# Hope language in patients undergoing epilepsy surgery

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## ARTICLE INFO

## ABSTRACT

Candidates for epilepsy surgery often use the word "hope" to express their attitudes and beliefs about surgery. However, studies suggest that hope has a multiplicity of meanings that are not well understood. The goal of this analysis was to evaluate whether Candidates for epilepsy surgery use hope language to express a traditional, expected optimism during presurgery interviews. We examined patients' uses of the word "hope" and its derivatives (hoping, hopeful, hopefully) through a secondary analysis of 37 interviews of adult patients prior to epilepsy surgery. Approximately 1/3 of all hope statements were coded as expressions of optimism, while 1/3 were not optimistic, and 1/3 had unclear meanings. In addition to traditionally optimistic uses of the term, other themes surrounding use of this word included ideas of dread, worry, uncertainty, and temporizing language. This information may help clinicians communicate more effectively with patients, enhancing the informed consent process for epilepsy surgery.

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## 1. Introduction

Patients who elect to undergo resective epilepsy surgery face difficult decisions because of uncertainty about outcomes and risk. Up to one-half of these patients will have at least one seizure after surgery, and roughly 85% who experience an initial recurrence will suffer from persistent seizures within six years [1]. Despite these potential outcomes, Candidates for epilepsy surgery also may view surgery as their last chance for a "cure" since their seizures have failed to improve from all medical treatments [1]. Clinicians are responsible for providing guidance to help these patients understand the risks of surgery. In these difficult discussions, clinicians must listen closely in order to facilitate informed consent. Ambiguities or potential miscommunication may arise when patients use language colloquially to express their feelings and beliefs about surgery.

Patients use language in different ways to express their beliefs about medical interventions. They may use the same words but intend different meanings. At times, patients' use of language may even be vague or deceptive. Patients may use seemingly positive language to introduce or facilitate the expression of negative or pessimistic feelings and beliefs

[2]. As a result, clinicians may misinterpret patients' feelings or beliefs about medical treatment. Research on the use of language underscores the difficulty and complexity of interpreting language. Numerous studies demonstrate that language use varies, reflecting individual differences related to gender, culture, and personality [3–5].

Patients with epilepsy often use "hope" language when discussing the decision to undergo resective brain surgery. However, determining the meaning of hope is difficult. Recent studies show that hope has a multiplicity of meanings, suggesting that different people use hope in different ways [6,7]. This conclusion may help to explain why, despite numerous studies offering definitions, models, and structural frameworks for understanding hope [6,8–13], there is no consensus on the meaning of hope. Efforts aimed at defining hope fall short because they do not adequately account for natural variance in language use. We argue that, for clinicians, the broader concepts of hope identified in the literature are not as important as determining what individual patients mean when they use the term "hope" in relation to their treatment goals.

Despite the complexity of interpreting hope language, media and health-care providers often relate the use of hope to optimism in innovative neurosurgical interventions [13]. In the media, hope language is frequently linked to stories of miracle cures, suggesting that the use of hope is always an expression of optimism. Health-care providers also link the use of hope to optimism, viewing hope language as having therapeutic value for patients. Studies have shown that many health-care

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providers believe that expressions of hope are positively linked to overall wellness, resiliency, and improved recovery [6,12,13]. Such interpretations of hope language reflect a traditionally optimistic definition, in which the use of hope is linked to expectation of a positive outcome [7,14–16]. However, given the complexity of language in general, and hope language in particular, clinicians should not assume that hope is always an expression of optimism.

Uses of hope may be particularly complex among patients undergoing epilepsy surgery. In this patient group, there is considerable clinical uncertainty because of failed antiepileptic medications and the risk of seizure recurrence after surgery. These patients, having exhausted other treatment options, choose surgery as a last resort. Given this uncertain outlook, they may be expected to use hope language to express a wide range of feelings and reasoning. Their uses of hope may not imply expectation of a good outcome; rather, they may be expressions of hoping that surgery does not go badly and that complications do not result and that they do not end up in worse condition than they were in prior to surgery.

Understanding the way candidates for epilepsy surgery use the term "hope" has important implications for surgical informed consent. Prior to performing elective neurosurgical interventions, like resective epilepsy surgery, clinicians must carefully assess the patients' individual, idiosyncratic aims for surgery. Evaluating these aims may provide an approximation of the patients' understanding of the surgery, providing clinicians an opportunity to clarify goals and address any unrealistic expectations [17]. In these conversations with clinicians, patients are likely to use hope language. Understanding the way patients use hope language is, therefore, an important first step for assessing a patient's understanding, goals, and expectations for surgery. If this process is not done properly, the patient may be left vulnerable to dissatisfaction caused by misinformation or unrealistic expectations [14].

