent from the established procedures. Moreover, it is crucial that we extend these advancements to future patients, ensuring that they too receive effective treatment and, above all, that we establish effective preventative measures. It is imperative that we ascertain the underlying causes of this condition, and it is equally crucial that we continue our research into its causes, despite the fact that, even after two centuries since the initial discovery of the condition by Dr. Parkinson, we have yet to make any significant progress*." (Patient 38, DBS long-term experience group).

This underscores the profound sense of frustration surrounding the dearth of knowledge concerning the origins of PD, thereby underscoring the necessity for effective preventative measures. Other patients articulated their aspirations for either the deceleration

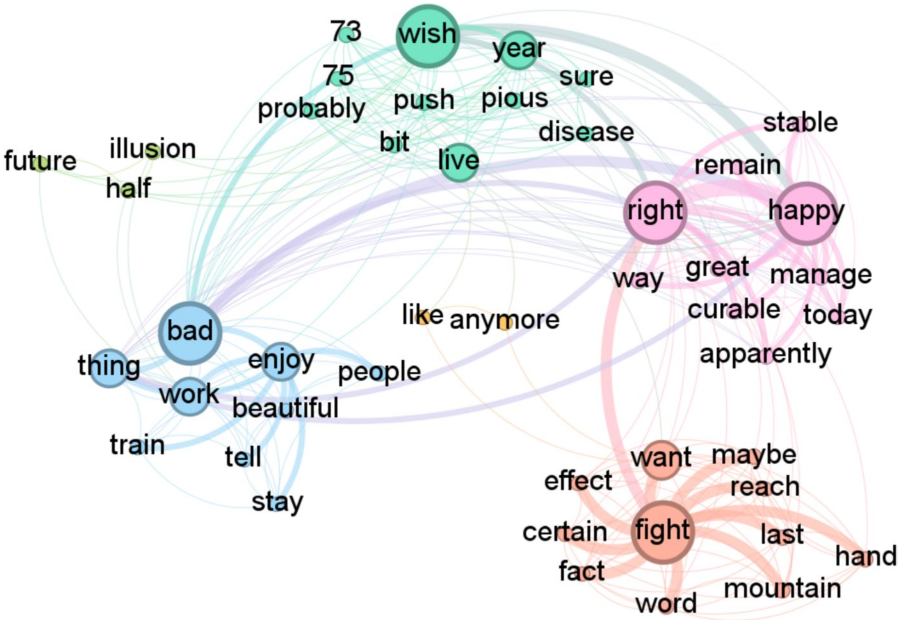

Fig. 11 Semantic network maps illustrating the theme 'Wishes for the future' for the DBS **medium-term** experience group. In this group, patients have a medium-term experience with DBS (3–6 years). These maps visually represent the interconnectedness and clustering of concepts within participants' narratives when asked about their aspirations and desires for the future across different time horizons post-DBS treatment. Nodes represent lemma frequencies; color and topology represent the cluster, based on modularity class; edges represent frequency of co-occurrence (see: Methods)

of progression or the maintenance of stability. One patient articulated their desire for the disease to progress as slowly as possible, expressing a hope for the development of effective treatments: "*That it progresses as slowly as possible. My wish, of course, is that they find something that really stops it, or at least maybe even regenerates it, but that's not going to happen.*" (Patient 12, DBS long-term experience group).

These statements reflect a balance between aspirations for breakthroughs and the desire for incremental progress or stability. Wishes of these patients' group reveal a complex landscape of hopes shaped by their experiences and challenges, offering valuable insights into their priorities and the goals of medical research.

Semantic Networks for 'Wishes for the Future' in the Long-Term Experience Group

In the long-term semantic maps (Fig. 12), we observe a gradual transition towards more abstract thematic clusters. In the medium-term, grounded sentiments such as the 'fight' clusters with co-occurring words relating to the possibility of performing certain activities are evident while in the long-term maps, clusters are more oriented towards prevention, stability, and longevity perspectives.

Discussion

We conducted a qualitative secondary analysis to re-examine—with a different research question—a previously collected dataset of interviews with patients who underwent DBS for PD, spanning different temporal phases post-treatment. Our analysis focused on themes that we identified as most indicative of the temporal evolution of the DBS experience, particularly concerning the presence of the device and its impact on patients' lives.

