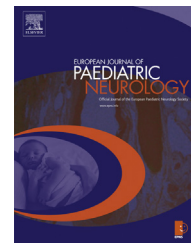




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## Original article

# ‘With the benefit of hindsight’: Would you opt again for epilepsy surgery performed in childhood?



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## ABSTRACT

**Background:** How adolescents and their caregivers look back on epilepsy surgery performed in early life, and whether epilepsy-related restrictions are still in force years after the operation, are insufficiently known.

**Aims:** To obtain retrospective evaluations of the decision for epilepsy surgery at an early age, and to inventory current epilepsy-related restrictions.

**Methods:** Of 177 children who underwent epilepsy surgery between 1992 and 2009, 129 could be approached. They and their parents received a rating list inventorying whether, in retrospect, they would opt again for epilepsy surgery, which were motives for their answer, how successful they felt surgery had been and which, if any, epilepsy-related restrictions were still in force.

**Results:** Forty-one of 44 seizure-free adolescents and 9 of 10 adolescents with current seizures were inclined to (re-)opt for surgery. Parents also would in majority re-opt for surgery. Age at surgery, post-surgical interval, nor type of surgery was statistically significantly related with re-opting for surgery. Seizure-freedom was the paramount motive of seizure-free respondents; respondents with current seizures in majority mentioned amelioration of seizures and/or medication. For parents of children with current seizures, a better developmental perspective was another important motive. Rare hesitation/refusal was related to uncertainties in weighing advantages and disadvantages. Current seizures were no reason to consider surgery as a failure. Among children who were free of both seizures and anti-epileptic drugs, 42% lived with restrictions.

**Conclusions:** Epilepsy surgery that does not result in seizure freedom is nevertheless felt to be beneficial. Proper advice should prevent meaningless continuation of restrictions.

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## 1. Introduction

Epilepsy surgery, nowadays even in very young and mentally retarded children a safe and effective treatment of pharmacologically intractable seizures,<sup>1</sup> fails to obtain seizure freedom in roughly 30% of children.<sup>2</sup> Seizure recurrence is considered to be a consequence of failing surgery,<sup>3</sup> a view, however, that may reflect the surgeons' perspective rather than that of the child and his family.

Four reasons prompted the present study. First, as also noted by Chin et al., there is a need for retrospective evaluations of the decision to have epilepsy surgery in very young children.<sup>4</sup> The age at surgery is often not clearly specified.<sup>5–9</sup> In their comprehensive assessment of epilepsy surgery outcome, Gilliam et al. examined 33 children whose ages at surgery ranged from 8 months to 12 years, but with respect to satisfaction they only asked parents.<sup>10</sup>

Second, there is little research on retrospective evaluations of both proxies and children themselves. Children have little involvement in the decision to proceed with epilepsy surgery, but their awareness of their situation increases with age, which may be reflected in retrospective evaluations. Also, evaluation by a proxy-respondent is not equivalent to that reported by the (former) patient.<sup>11</sup> Benifla et al. interviewed both patients and parents, but the study did not distinguish the two sources.<sup>5</sup> Third, most studies focus on retrospective evaluations of temporal lobe surgery.<sup>4–7,12</sup> Extra-temporal resections are less well represented in the literature, and in studies of mixed groups the effect of surgery type on retrospective evaluation is not reported.<sup>9,10</sup> In particular, retrospective evaluations of the decision for hemispherectomy are lacking. Fourth, the duration a parent has lived with an impaired, albeit possibly seizure-free, child may in the long run change retrospective evaluations of the decision for epilepsy surgery.<sup>6</sup>

Our aim was to find out how (former) patients and their parents/caretakers evaluate their decision to proceed with epilepsy surgery, at least one year after the operation. Rather than asking about satisfaction, we selected an 'action approach' by asking respondents whether they, with the benefit of hindsight, 'would do it again', i.e., opt again for surgery.<sup>4</sup> Further aims were to explore the motives behind responses for or against surgery, and to trace the effects of age at operation, duration of post-surgical interval and type of surgery, both for children with seizure recurrence and for those who were seizure-free. Finally, we inventoried epilepsy-related restrictions imposed on children at least one year after epilepsy surgery.

## 2. Materials and methods

### 2.1. Respondents (Fig. 1)

In the Netherlands, all pediatric candidates for epilepsy surgery are referred to the Dutch Collaborative Epilepsy Surgery Program (DuCESP) and all operations on eligible children are performed at the University Medical Center Utrecht (UMCU). Criteria for surgery are as recommended by Cross et al.<sup>13</sup>

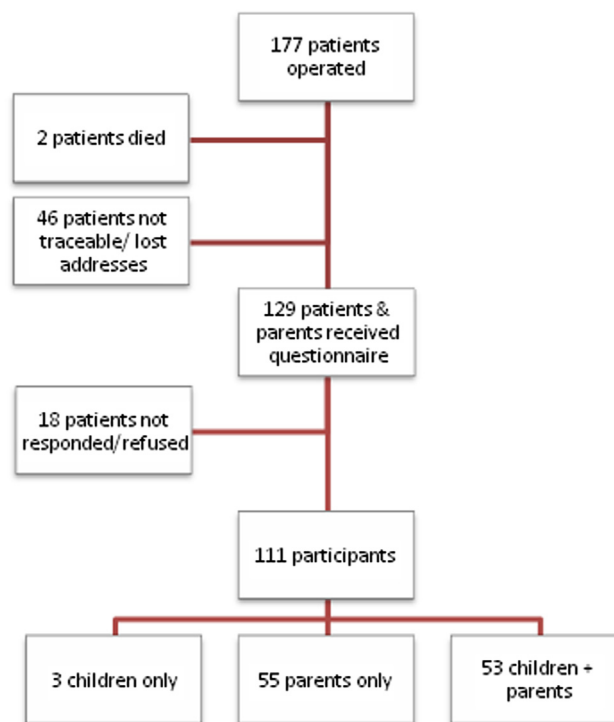


Fig. 1 – From total group to respondents.

Between January 1992 and April 2009, 177 children had undergone epilepsy surgery. Demographic data and data with respect to etiology, age at surgery, date of surgery and type of surgery were retrieved from the DuCESP database.

Two children died after the post-surgical period. Parents of the surviving 175 children were approached by letter, which set out the aims and objectives of the study and asked whether the parents and, where possible, their child were willing to take part. Assurance was given that non-participation would not have any treatment implications. Also enclosed were the rating list 'Would you re-opt for epilepsy surgery' (version for parents and one for children differing only in form of address), and the Euroqol questionnaire (to be reported separately). Independence of answering the questions by child and proxy was demanded but not checked. A stamped hospital envelope was included to return the completed documents.

All attempts failed to establish contact with 46 families. Eighteen of the remaining 129 families chose not to participate because their child had been seizure-free for more than 10 years ( $n = 3$ ), due to the emotional impact of continuing seizures ( $n = 1$ ), or for no specified reason ( $n = 14$ ). One hundred and eleven lists were filled out and returned (86% of the contacted sample), 53 completed by both parents and children, 55 by only the parents and three by only the child.

With respect to gender, etiology, type of surgery, duration of post-surgical period and seizure freedom, patients from whom no response was obtained did not differ from those who or whose parents responded. As far as could be ascertained from the medical files, intelligence quotients did not differ either, with a mean of 86 (range 50–120) in the participant group and 85 (range 47–123) in the non-participants.

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