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Assessing Preoperative Hope and Expectations Related to Functional Neurosurgery: A New Questionnaire.

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Abstract

Background: Despite successful functional neurosurgery, patients suffering from epilepsy or Parkinson's disease may experience postoperative psychological distress and social maladjustments. Difficulties in coping with postoperative changes, even positive ones, have shown to be related to patients' presurgery cognitive representations (i.e., expectations, hope, abstract vs. concrete representations). The aim of this study was to develop an instrument assessing various key features of surgery outcomes' representations, namely the Preoperative Hope and Expectations Questionnaire, PHEQ.

Methods: Participants were patients (n = 50) diagnosed with Parkinson's disease (n = 25) or epilepsy (n = 25), candidates for functional neurosurgery (i.e., Deep brain stimulation, anterior temporal lobectomy). At 2-3 weeks before the planned surgery, they were administrated items assessing their actual state, preoperative expectations, and hope regarding surgery outcomes. They also completed measures assessing optimism, quality of life and mood.

Results: Exploratory analysis resulted in a 16-item version of the PHEQ composed of two factors (*abstract representations*, including psychological well-being and *concrete representations*, such as functional aspects of everyday functioning). The PHEQ demonstrated high internal consistency and good convergent validity. Patients were more prone to express postoperative improvements in terms of hope rather than expectations. They generally focused on concrete rather than abstract features, although patients with Parkinson's disease had higher abstract future-oriented representations.

Conclusions: The PHEQ presents satisfactory psychometric properties and may be considered as a reliable instrument for research and clinical practice.

Keywords

Epilepsy surgery, Deep brain stimulation, Preoperative expectations, Hope, Questionnaire.

1. Background

Bilateral subthalamic nuclei deep brain stimulation (DBS) is known to reduce motor symptoms as well as dopaminergic-related complications in advanced Parkinson's disease (PD) (Weaver et al., 2005). While successful functional neurosurgery leading to the sudden alleviation of symptoms is expected to significantly improve patients' quality of life (QOL), growing evidence suggest that such positive effect is questionable (Agid et al., 2006; Bell et al., 2011; Gilbert, 2012; Schüpbach et al., 2006). This phenomenon has been well documented in surgical treatment of medically intractable epilepsy. More specifically, despite successful anterior temporal lobectomy (ATL) and alleviation of seizures, some patients experience postoperative psychological and socio-professional maladjustments (e.g., difficulties discarding sick role behaviors[1], family dysfunctions, occupational disabilities), leading to major deterioration in their postoperative QOL (e.g., Wilson, 2001; Wilson et al., 2007). In order to account for such peculiar phenomena, the concept of "burden of normality" (BON) syndrome has been proposed (Bladin, 1992; Wilson, 2001; Wilson et al., 2007). According to the BON model, successful life changing medical intervention gives rise to an evolving process of postoperative psychological and social adjustments. This process may depend on patients' propensity to switch from roles and self-representations from "chronically ill" to "healed". In this prospect, future-oriented cognitions, such as hope and expectations regarding surgery outcomes, has been suggested to play a key role in postoperative psychosocial adjustment process.

Hope and expectation can be defined as beliefs about the consequences of engaging in treatment (Constantino et al., 2011). Such preoperative projections have been significantly related to the success of rehabilitation (e.g. Albrecht & Higgins, 1977), to the level of postoperative

[1] Behaviors associated with being sick such as domestic, social, recreational, vocational underactivity or focusing on novel somatic or cognitive complaints.

functional recovery (e.g., Mondloch et al., 2001; Taenzer et al., 1986) and to postoperative QOL (e.g. Gonzalez Saenz de Tejada et al., 2010). In the particular case of candidates for functional neurosurgery, unrealistic expectations might play a pivotal role in postoperative dissatisfaction and adverse psychosocial outcomes (e.g., Baxendale & Thompson, 1996; Rose et al., 1995). Additionally, unspecific (e.g., *being normal, feeling like myself again*) or excessively high expectations have been connected to an increased postoperative psychological distress and a general dissatisfaction with surgery outcomes (e.g., Gilbert, 2012; Maier et al., 2013; Wilson et al., 1999). High expectations may further reduce patient's ability to accept less successful outcomes, as well as his capacity to face psychological and social changes brought about by functional neurosurgery (Bell et al., 2010).

Numerous studies have explored preoperative expectations of patients candidates for DBS or ATL (see Table 1). Nevertheless, these studies vary widely in conceptual and methodological approaches, ranging from qualitative design with structured or semi-structured interviews (e.g., Maier et al., 2013; Törnqvist et al., 2007; Wheelock et al., 1998; Wilson et al., 1998) to *ad hoc* questionnaires (e.g., Baca et al., 2009; Reddy et al., 2014; Rose et al., 1995), and only a few studies have used validated instruments (e.g., Mancuso et al., 2001, 2002; Salgado et al., 2008). Some studies have provided a modified satisfaction scale or modified standard measures of symptoms used as an expectation scale (Hasegawa et al., 2014; Nisenzon et al., 2011), in which patients are asked to rate for each question the current symptom severity (e.g. ranging from *no problem* to *severe problem*) and the expectation for change after treatment (e.g. ranging from *expected to be very much worse* to *expected to be very much improved*). However, the transferability of dimensions from satisfaction or functional state to the measurement of expectations has received limited justification.