Different lengths of time with the device lead to different experiences

In the **short-term**, many DBS patients experience an initial wave of euphoria immediately after surgery, which serves to validate their decision to undergo the procedure, as has been found in other studies [15, 33]. This euphoria can create a positive outlook, influencing patients' perceptions of the changes brought about by the procedure, instilling a sense of hope and satisfaction. However, this initial phase of excitement is often followed by a period of adjustment, during

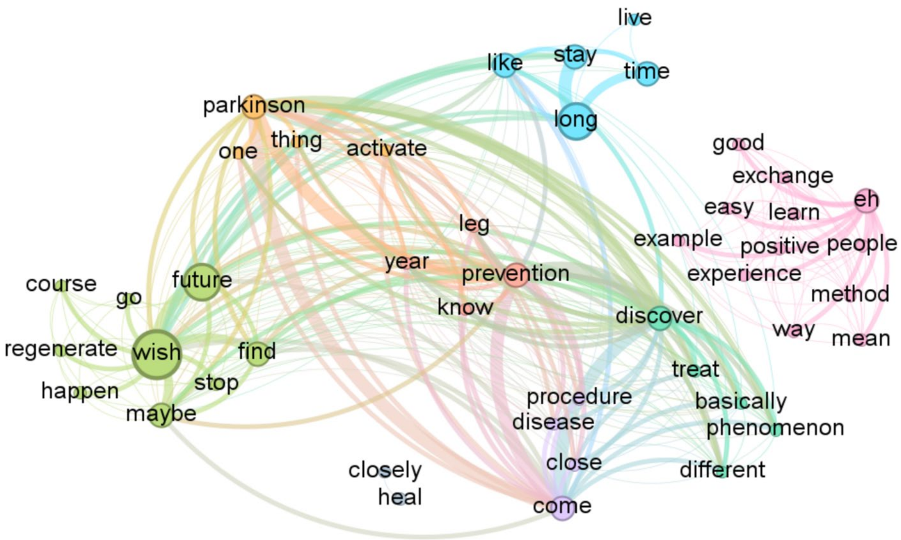

Fig. 12 Semantic network maps illustrating the theme 'Wishes for the future' for the DBS **long-term** experience group. In this group, patients have a long-term experience with DBS (7–10 years). These maps visually represent the interconnectedness and clustering of concepts within participants' narratives when asked about their aspirations and desires for the future across different time horizons post-DBS treatment. Nodes represent lemma frequencies; color and topology represent the cluster, based on modularity class; edges represent frequency of co-occurrence (see: Methods)

which patients must learn to manage their expectations and adapt to the new reality of living with the device. While some individuals swiftly regain motor function and experience a renewed sense of agency, others may require a more protracted period to experience the full benefits of the treatment. Furthermore, psychological challenges such as anxiety or frustration may be encountered by some patients during this transitional period [34]. The initial years of DBS treatment are often the most delicate, as patients begin to evaluate their initial expectations and establish new ones based on the benefits they experience from stimulation. For those requiring a more protracted period to experience the effects and attain stability, unmet expectations have the potential to engender frustration, which can render them more vulnerable and less inclined to cooperate or maintain an optimistic outlook regarding future improvements. Furthermore, the intricate process of identifying optimal stimulation parameters and achieving equilibrium with pharmacological interventions has been demonstrated to engender considerable frustration, potentially stemming from the reliance on healthcare professionals to adjust and manage their condition [35, 36]. This dynamic can exert a substantial influence on the ultimate health outcomes of the individual. Consequently, it is imperative that patients are adequately informed about the probable course of treatment, including its potential benefits and limitations.

Patients in the **medium-term** phase (3–6 years post-surgery) generally exhibited positive outcomes; however, they reported a gradual decline in DBS efficacy. This decline underscores the importance of acknowledging the variable nature of DBS outcomes, particularly as patients face new challenges related to disease progression. Nevertheless, the sense of control offered by DBS remained a key benefit, allowing patients to manage their symptoms more effectively than they could with medication alone. This notion of autonomy aligns with the observations of Lozano et al. [37], who highlighted that patients continue to regard DBS as a highly effective instrument in managing the variable and unpredictable nature of Parkinson's disease.