## 2. Methods

Data for this IRB-approved project were obtained from a larger study examining the ethics of control and consent in patients undergoing epilepsy surgery. Thirty-eight adult patients scheduled to undergo epilepsy surgery were enrolled in the primary study, and signed informed consent was obtained from all participants. All candidates were screened for eligibility. Inclusion criteria required that participants be (1) appropriate candidates for epilepsy surgery as determined by a multidisciplinary surgical selection team in accordance with standard clinical care, (2) aged 21 years or older, (3) native English speakers, (4) able and willing to give informed consent for participation in this research project, and (5) Full scale IQ of 75 or greater. Inclusion criteria were designed to facilitate enrollment of a cohort representing a wide range of backgrounds. Patients were included without regard to past surgical history in order to reflect the natural variance clinicians encounter in informed consent discussions for epilepsy surgery. All but three participants underwent resective epilepsy surgery for the first time. Demographic characteristics of the participants were consistent with those of our general adult candidates for epilepsy surgery (see Table 1).

Following completion of the informed consent process, participants completed a semistructured interview one day prior to surgery. The baseline interview questions explicitly addressed the participants' current quality of life, as well as their understanding of disease and surgery, perceptions of control of their life, and goals and expectations for surgery. Although there was a set of established questions, consistent with standard qualitative interviewing techniques, the interviewer was trained to allow the answers to open-ended questions to proceed in the direction that the participants wished. The interviewer prompted and redirected the participants as needed in order to acquire a full expression of values and understanding. Interview questions were not designed to investigate participants' concepts of hope or to assess their uses of hope language, and the interviewer was not instructed to prompt any discussion of hope. Audio-recorded interviews were

**Table 1**
Participant demographics (N = 37).

| | Total N (%) | Std. dev. | Range |
|---|---|---|---|
| Characteristics | | | |
| Mean age at operation (years) | 44.81 | 12.17 | 24–66 |
| Mean education (years) | 13.56 | 2.27 | 10–18 |
| Mean WAIS-III FSIQ | 97.56 | 13.81 | 76–129 |
| Gender | | | |
| Male | 16 (43.2) | | |
| Ethnicity | | | |
| Caucasian (Non-Hispanic) | 47 (100) | | |
| Marital status | | | |
| Married | 20 (54.1) | | |
| Single | 9 (24.3) | | |
| Divorced | 6 (16.2) | | |
| Other | 2 (5.4) | | |
| Disease characteristics | | | |
| Mean age at first seizure (years) | 26.46 | 17.93 | 0–57 |
| Mean duration of epilepsy (years) | 18.76 | 16.38 | 0.5–53 |
| Site of surgery | | | |
| Resection only within temporal | 24 (65.9) | | |
| Invasive localization | 16 (43.2) | | |

conducted by a trained nonclinician interviewer [KY] and later transcribed verbatim.

All baseline interview transcripts were analyzed and coded thematically using standard qualitative analysis software [QSR NVivo 8] utilizing an inductive approach consistent with grounded theory [18–20]. During the initial inductive analysis, themes surrounding the use of hope language became apparent and generated a new set of research questions. A secondary analysis ensued and all baseline transcripts were coded with specific attention to uses of the word "hope" and its derivatives (hoping, hopeful, hopefully). To examine how participants used hope, one author [DP] reviewed each of the transcripts and consulted frequently with the senior author [PF] to identify themes and to further develop a coding structure. After reviewing the transcripts, a trinary framework that categorized hope statements as optimistic, not optimistic, or unclassifiable was created. This framework was created to determine the extent to which participants' uses of the word "hope" expressed the traditional optimism associated with hope language in health-care settings and the media. The purpose of this framework was to identify hope language that clearly fell on either extreme of the continuum from clearly optimistic to clearly not optimistic. Our purpose was not to make judgment calls when meaning was unclear. As such, we used strict criteria to define optimistic and not optimistic hope. In this context, optimistic and not optimistic hope was defined using the model of "hope-as-want" and "hope-as-expectation," respectively [12]. Optimistic uses of hope are those statements that imply an expected good—"hope-as-expectation" [12]. These statements reflect the traditional optimism frequently ascribed to hope language in the media and in health-care settings [7,14–16]. Statements that clearly do not satisfy this criterion are not optimistic. Rather, these statements expressed some form of "hope-as-want," indicating desire for a positive outcome without endorsing an expectation of its realization. During analysis of these themes, a third category emerged in which meaning could not be clearly determined. These statements were left unclassified to prevent unreliable categorization. Utilizing these categories, statements were analyzed and classified. Throughout the coding process, further thematic analyses were inductively identified. As themes arose phenomenologically, statements were further classified into subcategories. Among optimistic statements, subthemes included reasoned hope based on experiential and nonexperiential reasoning, positive emotional expressions, and positive expectations. Not optimistic statements included subthemes expressing dread, tempered expectations, and uncertainty about the surgery and/or postsurgical outcome.