INSERT HERE TABLE 1

Furthermore, most studies have failed to make a distinction between hope and expectation, while they are in fact linked but distinct constructs. Both seem to pertain to general construct of dispositional optimism (Leung et al., 2009). However, Uhlmann et al., (1984) highlighted an important distinction between expectation (probabilistic beliefs that something will happen) and hope (desire that the specific outcome would occur). More specifically, they suggested that patients' expectations and hope pertain to two distinct perceptual dimensions: expectancy and value. Expectancy primarily reflects a perception that the occurrence of a given outcome is likely. Patients' hope, in contrast to expectations, primarily reflect a valuation, a perception that a given outcome is desired. An outcome may be wanted but not expected (e.g. *I hope my disease will be cured, but I do not expect that*) or, inversely, expected but not desired (e.g. *I expect to receive, but do not want, a painful injection*). More recent studies further suggested to differentiate probability expectations (rational projections) and idealized expectations (or hopes) in exploring patients' expectations in clinical trials (Sherman et al., 2014). In their study based on cognitive interviews, patients defined hope as what they wished for or wanted to occur at the highest levels of aspiration, unconstrained by reality, prior knowledge or experience, and expectations as the most realistic projections of what might happen based on prior experience and illness history. This distinction was consistent across participants.

To sum up, patients' future-oriented cognition constitutes an important determinant of clinical outcomes following functional neurosurgery. Discrepancies between anticipated outcome and postsurgical reality, even in the case of significant symptoms reduction, may yield to disappointment and psychosocial maladjustments (Montel & Bungener, 2009). Although several tools have been proposed to explore preoperative representations of patients candidates for DBS or ATL, the nature of such representations (expectation vs. hope) and their content (concrete vs. abstract) failed to be assessed properly. The aim of the present study was to develop an

instrument assessing the various key features of prior representations related to surgery outcomes, namely the Preoperative Hope and Expectation Questionnaire (PHEQ). More specifically, items were generated by assessing patients' hope and expectations regarding postoperative improvements across abstract (e.g. psychological well-being) and concrete (e.g. symptoms reduction) life domains. The factor structure and internal consistency of the PHEQ were then evaluated. The external validity of the final version of the PHEQ was assessed by examining its relationships with measures of optimism, mood, mental and physical QOL. A high level of hope and expectations was expected to be correlated to dispositional optimism and negatively correlated to anxio-depressive symptoms (Alarcon et al., 2013). Additionally, concrete hope and expectations were expected to be specifically connected to physical QOL, while abstract hope and expectations to mental QOL. Finally, this study aimed to explore whether preoperative future-oriented representations vary according to the type of functional neurosurgery (DBS vs. ATL).

2. Materials and Methods

2.1. Participants and procedure

Patients diagnosed with PD or epilepsy and potential candidates for functional neurosurgery were recruited from the University Hospitals of Geneva in Switzerland. Inclusion criteria were a DBS or epilepsy surgery medical indication established by neurologist, neurosurgeon, psychiatrist and neuropsychologist. The main selection criteria for DBS surgery were disabling motor complications of dopaminergic treatment, the absence of dementia (based on a cutoff score of 130 on the Mattis Dementia Rating Scale), and severe depression with suicidal ideations. Motor symptoms were assessed before surgery using the Unified Parkinson's Disease Rating Scale III (UPDRS III, Fahn & Elton, 1987). The selection for ATL was a thorough procedure aimed at identifying potential candidates for surgery by determining the risk-

benefit ratio for each patient. Patients clinically accepted for DBS or epilepsy surgery were invited to participate in the present study. They were selected from the French speaking community since self-administered questionnaires are in French. Based on these criteria, 50 patients (32 males and 18 females) aged between 18 and 73 (Mean of overall sample: 46.16 years, *SD* = 17.05) were selected for the present study. Twenty-five patients with PD (17 men and 8 women; mean age: 59.60 years, *SD* = 7.41) were candidates for DBS, and 25 patients with epilepsy (15 men and 10 women; mean age: 32.72 years, *SD* = 12.75) were candidates for ATL.

Informed consent was obtained from all participants following a full explanation of the experimental procedure. Detailed written and oral instructions explained that participants would be asked questions about different aspects of their everyday life as well as regarding their programmed neurosurgery. They were participating on a voluntary basis. At 2-3 weeks before the planned intervention, participants completed all the measures described below, which were counterbalanced.

2.2. Materials

2.2.1. The Preoperative Hope and Expectation Questionnaire (PHEQ)

The process by which the PHEQ has been developed was described in the present section. Psychometric properties of the PHEQ (factorial structure, internal consistency and convergent validity) were reported in the Results section (see Section 3).

Item selection. A qualitative review of studies exploring preoperative expectations on DBS and ATL populations by means of questionnaires, interviews and semi-structured interviews was conducted (see Table 1). This review first revealed that preoperative expectations relate to four distinct life domains: (1) physical and mental state; (2) autonomy in daily living activities; (3) psychological and emotional well-being; and (4) social-relational life. Based on these features, an initial pool of 24 items has been generated. All items consisted in affirmations

regarding the above-mentioned life domains. Any disease-specific reference (e.g., tremor, stiffness, dyskinesia, freezing, dystonia, fatigue, seizures, etc.) has been systematically replaced by the general term of *reduction of symptoms*. It is worth noticing that expectation and hope, which are in fact two distinct concepts (Uhlmann et al., 1984), appeared to be mixed up in previous measures. Thus, in order to examine expectation and hope separately, each item has been framed in the context of realistic expectations (e.g. *Regarding physical pain, I realistically expect…*) and in the context of hope/desire (e.g. *Regarding physical pain, I really hope for…*), and rated on a 5-point scale (0 = *no improvement at all* to 4 = *total improvement or symptom relief*). Additionally, each item has been assessed regarding actual state (e.g. *I have physical pain*), by means of a 5-point scale (0 = *not at all* to 4 = *extremely*).