Patients in the **long-term** phase (7–10 years post-surgery) reflect on the complexities of disease progression and DBS's therapeutic impact. While some symptoms, such as walking and speech, are known to deteriorate over time, which is consistent with long-term follow-up studies that highlight the limits of DBS in addressing all symptoms of PD [38], patients generally maintain a positive outlook, appreciating DBS's role in improving their quality of life. Patients have been observed to demonstrate a deeper acceptance of their condition and advocate for ongoing research to prevent PD progression, indicating a shift from immediate symptom relief to broader concerns about future advancements and the overall management of the disease.

Surgery is the toughest moment

The surgical procedure is consistently portrayed as frightening, lengthy, and at times unbearable, particularly during the skull drilling phase, with some patients expressing hesitance about undergoing the procedure again due to its impact. These observations corroborate findings from Mulroy and colleagues [39], which also emphasizes the importance of examining patients'sensations during the procedure and using this knowledge to target the best time to infuse painkillers or other medications and effectively manage various stages of the intervention. However, despite the challenging nature of the procedure, patients from all groups often describe feeling like survivors after, ultimately considering the surgery worthwhile, particularly due to the benefits they experience afterward. We also uncovered nuances between the groups through the semantic network maps where narratives about the surgery become less detailed and expressive based on the time passed since the intervention. This shift may suggest that as time passes, memories about the intervention tend to fade, leading to less richness and articulation in recounting the surgical experience. The surgery is evidently a crucial moment for patients, and therefore understanding this information could inform the education of patients and their families and prepare them thoroughly for the surgery and the potential sensations they may experience, offering comprehensive support, including the psychological, during and after the procedure.

Device control preferences

Patients transversely expressed preferences for relying on medical guidance in managing technical aspects of the DBS device, reflecting the importance of ongoing clinician-patient collaboration in device management and optimization. While remote control offered convenience for some patients, preferences varied regarding its utility for modifying stimulation settings. It has also been shown that device control preferences may also vary over time [40]. These findings underscore the necessity for individualized device programming and patient education to empower individuals in effectively managing their treatment. In the present study, the issue of battery longevity was raised, and patients held divergent views. It is crucial to emphasise that individuals should be informed about the various battery options, including their rechargeable or fixed-life functionality, prior to undergoing surgery. This is essential for ensuring that individual preferences are met and for facilitating better daily management. While rechargeable batteries may necessitate regular charging, for some patients, undergoing subsequent surgery to replace the battery may be preferable after a few years. By taking these factors into consideration at the outset, healthcare providers can facilitate patient decision-making that aligns with lifestyle and long-term treatment goals, as has been observed in other studies [41, 42].

A novel informative approach to the study of patients' experiences

Our study took an innovative approach by combining qualitative data with quantitative exploration using semantic network analysis [16, 43]. Despite the limitations posed by sample size and data heterogeneity, the semantic network maps provided valuable insights that aligned closely with our qualitative findings, but also uncovered nuances that were not identified by a human-driven analysis alone. Human-led qualitative analysis is driven by interpretive insight, allowing for a nuanced understanding of themes, emotions and contexts that emerge organically from the patients' narratives. This allows the identification of subtle, latent themes that may not be immediately apparent, drawing on researchers' knowledge and experience to interpret the meaning of the data. In contrast, NLP-based methods, such as semantic network analysis, are algorithmically driven and rely on frequency and co-occurrence patterns of words. This can highlight associations or clusters of terms that a human-led analysis might miss due to cognitive biases or subjective interpretations [44]. NLP can reveal unexpected or hidden patterns, such as the emergence of a cluster in the analysis, which was not captured by the qualitative coding process. However, NLP lacks the capacity for deep contextual understanding and may misinterpret terms or emphasise superficial connections. Thus, integrating both methods, could be beneficial for research considering the strengths of each approach: the richness and interpretive depth of qualitative analysis, and the pattern recognition and scale of NLP. This combination allows for a richer exploration of the data, while also encouraging critical reflection on how different methods can provide divergent or complementary insights [16].

Using semantic network analysis to complement qualitative methods is better when large interview samples are available. In our case, given our small sample size, the full potential of this integration could not be realised. Nevertheless, these findings suggest that this combined approach represents a promising frontier for understanding patient experience, with significant implications for future research and clinical practice.

