Epilepsy & Behavior 33 (2014) 144–151

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Targeted Review

Common experiences of patients following suboptimal treatment outcomes: Implications for epilepsy surgery

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ARTICLE INFO

Article history:
Received 30 December 2013
Revised 12 February 2014
Accepted 14 February 2014

Keywords:
Unsuccessful medical interventions
Epilepsy surgery
Psychological adjustment
Surgical outcome
Psychosocial outcome
Qualitative research

ABSTRACT

Few studies have investigated the patient experience of unsuccessful medical interventions, particularly in the epilepsy surgery field. The present review aimed to gain insight into the patient experience of seizure recurrence after epilepsy surgery by examining the broader literature dealing with suboptimal results after medical interventions (including epilepsy surgery). To capture the patient experience, the literature search focused on qualitative research of patients who had undergone medically unsuccessful interventions, published in English in scholarly journals. Twenty-two studies were found of patients experiencing a range of suboptimal outcomes, including seizure recurrence, cancer recurrence and progression, unsuccessful joint replacement, unsuccessful infertility treatment, organ transplant rejection, coronary bypass graft surgery, and unsuccessful weight-loss surgery. In order of frequency, the most common patient experiences included the following: altered social dynamics and stigma, unmet expectations, negative emotions, use of coping strategies, hope and optimism, perceived failure of the treating team, psychiatric symptoms, and control issues. There is support in the epilepsy surgery literature that unmet expectations and psychiatric symptoms are key issues for patients with seizure recurrence, while other common patient experiences have been implied but not systematically examined. Several epilepsy surgery specific factors influence patient perceptions of seizure recurrence, including the nature of postoperative seizures, the presence of postoperative complications, and the need for increased postoperative medications. Knowledge of common patient experiences can assist in the delivery of patient follow-up and rehabilitation services tailored to differing outcomes after epilepsy surgery.

Key questions

1. What are the common experiences described by patients following suboptimal treatment outcomes?
2. How do these relate to the experience of epilepsy surgery with seizure recurrence?
3. How can we apply this knowledge to improve care after epilepsy surgery?

1. Introduction

There has been a steadily growing body of research investigating the psychological and social impact of major medical interventions on the patient. Cay and colleagues noted that "a satisfactory result in the eyes of the surgeon may be regarded as failure by the patient. … by contrast, success to the patient does not necessarily mean absence of physical symptoms" [1], p. 30. This implies that there may be a discrepancy between patient perceptions and medical opinion regarding the success of an intervention. For instance, research into outcomes after epilepsy surgery has shown that despite being seizure-free, patients can experience suboptimal outcomes because of difficulties in adjusting to life without epilepsy and learning to be well [2–5]. Very few studies, however, have explored the perceptions of patients after medically unsuccessful interventions. This is particularly apparent in the epilepsy surgery field where the experience of seizure recurrence has been relatively neglected [6].

Qualitative research provides a rich source of information about key issues spontaneously raised by patients and their families and offers a powerful method for understanding differences between medical and patient perspectives that are relevant to clinical practice. It also has the potential to inform future quantitative studies by fully documenting the nature and range of issues experienced by patients, thereby ensuring that the focus of future research is relevant and that

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http://dx.doi.org/10.1016/j.yebeh.2014.02.018
1525-5050/

the development of quantitative measures is sensitive to patient issues of greatest concern. However, while several qualitative studies have investigated patient experiences of seizure recurrence as part of larger studies (e.g., [2,7]), to date, only one study has focused solely on patients with seizure recurrence [8]. We aimed to gain insight into the patient experience of seizure recurrence after epilepsy surgery by examining this study [8] as part of the broader literature dealing with suboptimal outcomes, including other (nonepilepsy) major interventions. Specifically, this review aimed to identify common themes reported by patients in the broader literature and discuss their relevance to seizure recurrence after epilepsy surgery. We also considered how this knowledge might be applied to improve clinical care and postoperative follow-up of patients epilepsy after surgery.