Qualitative evaluation of the initial pool of item. Three judges (a neurologist, a psychiatrist and a neuropsychologist), who were familiar with the concept of preoperative expectations, were asked to rate the level of clarity and consistency of each item. Based on the judges' evaluation, 6 items were discarded as they appeared irrelevant (*pregnancy concerns, others' worries, new activities, economic worries, general health improvement, risk of injury*), 4 items were replaced by 2 more general items (the item *To be able to participate in leisure activities* included *sports, travel, etc.*; the item *To be able to work*, included *professional activity, housework, etc.*). Additionally, 4 new items were generated based on experts' proposals in order to explore more precisely issues frequently reported by patients in clinical settings (*physical appearance, ability to enjoy life, feeling comfortable in social situations, achieve projects*). The new 20-item form was then administered to 10 candidates for DBS (n = 5) and ATL (n = 5). A free response section was included at the end of the questionnaire allowing respondents to write down any additional expectation that did not appear in the PHEQ. Based on patients' responses, two new items were added (*To feel more like myself* and *To be like everyone else*).

The PHEQ. Based on experts and patient's evaluation of the initial pool of item, a preliminary version of the PHEQ comprised 22 items (see Table 3), assessing preoperative expectation and hope varying in level of abstraction (11 items expected to assess abstract hope and expectations and 11 items expected to assess concrete hope and expectations). The questionnaire was presented in 3 parts, each item has been rated regarding the following conditions: (a) the current state (Actual State, AS), (b) patients' realistic prediction of outcomes (Preoperative Expectations, PE), and (c) patients' wishes or desires concerning surgery outcomes (Preoperative Hope, PH). Six items are reverse-scored in PHEQ AS scale (i.e., items 2, 12, 19, 20, 21 and 22). For each PHEQ measure, scores are summed, so that high scores on PE and PH measures indicate an increased tendency to have high expectations and high hope regarding postoperative QOL improvements, while high scores on AS measures indicate better self-evaluation of current physical, mental, psychological and relational life.

2.2.2. Other measures

Quality of life. The French version of the Medical Outcome Study Short Form (MOS-SF-36; Leplège et al., 1998) was administered in order to assess patients' subjective QOL. This self-report measure consists of 36 questions about QOL and care outcomes. It evaluates eight dimensions, including the Physical Component Summary score (PCS) and the Mental Component Summary score (MCS). Each subscale's scores range from 0 (*worst condition*) to 100 (*best condition*). In the present study, Cronbach's alphas indicate excellent internal consistency for the PCS (.94) and the MCS (.91) measures.

Dispositional optimism. The French version of the Life Orientation Test Revised (LOT, Trottier et al., 2008) was administered in order to assess dispositional optimism. This scale consisted of 10 items, rated on a 5-point scale (0 = *strongly agree* to 4 = *strongly disagree*), assessing the persons' expectations regarding the favorability of future outcomes (e.g., *In*

uncertain times, I usually expect the best). The dispositional optimism is a personality characteristic relatively stable across time. In the present study, Cronbach's alpha indicates acceptable internal consistency for the LOT-Optimism measure (.78).

Mood. The French version of the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) was administrated in order to examine participant's mood status. The HADS is composed of 14 items measuring anxiety and depression symptoms. Participants had to determine to what extent the situation described in each particular statement applied to them during the last 7 days, using a 4-point scale (0 = *not at all*; 3 = *extremely*). Seven items assess the respondents' state of depression (HADS-D), while the 7 remaining items constitute a self-reported measure of general anxiety (HADS-A). In the present study, Cronbach's alphas indicate good to acceptable internal consistency for the HADS-A (.85) and HADS-D (.78) measures.

2.3. Statistical analyses

Exploratory factor analysis was performed to select items according to their level of abstraction (concrete vs. abstract). The correlation matrix was analyzed with an EFA computed with two factors, using the maximum likelihood method. The Kaiser-Meyer-Olkin (KMO) method was used to measure sampling adequacy, and Bartlett's test of sphericity was computed to test the null hypothesis that the variables in the correlation matrix are uncorrelated. A KMO between .50 and 1.0 and a significant Bartlett's test of sphericity are considered appropriate for factor analysis (Kline, 2014). Considering the small size of the sample, EFA has been conducted by means of Bayesian estimations (Lee & Song, 2004), using the JASP software. The reliability of each PHEQ measure was then examined with Cronbach's alpha. Convergent validity has been explored by means of Pearson's correlations and regression analyses. Finally, future oriented cognitions were explored across the two groups of patients by means of a mixed-design ANOVA.

3. Results

Descriptive statistics for the entire sample and for each group of patients on all the variables of interest are reported in Table 2. The two groups of patients differed on age (t_{48}=-9.12, p<.001), physical QOL (t_{43}=-6.73, p<.001) and disease duration (t_{43}=3.41, p<.001). There was no difference in mental QOL, in symptoms of anxiety and depression, in level of education and in optimism.

