

PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (<http://bmjopen.bmj.com/site/about/resources/checklist.pdf>) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Parent perceptions and decision-making about treatments for epilepsy: a qualitative evidence synthesis
AUTHORS	Uhl, Stacey; Konnyu, Kristin; Wilson, Renee; Adam, Gaelen; Robinson, Karen; Viswanathan, Meera

VERSION 1 – REVIEW

REVIEWER	Debopam Samanta
REVIEW RETURNED	09-Aug-2022

GENERAL COMMENTS	<p>The authors reported a qualitative synthesis regarding parent perceptions and decision making about epilepsy surgery. We have recently performed a systematic review regarding this topic(Samanta D, Hoyt ML, Perry MS. Parental experience and decision-making for epilepsy surgery: A systematic review of qualitative and quantitative studies. <i>Epilepsy Behav.</i> 2021 Oct;123:108263. doi: 10.1016/j.yebeh.2021.108263. Epub 2021 Aug 21. PMID: 34428615; PMCID: PMC8478881).</p> <p>I would encourage the authors to compare and contrast this paper with this recent publication. There are few other relevant papers included in this paper that may further strengthen this qualitative synthesis.</p>
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REVIEWER	Colin Reilly Young Epilepsy, research
REVIEW RETURNED	22-Oct-2022

GENERAL COMMENTS	<p>General I enjoyed reading this review and was particularly taken by the lack of research on perceptions and decision making about treatments other than surgery. It is well written.</p> <p>Abstract</p> <ul style="list-style-type: none">• I wonder would caregivers' perspectives be better than parents' perspectives throughout article• I feel that the term antiseizure medications (ASMs) is more appropriate than anti-epileptic drugs <p>Introduction</p> <ul style="list-style-type: none">• When epilepsy is described/categorised I feel that it is important to refer to etiology as indicated in 2017 classification• I think the risks of epilepsy surgery are exaggerated in the current paper and a more nuanced approach is needed. The risks for complications are very known.
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	<p>Results</p> <ul style="list-style-type: none"> • I think this section is well written <p>Discussion</p> <ul style="list-style-type: none"> • I think the discussion would benefit from a clearly defined section on clinical implications of findings and directions for future research to make the review valuable for clinicians and researchers. There is a clear need for caregiver and patient views on other non-surgical treatments and the researchers could make suggestions on what this research might look like.
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VERSION 1 – AUTHOR RESPONSE

Reviewer 1 comments	Author response
<p>The authors reported a qualitative synthesis regarding parent perceptions and decision making about epilepsy surgery. We have recently performed a systematic review regarding this topic (Samanta D, Hoyt ML, Perry MS. Parental experience and decision-making for epilepsy surgery: A systematic review of qualitative and quantitative studies. <i>Epilepsy Behav.</i> 2021 ct;123:108263. doi: 10.1016/j.yebeh.2021.108263. Epub 2021 Aug 21. PMID: 34428615; PMCID: PMC8478881).</p> <p>I would encourage the authors to compare and contrast this paper with this recent publication. There are few other relevant papers included in this paper that may further strengthen this qualitative synthesis.</p>	<ul style="list-style-type: none"> • Thank you for reviewing our synthesis of the literature. We became aware of the Samanta et al. (2021) review as we were finalizing ours. It is good to know that this is an area receiving more attention. In the Discussion section of our review, we added a brief paragraph (pg 9, 2nd paragraph) highlighting similarities in findings along with differences in methods between our review and the Samanta review. The main differences being scope (we sought evidence on all treatments for epilepsy) and our use of methodological tools, such as CASP, TDF and GRADE-CerQual. Use of these tools helps to strengthen similar findings. • We appreciate that you suggest additional studies. However, it appears that we utilized different study selection criteria, which explains differences in the evidence base between the two reviews. Our selection criteria was limited to qualitative studies, whereas the Samanta review also included quantitative studies that collected data through medical records and close-ended questionnaires. Based on a comparison of the evidence bases between the two reviews, it seems that both reviews include the most content and methodologically relevant studies.
Reviewer 2 comments	Author response
<p>General</p> <p>I enjoyed reading this review and was particularly taken by the lack of research on perceptions and decision making about treatments other than surgery. It is well written.</p>	<ul style="list-style-type: none"> • Thank you.
<p>Abstract</p> <p>I wonder would caregivers' perspectives be better</p>	<ul style="list-style-type: none"> • While our eligibility criteria were open to all caregiver's, we chose to report the study results with respect to parents as this was the term used to