Implications on research, healthcare, and clinical practice.

The present study has several implications for healthcare, research, and clinical practice. The advent of neurotechnology signifies a pivotal moment in the evolution of treatment modalities and patient care paradigms, wherein cutting-edge technologies intersect with personalised medicine to redefine therapeutic approaches [45]. DBS, for instance, exemplifies highly individualised treatment strategies tailored to each patient's unique needs and circumstances. This paradigm shift has the potential to influence healthcare policy and the doctor-patient relationship, emphasizing the critical importance of patient perspectives, expectations, needs, and desires in influencing health outcomes [46].

This encompasses comprehensive preoperative counselling, sustained postoperative support, and regular assessment of patient outcomes and preferences. The qualitative assessment of patients' lived experiences before and at various time points after surgery is essential to ensure optimal support and to understand even subtle or subclinical effects of neurostimulation from an experiential point of view. By integrating the in-depth, patient-centered insights from qualitative data with the broader, system-level trends revealed through quantitative analysis, healthcare providers can identify and address gaps in service delivery more effectively. For instance, this approach enables precise identification of factors influencing treatment outcomes, leading to targeted interventions and continuous quality improvement initiatives.

From a research perspective, this study promotes the integration of qualitative and quantitative methodologies to thoroughly explore patient preferences and the phenomenological experience of treatment at different stages. Such comprehensive analyses can support the development of more nuanced, evidence-based models that can inform policy, optimize clinical guidelines, and ultimately foster more personalized care. This approach is of particular importance for interventions such as DBS, which are both life-changing and delicate. Furthermore, interdisciplinary collaboration among neurologists, nurses, psychologists, and data scientists could bridge the gap between empirical data and lived experiences, fostering a more holistic and adaptive approach to managing DBS outcomes. These advancements have the potential to transform both research and clinical practice, offering more responsive, informed, and personalised care to individuals undergoing neurostimulation therapies.

Conclusions

In conclusion, our mixed-methods approach to analyzing the experiences of DBS patients has important implications for future research and clinical practice in neurological care, as well as for the study and quantification of patients' subjective experiences of illness and treatment. Here, we were able to trace a timeline of patients' experiences on short, medium, and long-term journeys with DBS. This study contributes to our understanding of the lived experiences of individuals undergoing long-term DBS treatment and highlights the importance of patient-centered care, personalized device management, and interdisciplinary collaboration in optimizing treatment outcomes and quality of life for DBS recipients. Incorporating these findings and considerations of patient needs and preferences in DBS management can improve the delivery of DBS therapy and provide better support to individuals in their journey to improved well-being and long-term resilience.

Limitations

While this secondary analysis provides valuable insights, it is essential to acknowledge potential limitations associated with differences in the primary study's design, potential biases in the existing data, and constraints imposed by the original research objectives. Despite rigorous translation protocols, subtle meanings and connotations may have been lost or altered.

The interviews analysed were not originally conducted with the specific research questions we are addressing in the present study. As such, the breadth and depth of responses may not be fully consistent with the nuances and insights sought for our study. Individuals implanted for longer durations must be contextualized within a framework of medical, scientific, technological, and pharmacological advancements that may differ from those experienced by individuals receiving implants in the short term. Such variations in the temporal context could influence the interpretation and generalizability of findings across different groups. In addition, our sample represents the experiences of patients who have lived with DBS for varying lengths of time, rather than following the same individuals longitudinally. This distinction is important because it means that our analysis should not be seen as a precise temporal progression of themes. Instead, it captures a cross-sectional snapshot of different patients' experiences at different stages of DBS treatment. Consequently, the thematic findings should be interpreted as reflecting a range of experiences rather than a continuous progression over time.

The construction of semantic network maps is constrained by the quantity and diversity of the input data. Our dataset is small and probably lacks sufficient variability, so that the resulting network maps may not fully capture the complexity and richness of the underlying semantic relationships so then the interpretation of these maps should be approached with caution. Future research could benefit from the expansion of the dataset utilized for semantic network analysis, by incorporating data from a greater number of interviews or segments.

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Data Availability Due to the sensitive nature of the original interview data that support the findings of this study, they are available from the corresponding author upon reasonable request in compliance with privacy and data protection regulations.

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