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3.1. Factor structure

The item-total correlations for the 22 items ranged from -.06 to .73, with a mean of .28 for the preliminary PE, and from .09 to .74 with a mean of .27 for the preliminary PH. Univariate normality was explored for the 22 items of preliminary PE and PH measures by calculating the skewness and kurtosis of each item for each measure. The results showed that skewness ranged from −.70 to 1.86 for preliminary PE and from -1.78 to 1.25 for preliminary PH; while kurtosis ranged from −1.62 to 2.91 for preliminary PE and from -1.62 to 2.78 for preliminary PH, indicating no strong deviation from normality (absolute values are considered to be extreme for skewness greater than 3 and kurtosis greater than 20; Weston & Gore, 2006).

In order to classify items according to their level of abstraction (i.e., concrete vs. abstract), the correlation matrix was analyzed with an EFA computed with two factors, using the maximum likelihood method (as the data were normally distributed), and an orthogonal rotation (assuming that the factors were not correlated). The KMO measure of sampling adequacy and Bartlett's test of sphericity indicated that the 22 items of the preliminary PE measure were adequate for factor analysis (KMO = .73, Bartlett's $\chi 2$ = 613.37, p < .0001).

This EFA explained 39% of the total variance (factor 1 = 20% and factor 2 = 19%). Based on a factor loading cut off of .40, factor 1 included items 3, 4, 5, 7, 9, 12, 14 and 17, and factor 2

encompassed items 1, 10, 11, 13, 15, 19, 20 and 22 (see Table 3). It should be noted that item 22 has been included in factor 2, despite a factor loading of .37, in order to have the same number of items in the two factors (i.e. $n = 8$) and since it loaded unambiguously on factor 2. Items 2, 8 and 6 loading values were below .35 and were consequently excluded. Items 16, 18 and 21 loaded equally in the two factors and were therefore excluded. Thus, the factor 1 was labeled *Abstract domains*; items loading on this factor relate to the notion of self-identity and social/relational life. Factor 2 was labeled *Concrete domains*; items loading on this factor relate to functional aspects of everyday life and physical health.

INSERT HERE TABLE 3

3.2. Reliability and construct validity

Cronbach's alphas indicated good to acceptable internal consistency for all the PHEQ measures (PE-Total score: .88; PE-Concrete: .79; PE-Abstract: .87; PH-Total score: .88; PH-Concrete: .77; PH-Abstract: .87). Pearson's correlations were first computed in order to examine inter-correlations between the PE-Total score, the PH-Total score and AS measure. These analyses revealed that the measures of expectations and hope are highly correlated with each other ($r = .82$, $p < .001$; 95%CI: 0.71, 0.90), consistent with the idea that they are linked constructs. AS-Total score was negatively related to both expectations ($r = -.31$, $p = .03$; 95%CI: -0.54, -0.04) and hope ($r = -.50$, $p < .001$; 95%CI: -0.69, -0.26), supporting the idea that dissatisfaction regarding AS may lead to increased expectations and desire of substantial changes following neurosurgery. Pearson's correlation analyses also revealed that age was moderately related to both expectations ($r = .37$, $p = .008$; 95%CI: 0.11, 0.59) and hope ($r = .36$, $p = .009$;

95%CI: 0.10, 0.58). There was no relationship between the PHEQ measures and the level of education (*p*s >.170). There was no gender effect on PHEQ measures (*p*s >.315).

Finally, Pearson's correlations computed to examine convergent validity revealed that generalized optimism was related to both expectations ($r = .43$, $p = .002$; 95%CI: 0.17, 0.63) and hope ($r = .51$, $p < .001$; 95%CI: 0.26, 0.69), which is consistent with previous studies (Leung et al., 2009). There was no correlation between depression and anxiety dimensions of the HADS and the PHEQ measures (*r*s < .22, *p*s > .58). Finally, the physical QOL dimension (PCS) of the MOS-SF was negatively correlated to both expectations ($r = -.53$, $p < .001$; 95%CI: -0.71, -0.28) and hope ($r = -.39$, $p = .008$; 95%CI: -0.61, -0.11) measures. The mental QOL (MCS) was negatively associated with PH ($r = -.43$, $p = .003$; 95%CI: -0.64, -0.16) but not with PE ($r = -.21$, $p = .170$; 95%CI: -0.47, 0.09).

Considering the potentially confounding influences of the intercorrelations between all the variables of interest, zero-order correlations cannot determine the independent contribution of each measure (i.e. once the effect of the other variables has been removed). Hence, to investigate the specific relationship between PHEQ measures (PE-Total score, PH-Total score) and the other variables of interest (age, AS assessment, HADS mood measures, mental and physical QOL and optimism), two regression analyses were performed. The THEQ measures were used as dependent variables, and age, AS-Total score, HADS-A, HADS-D, MOS-SF-PCS, MOS-SF-MCS and LOT-Optimism as independent variables, using the backward exclusion selection procedure. As can be seen in Table 4, optimism and physical QOL emerged as significant independent predictors of PE-Total score, whereas optimism, AS measure and depression symptoms were significant independent predictors of the PH-Total score.

Specific relationships between expectations and hope and the other variables of interest were also examined, by taking the level of abstraction of life domains into account. In this

prospect, four additional regression analyses have been performed, with PE-Abstract, PH-Abstract, PE-Concrete and PH-Concrete as dependent variables, and age, HADS-A, HADS-D, MOS-SF-PCS-, MOS-SF-MCS, LOT-Optimism and AS-Total score as independent variables, using the backward exclusion selection procedure. As can be seen in Table 4, age, actual state, optimism and depression symptoms emerged as significant independent predictors of PH-Abstract, whereas optimism and age were significant independent predictors of the PE-Abstract. Optimism and mental QOL emerged as significant independent predictors of the PH-Concrete, whereas physical QOL and optimism were significant independent predictors of the PE-Concrete.