than parents' perspectives throughout article	describe participants in all of the studies. Thus, we use 'caregiver' in the introduction and methods to describe the planned scope, but parents in the results to reflect the data obtained. However, we defer to the editor about preferred language.
Abstract I feel that the term antiseizure medications (ASMs) is more appropriate than anti-epileptic drugs	<ul style="list-style-type: none"> • Thank you for this suggestion. We have made this change throughout
Introduction When epilepsy is described/categorised I feel that it is important to refer to etiology as indicated in 2017 classification	<ul style="list-style-type: none"> • Thank you. We did use the Scheffer 2017 position paper on epilepsy classification and terminology as one of our resources for describing epilepsy classification and type. The Scheffer paper is listed under the references (ref #4).
Introduction I think the risks of epilepsy surgery are exaggerated in the current aper and a more nuanced approach is needed. The risks for complications are very know.	<ul style="list-style-type: none"> • Thank you for this comment. We have removed risk of death from the list of potential risks associated with surgery, as this risk is very rare. However, given word count limitations, we cannot provide a detailed discussion about the potential risks and benefits of surgery, or any of the other treatments we sought to cover in this review.
Results I think this section is well written	<ul style="list-style-type: none"> • Thank you
Discussion I think the discussion would benefit from a clearly defined section on clinical implications of findings and directions for future research to make the review valuable for clinicians and researchers. There is a clear need for caregiver and patient views on other non-surgical treatments and the researchers could make suggestions on what this research might look like.	<ul style="list-style-type: none"> • Thank you for your suggestion. We have added a brief discussion about the need for qualitative studies of non-surgical treatments to the current text in the Discussion section (paragraph 4, pg. 9) where we describe other identified gaps in the literature.

VERSION 2 – REVIEW

REVIEWER	Colin Reilly Young Epilepsy, research
REVIEW RETURNED	08-Jan-2023

GENERAL COMMENTS	The authors in my view have carefully and adequately addressed the feedback I provided in the initial review.
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REVIEWER	Vrajesh Udani PD Hinduja National Hospital and Medical Research Centre
REVIEW RETURNED	08-Jan-2023

GENERAL COMMENTS	Thanks to the authors for a well designed meticulously done review in an area where little work has been done. In fact an important
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	<p>finding of this review is the paucity of well done studies addressing this important question.</p> <p>These are few of my suggestions for inclusion in the discussion</p> <p>1) The time period of the review is right from 1999 -2021. However the earliest reviewed study was in 2015. This would suggest that many of those operated had their surgery in a time when surgical treatment of epilepsy, attitudes towards "brain surgery" maybe quite different from those who had their surgery later or were not yet operated. Did the authors find any differences in the parental responses between the earlier and later cases;</p> <p>2) It is interesting that all the studies were from advanced economies where the level of education / awareness amongst the lay public is higher vis-a- vis the developing countries. Though this is mentioned briefly as a limitation, it may merit a little more discussion</p>
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VERSION 2 – AUTHOR RESPONSE

Reviewer: 2

Dr. Colin Reilly, Young Epilepsy

Comments to the Author:

The authors in my view have carefully and adequately addressed the feedback I provided in the initial review.

Responses: Thank you for your review of our manuscript.

Reviewer: 3

Dr. Vrajesh Udani, PD Hinduja National Hospital and Medical Research Centre

Comments to the Author:

Thanks to the authors for a well designed meticulously done review in an area where little work has been done. In fact an important finding of this review is the paucity of well done studies addressing this important question.

These are few of my suggestions for inclusion in the discussion:

1) The time period of the review is right from 1999 -2021.

However the earliest reviewed study was in 2015. This would suggest that many of those operated had their surgery in a time when surgical treatment of epilepsy, attitudes towards "brain surgery" maybe quite different from those who had their surgery later or were not yet operated. Did the authors find any differences in the parental responses between the earlier and later cases;

Response: We appreciate your comment. We did not observe a difference in the findings based on time (included studies spanning 5 years from 2015 to 2020).

2) It is interesting that all the studies were from advanced economies where the level of education / awareness amongst the lay public is higher vis-a- vis the developing countries. Though this is mentioned briefly as a limitation, it may merit a little more discussion.

Response: We appreciate your comment and have revised the wording in our discussion to read: Similarly, we found limited evidence for the domain of Environmental Context and Resources. Further evidence is needed to understand how culture and equity play a role in parents' perceptions about treatment and their capacity to access care for their child. For example, parents reported important barriers in knowledge, access to professionals to diagnose and treat their child, and challenges with accessing and paying for surgery. The extent to which these factors would be the similar among families from different cultural or socio-economic backgrounds or from countries with varying economic, educational, and social resources needs further exploration.