2. Methods

The present literature review was designed to be exploratory and, therefore, focused on qualitative research (including case studies), or articles that incorporated data from semistructured interviews in conjunction with quantitative measures (mixed method studies), to investigate patient perspectives on suboptimal treatment outcomes. The inclusion criteria were scholarly journal articles written in English that assessed adult human participants (i.e., aged 18 years or older) who had undergone medically unsuccessful interventions. Searches of databases including PubMed, PsycINFO, CINAHL, Psychology & Behavior, Web of Science, Scopus, Taylor & Francis Online, Ovid, and Google Scholar were conducted between June and September 2012. A summary of search terms used is included in the Appendix. Initial searches focused on general terms only, but these were later combined with intervention-specific terms. Note that not all search terms yielded eligible studies. For example, the literature search on deep brain stimulation (DBS) for Parkinson's disease failed to identify studies investigating the patient impact of medically unsuccessful DBS, although there were several studies looking at medically successful DBS.

Reference lists of identified studies were also examined for relevant articles. Abstracts were screened, and those that did not meet the inclusion criteria were removed. All studies that appeared to include relevant data were retrieved, and the full-text article was analyzed to check suitability. In total, 22 qualitative studies across seven research fields formed the basis of the review (see Table 1). Relevant articles were found in a range of areas including seizure recurrence, cancer progression and recurrence, unsuccessful joint replacement (e.g., knee or hip), unsuccessful infertility treatment (e.g., in vitro fertilization (IVF)), organ transplant rejection (e.g., kidney, liver, lung, and heart), outcome after coronary artery bypass graft (CABG) surgery, and unsuccessful weight-loss surgery (e.g., gastric banding or gastric bypass). Some articles were found using general search terms only (e.g., cancer recurrence, unsuccessful infertility treatment), while others were located using a more targeted approach including intervention-specific terms (e.g., articles examining transplant rejection).

3. Data analysis

An iterative process was used to derive common patient experiences of suboptimal treatment outcomes from the 22 studies identified. First, each article was read carefully and annotated for (i) intervention-specific factors that were related specifically to a particular intervention and (ii) generic psychosocial factors that might apply to a range of medical interventions. For example, an intervention-specific factor for unsuccessful infertility treatment would be '*an unfulfilled desire to have a baby*'. In contrast, '*the need for posttreatment support*' could be raised by patients following a range of suboptimal treatment outcomes and, thus, constitutes a generic psychosocial factor. For the purposes of this review, only the generic psychosocial factors from each article were grouped into subthemes, for example, '*the importance of support from others*'. This allowed patient experiences that are central to a range of different treatments to be extracted from the available literature. These subthemes were then reviewed and updated as more articles were read to ensure that all relevant aspects of the patient experience were captured, for example, '*social interactions posttreatment*'. Finally, these subthemes were incorporated into broader, overarching themes, such as '*altered social dynamics and stigma posttreatment*'. In order to focus on themes more likely to generalize across interventions, subthemes that were not reported in the literature for at least two different types of medical intervention were discarded.

Fig. 1 was created as a means of determining the relative frequency of themes and subthemes in the literature. Many patients might be expected to experience these themes, and, thus, they represent common patient experiences after unsuccessful medical interventions. In general, it was not possible to determine the temporal sequence of particular experiences as most studies were cross-sectional rather than longitudinal.

4. Results

4.1. Common patient experiences following suboptimal treatment outcomes

Tables 2 and 3 summarize the themes identified in the literature. Psychological themes included hope and optimism (both before and after treatment), unmet expectations subsequent to unsuccessful treatment, control-related issues, negative emotions and clinical psychiatric symptoms, and the use of coping strategies. Social themes included

Table 1
Articles used in the review of the impact of unsuccessful interventions on patients.

Research area	Studies (N)	Years spanned	Type of study	Participants (N)
Seizure recurrence after epilepsy surgery	1	2009	1 qualitative	15
Cancer recurrence/progression	3	1984–2009	1 qualitative 2 mixed method	82[a]
Unsuccessful joint replacement (knee, hip)	1	2010	1 longitudinal qualitative	12
Unsuccessful infertility treatment (e.g., IVF)	5	2003–2010	5 qualitative	174
Organ transplant rejection (kidney, lung, liver, heart)	6	1984–2009	3 qualitative 1 longitudinal case 2 reviews	59
Weight-loss surgery (gastric banding/gastric bypass)	2	2009–2011	2 qualitative	21
Coronary artery bypass surgery (CABG)	4	1991–2008	4 qualitative	306[b]
Total	22	1984–2011		669

Note. Some studies included patients who had successful interventions as well as patients who had unsuccessful interventions. IVF = in vitro fertilization.
[a] Includes 10 spouses.
[b] Includes 10 health professionals.