INSERT HERE TABLE 4

3.3. Group comparisons

Future oriented cognitions across the two groups of patients were explored by means of a 2 (Type of content: Hope, Expectations) × 2 (Level of content: Concrete, Abstract) × 2 (Type of neurosurgery: DBS vs. ATL) mixed-design ANOVA. A main effect of type of content was observed suggesting that patients candidates for neurosurgery expressed higher desire of changes than realistic expectations regarding the outcome of surgery $F(1, 48) = 44.56$, $p < .001$, $\eta^2 = .48$ (a small to medium effect size, according to Cohen's criteria; Cohen, 2013). There was also a main effect of group, suggesting that patients with PD expressed overall higher hope and expectations as compared to patients with epilepsy, $F(1, 48) = 6.57$, $p = .013$, $\eta^2 = .12$ (a small effect size, according to Cohen's criteria), while there was no interaction Group × Type of content. The main effect of level of content was significant, suggesting that patients expressed hope and desire predominantly regarding concrete aspects of QOL, $F(1, 48) = 118.81$, $p < .001$, $\eta^2 = .71$ (a medium to large effect size, according to Cohen's criteria). The interaction Type of content × Level of content was significant, $F(1, 48) = 5.93$, $p < .019$, $\eta^2 = .11$ (a small effect size, according

to Cohen's criteria). This interaction effect, which has been further examined by means of Bonferroni post hoc tests, suggests that all PHEQ subscores were significantly different (see Table 2) with PH Concrete > PE Concrete > PH Abstract > PE Abstract. There was also an interaction Group x Level of content $F(1, 48) = 26.19$, $p < .001$, $\eta^2 = .35$ (a small to medium effect size, according to Cohen's criteria). Bonferroni post hoc tests suggest the two groups had comparable levels of concrete representations but PD patients had significantly higher abstract representations as compared ATL patients ($p < .001$) (see Figure 1). Finally, there was no triple interaction Type of content x Level of content x Group.

INSERT HERE FIGURE 1

4. Discussion

The aim of this study was to develop a tool assessing future-oriented cognitions in the context of functional neurosurgery, by examining separately two types of preoperative cognitions (hope vs. realistic expectations) and the level of representations (*concrete* such as independence in everyday life and symptom reduction vs. *abstract* such as psychological and interpersonal well-being). The results can be summarized as follows.

First, the results suggested that the PHEQ is a reliable instrument with satisfying psychometric properties. Previous findings regarding the relationships between preoperative representations and dispositional optimism (Alarcon et al., 2013) have been replicated in the present study. The pattern of correlations observed in this study further support the idea that hope and expectations are two distinct, although linked constructs (Leung et al., 2009). More specifically, expectations were highly correlated with hope, but these two constructs showed distinct patterns of associations with other measures. Indeed, lower preoperative expectations were associated with low optimism and high physical QOL, while low preoperative hope was

specially associated with high actual state, low optimism and high depression symptoms. These findings support the idea that patients exhibiting depressive attitudes tend to demonstrate hopelessness (Rose et al., 1995). Statistical analyses further suggest that factors influencing preoperative future-oriented cognitions may also depend on the level of representations. Indeed, high abstract hope was predicted by age, AS, depression symptoms and optimism, while abstract expectations were predicted by age and dispositional optimism. On the other hand, optimism and mental QOL predicted concrete hope while optimism and physical QOL predicted concrete expectations.

Results also showed that patients candidates for neurosurgery had preoperative representations of outcomes that were more attuned towards concrete aspects of life. They also reported hope for improvement of their QOL that was significantly higher than realistic expectations. This suggests that they may experience strong desires for substantial changes following neurosurgery that may, at the same time, be perceived as poorly probable. Such discrepancies between desire of outcomes and evaluation of the probability that such outcomes may occur might interfere with postoperative adjustments process. It is also worth mentioning that patients with PD expressed overall higher hope and expectations than patients with epilepsy. Thus, future-oriented cognition may be determined by the type of diagnostic or surgery (DBS vs ATL). Future studies should be conducted in order to refine these results.

Before concluding, some limitations of the present study should be emphasized. First, the nature of the relationships found between the PHEQ and the other related constructs should be further refined, as the potential confounding effect of other factors, such as cognition, disease severity or duration were not controlled for, although patients with severe cognitive deficits were excluded during selection for DBS or ATL (based on a cutoff score of 130 on the Mattis Dementia Rating Scale). It is noteworthy that an important factor that potentially affects

presurgical expectations has not been explicitly controlled in this study, namely the attitude of practitioners in providing information related to surgery. For instance, the extent to which a neurologist delivers an optimistic perspective or highlights predominantly potential benefits vs. a realistic perspective focused on risks and adverse effects, may affect the way candidates will perceive the outcomes. It should be noted however that in our study information was given to the candidates by means of a standardized brochure which fully explained all surgery aspects and by the neurologist's explanations that were putatively comparable from one candidate to another. Further studies as well as health care providers should take the aforementioned parameter into account. Finally, although this tool appears to be reliable and may help patients in anticipating potential psychosocial maladjustments, it remains to confirm its complex factor structure by means of a confirmatory factor analysis in a new but comparable sample.

5. Conclusions

On the basis of our findings, the PHEQ can be recommended to assess preoperative expectations and hope in patients candidates for functional neurosurgery. A better characterization of particular features of preoperative expectations may help clinicians to better understand what is important for their patients and enhance their adherence to treatment. Moreover, measuring changes in or fulfillment of expectations and their impact on satisfaction and clinical outcomes may help clinicians to optimize treatment strategies. Importantly, implementing tailored preoperative preparation consisting of cognitive restructuration of unsuitable expectations may prevent adverse events, thereby improving postoperative psychosocial adjustment and QOL.

6. List of abbreviations

AS, Actual State

ATL, Anterior temporal lobectomy

BON, Burden of normality

DBS, Deep brain stimulation

HADS, Hospital Anxiety and Depression Scale

HADS-A, Hospital Anxiety and Depression Scale - Anxiety

HADS-D, Hospital Anxiety and Depression Scale - Depression

KMO, Kaiser-Meyer-Olkin

LOT, Life Orientation Test Revised

MCS, Mental Component Summary score

MOS-SF-36, Medical Outcome Study Short Form

PCS, Physical Component Summary score

PD, Parkinson's disease

PE, Preoperative Expectations

PH, Preoperative Hope

PHEQ, The Preoperative Hope and Expectation Questionnaire

QOL, Quality of life

UPDRS, Unified Parkinson's Disease Rating Scale III

7. Declarations

Ethics approval and consent to participate

The present study complies with the Code of Ethics of the World Medical Association (Declaration of Helsinki, version 2004) and was approved by the Geneva Research Ethics Committee CCER (approval 14-182). Informed consent was obtained from all patients participating in this study.

Consent for publication.

Informed consent for publication was obtained from all patients enrolled in the study.

Availability of data and materials

The de-identified data that support the findings of this study are available on the Figshare repository https://doi.org/10.6084/m9.figshare.14522778.v2.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

The authors confirm contribution to the paper as follows: study conception and design: M.R., J.F.A.D.S., K.W., M.B., P.R.B., F.H., A.C.; data collection: M.R., M.B., J.F.A.D.S.; analysis and interpretation of results: M.R., S.B., F.H.; draft manuscript preparation: M.R.; substantive revision of the work: N.F., P.R.B., A.C.; all authors reviewed the results and approved the final version of the manuscript.

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Table 1. Characteristics of reviewed studies exploring expectations of patients candidates for functional neurosurgery (DBS and ATL).

Authors	Surgery	Sample	Method	Domain of assessed preoperative representations
Reddy *et al.*, (2014)	DBS	22 patients with PD	Ad hoc questionnaire: Patient Reported Outcomes in Advanced Parkinson's disease scale (PRO-APD) Patients were asked to rate for each question: (1) the symptom severity, (2) the expectation for change after therapy: −3 (expected to be very much worse), to +3 (expected to be very much improved).	- Motor domain: tremor, stiffness, off periods, dyskinesia, freezing, dystonia, speech, balance - Non-motor domain: swallowing, sleep, bowels, bladder, pain, fatigue, sexual function Cognitive/psychological domain: concentration, memory, impulsive behavior, hallucinations/psychosis, mood, anxiety, apathy - Social and ADL: self-care, work, leisure/hobbies, socializing
Maier *et al.*, (2013)	DBS	30 patients with PD	Semi-structured interview regarding preoperative expectations	- Health: motor improvement, reduction of medication, improvement of walking, improvement of tremor, less dyskinesia, improvement of general health - ADL: carry out hobbies, car driving, trips, travels, - Social: more socializing, improvement of partnership - Psychological: improvement of quality of life, improvement of mental state
Nisenzon *et al.*, (2011)	DBS	148 patients with PD	Modified version of the Patient-Centered Outcomes Questionnaire (PCOQ-PD), patients were asked to rate for each domain: (1) Usual levels of difficulty over the past week, (2) success criteria, (3) expectations, (4) importance	10 motor and non-motor functional domains - Health: Pain, fatigue, tremor, stiffness in limbs, slowness in movement, walking problems, sleep - Psychological: Emotional distress, thinking - ADL: Interference with daily activities (work, leisure)
Törnqvist *et al.*, (2007)	DBS	8 patients with essential tremor 8 patients with PD	Semi-structured interview Standardized open questions: What motor/social activities can you perform today/ would you like to be able to perform when your tremor has decreased?	Definition of personal goals related to symptoms commonly reduced by the treatment - Motor activity: housekeeping, hygiene, eating and drinking, writing, working, leisure activities - Social activity: being with other people, participating in social activities
Bower *et al.*, (2009)	ATL	389 patients with epilepsy	Ad hoc questionnaire based on the literature and clinical experience 12 items, each item rated on a scale from 1 (not at all important) to 10 (extremely important)	- ADL: driving limitations, limitations in bicycling, swimming, other physical activities - Social: participation in social situations - Health: level of fatigue, cosmetic physical aspects, pregnancy concerns, having to take epilepsy medications - Psychological: emotional well-being, memory problems, language problems, concentration or attention problems, economic worries
Baca *et al.*, (2009)	ATL	396 patients with epilepsy	Interview Open-ended questions about expectations for surgical outcome - "In what ways do you feel limited by your epilepsy?" - "What do you most hope to change as a result of this surgery?"	- Expectations endorsed by > 15% of the sample: driving, job/school, independence, seizure cessation, social functioning, quality of life, medication discontinuance, physical activities, cognition - Expectations endorsed by less than 15% of the sample: embarrassment/stigma, emotional, fatigue, general health, family planning, and no limitation
Salgado, Fernandes and Cendes, (2008)	ATL	73 patients with epilepsy before surgery 63 patients with epilepsy after surgery	Validation of the pre-surgery expectations questionnaire 18 yes/no questions	- Health: take less anti-epileptic medication, be healthy - ADL: drive, work or study, take care of my house / of my family, have fun, be safe to hang out alone - Social: have children, improve my social life, marry, improve my sexual life, be accepted by my family - Psychological: improve my memory, be happy, be less worried, feel free, be less nervous, feel ordinary
Wheelock, (1998)	ATL	32 patients with epilepsy 17 significant others	Semi-structured Interview about Epilepsy Surgery (SIAES) (1) Ways in which seizure elimination would affect the patient's relationships with significant others (2) …would be a good or positive change (3) …would be a difficult or negative change	- Have more friends, be less dependent, others will worry less, marital and family relations will improve - Be able to drive, to work, continue education, do more activities, mood improvement, risk of injury or accident eliminated, reduces medication, anxiety eliminated, not feel as seek, not feel tired - Negative side effects of surgery, less attentions of others, face new responsibilities, no longer need of significant other
Wilson *et al.*, (1998)	ATL	60 patients with epilepsy	Standardized, semi-structured clinical interview (1) What is the main reason you have sought surgical intervention? (2) Do you see the operation as a chance to change your life? (3) Have you made any postoperative plans? (4) Do you plan on engaging in any new activities/ hobbies postoperatively?	Expectations of surgery - Health: seizure ablation, medication - ADL: driving, employment, independence, new activities - Psychological: self change, general improvement - Social: family, relationships
Rose, Derry and McLachlan, (1995)	ATL	17 patients with epilepsy	Ad hoc questionnaire The Epilepsy Expectations Questionnaire (EEQ) Responses are based on future expectations (1 year), rated on a 7-point Likert-type scale ranging from 1 (I do not expect this) to 7 (I very strongly expect this)	20 questions assessing: - Physical health, epilepsy medication, seizure frequency - Mood, quality of life - Social adjustment - Driving, occupation

Note. PD = Parkinson's Disease, DBS = Deep Brain Stimulation, ATL = Anterior Temporal Lobectomy, ADL = Activities of Daily Living.

Table 2. Demographic and clinical characteristics of Patients in the entire sample and in each group (epilepsy and Parkinson's Disease (PD)).

		Groups of patients	
Dependent variables	Whole sample (*n*=50)	Epilepsy (*n*=25)	PD (*n*=25)
Age	46.16 (17.05)	32.72 (12.75)	59.60 (7.41)
Level of education	12.57 (4.26)	12.00 (2.83)	13.33 (5.65)
AS-Total score	38.86 (8.66)	42.08 (8.55)	35.64 (7.64)
PE-Total score	21.00 (11.38)	17.12 (8.53)	24.88 (12.66)
PE-Concrete	13.98 (6.17)	13.76 (6.34)	14.20 (6.11)
PE-Abstract	7.02 (6.66)	3.36 (3.16)	10.68 (7.31)
PH-Total score	28.04 (13.00)	23.92 (10.39)	32.16 (14.20)
PH-Concrete	18.08 (6.45)	17.84 (6.30)	18.32 (6.73)
PH-Abstract	9.96 (8.02)	6.08 (5.62)	13.84 (8.26)
HADS-D	5.47 (3.24)	4.83 (3.26)	6.13 (3.15)
HADS-A	7.75 (4.01)	7.91 (4.18)	7.59 (3.91)
MOS-SF-PCS	43.89 (10.95)	51.48 (7.68)	35.95 (7.78)
MOS-SF-MCS	40.20 (9.69)	40.69 (10.39)	39.95 (9.11)
LOT-Optimism	16.66 (4.31)	16.68 (4.59)	16.64 (4.11)

Note. PE = Preoperative expectations, PH = Preoperative Hope, HADS-A = Hospital Anxiety and Depression Scale - Anxiety, HADS-D = Hospital Anxiety and Depression Scale - Depression, MOS-SF-PCS = Medical Outcome Study - Short Form - Physical Component Summary, MOS-SF-MCS = Medical Outcome Study - Short Form - Mental Component Summary, LOT = Life Orientation Test.

Table 3. Factor loadings for the 22 items.

#	Item	Factor 1	Factor 2
1	To be satisfied with my life	0.15	**0.48**
2	To reduce symptoms of my disease	-0.08	0.01
3	To be independent in my personal care (e.g. hygiene, clothing)	**0.80**	0.13
4	To feel good about myself	**0.43**	0.31
5	To be satisfied with my relationship / romantic life	**0.52**	0.39
6	To be able to travel alone (e.g. driving, taking public transport)	0.30	0.15
7	To be satisfied with my physical appearance	**0.95**	0.12
8	To get better sleep quality	0.15	0.35
9	To be satisfied with my social life (family, friends)	**0.58**	**0.48**
10	To be able to achieve my projects	0.17	**0.45**
11	To be able to participate in leisure activities (e.g. sports, travel)	**0.41**	**0.60**
12	To feel more like myself	**0.63**	0.26
13	To be satisfied with my intellectual functioning (e.g. concentration, memory)	0.13	**0.59**
14	To be satisfied with my sex life	**0.42**	0.33
15	To be able to work (professional activity, housework)	0.30	**0.57**
16	To be like everyone else	**0.44**	**0.43**
17	Not to experience negative feelings (e.g. sad, anxious)	**0.51**	0.37
18	To feel comfortable in social situations (e.g. outings, parties)	**0.50**	**0.60**
19	To be able to enjoy life	0.21	**0.74**
20	To be less tired, have more energy	0.18	**0.58**
21	To reduce physical pain	0.39	0.39
22	To get off medications	-0.19	0.37

Note. Values greater than .40 are in bold.

Table 4. Standardized regression coefficients, *t* and *p* values. for the variables of interest regressed on expectations and hopes measures.

	Dependent variables																			
	Age			AS-Total score			HADS-A			HADS-D			MOS-SF-PCS			MOS-SF-MCS			LOT-Optimism		
Independent variables	β	t	p	β	t	p	β	t	p	β	t	p	β	t	p	β	t	p	β	t	p
PH-Total score	**.27**	**2.55**	**.015**	**-.52**	**-2.61**	**.013**		NS		**-.24**	**-2.13**	**.040**		NS			NS		**.52**	**5.26**	**<.000**
PE-Total score		NS			NS			NS			NS		**-.353**	**-2.36**	**.023**		NS		**.41**	**3.57**	**<.001**
PH-Concrete		NS			NS			NS			NS			NS		**-.41**	**-2.64**	**.012**	**.39**	**3.35**	**.002**
PH-Abstract	**.41**	**3.90**	**.001**	**-.35**	**-2.98**	**.005**		NS		**-.24**	**-2.13**	**.039**		NS			NS		**.50**	**5.06**	**<.001**
PE-Concrete		NS			NS			NS			NS		**-.32**	**-2.42**	**.020**		NS		**.36**	**2.70**	**.010**
PE-Abstract	**.31**	**2.33**	**.025**		NS			NS			NS			NS			NS		**.37**	**3.43**	**.001**

Note. Bold values indicate predictors significant at $p < .05$. NS = non-significant.
PE = preoperative expectations, PH = preoperative hopes.

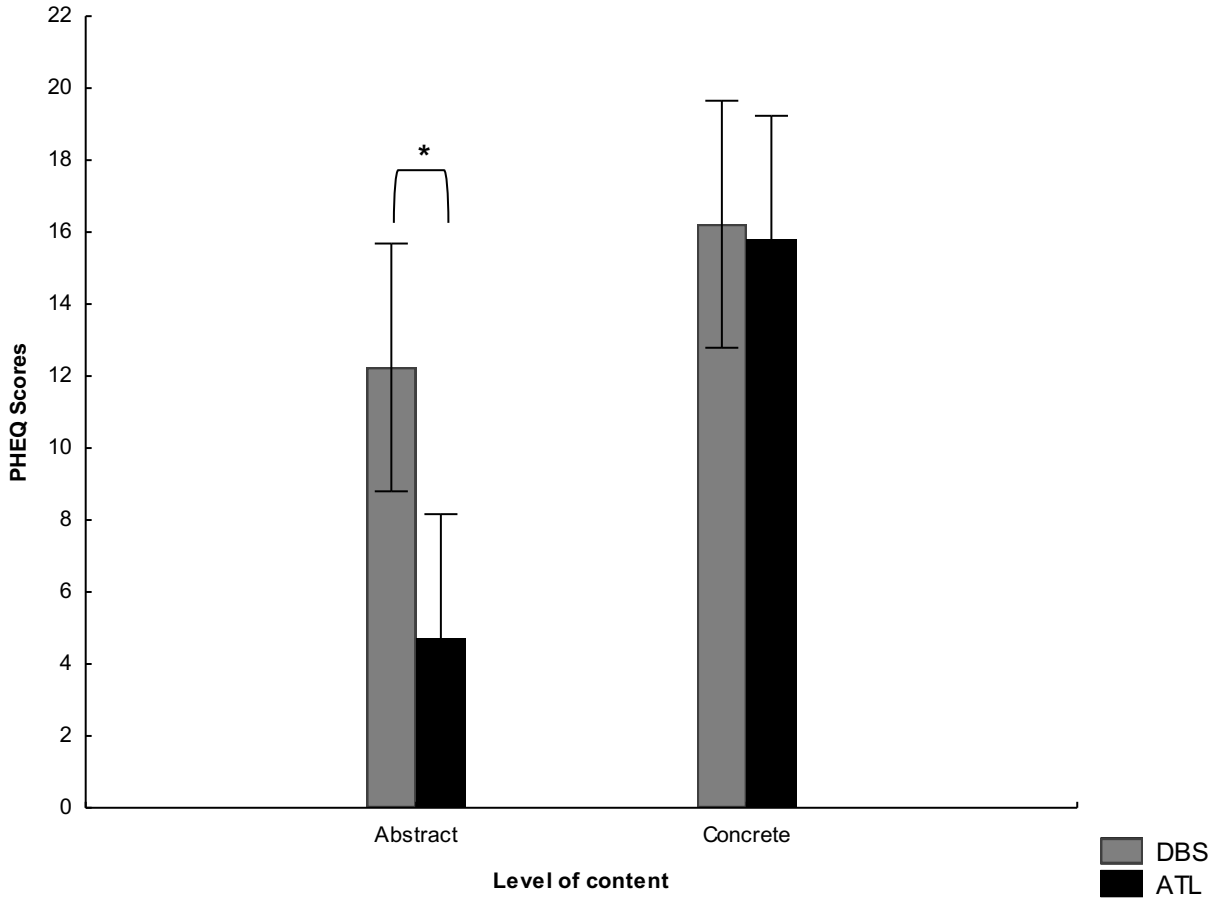

Figure 1. Interaction between Group and Level of content.
* = significant mean differences.