

Ethical Implications of Inconsistent Definitions of "Palliative" in Neurosurgical Research



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# Background

- Palliative care is increasingly recognized as important in the treatment of neurosurgical patients, but misunderstandings about the definition and role of palliative care can present barriers to access.
- Neurosurgical interventions such as deep brain stimulation (DBS) and ulletepilepsy surgery can be powerful tools in a palliative plan of care.
- Published results from neurosurgical research describe treatments as "palliative" inconsistently and often without explicit definition. (Blackstone et al., 2021)

Aims

#### **Examples from literature** Definitions The authors define Epilepsy surgery: "The term palliative epilepsy surgery is usually used palliative as a reduction in when a surgical intervention does not offer a high seizure frequency. chance for complete seizure freedom but aims at ceasing particularly disabling seizure types or at decreasing the global seizure frequency." (Wellmer et al., 2016) The authors define Epilepsy surgery: "The palliative nature of surgical treatment for DS palliative benefit as makes actual seizure frequency less important than improvement in overall overall quality of life improvement gained." quality of life. (Dlouhy et al., 2016) DBS for dystonia: This quote seems to use two different definitions of "DBS inserted as a palliative measure but nonrechargeable battery not replaced, therefore "palliative": non-curative and comfort measures at stimulation ceased. Patient died with full palliative end-of-life. care support."

- Elucidate the ways in which benefits of neurosurgical interventions are presented as "palliative" in research.
- Identify how neurosurgical researchers define palliative benefit.  $\bullet$
- Provide recommendations for future research based on findings.

## Methods

- A focused narrative review of published research in epilepsy surgery • and DBS was conducted using the following search terms: palliative, neurosurgery, epilepsy surgery, deep brain stimulation.
- Research articles using the term "palliative" were analyzed to discern • whether and how the term was defined. When an explicit definition was lacking, contextual clues were used to infer meaning.

#### References

- Blackstone, E., Ford, P., & Sankary, L. (2021). Clarity on Palliative Neurosurgery: A Neuroethics Perspective. World Neurosurgery, 156, 56-58.
- Wellmer, J., Parpaley, Y., Rampp, S., Popkirov, S., Kugel, H., Aydin, U., Wolters, C., von Lehe, M., & Voges, J. (2016). Lesion guided stereotactic thermocoagulation for palliative, in selected cases curative epilepsy surgery. Epilepsy Research, 121, 39-46.

(Kaminska et al., 2017)

## Results

- Forty-eight articles published between 2004 and 2022 were identified in the review.
- Only 3 articles provided an explicit definition of "palliative." Both explicit and inferred definitions based on context implied inconsistent goals of treatment.
- Definitions of "palliative" included any non-curative intervention, a last resort for treatment-refractory disease, improving a particular symptom, or improving overall quality of life.

## Conclusion

Researchers should be clear about how they define and measure palliative benefit of neurosurgical interventions. Measuring palliative benefits may require the addition of patient- and family-reported outcomes and lengthening post-trial follow-up.

Dlouhy, B., Miller, B., Jeong, A., Bertrand, M., Limbrick Jr., D., & Smyth, M. (2016). Palliative epilepsy surgery in Dravet syndrome – case series and review of the literature. Childs Nerv Syst, 32, 1703-1708. Kaminska, M., Perides, S., Lumsden, D. E., Nakou, V., Selway, R., Ashkan, K., & Lin, J. P. (2017). Complications of Deep Brain Stimulation (DBS) for dystonia in children - The challenges and 10 year experience in a large paediatric cohort. Eur J Paediatr Neurol, 21(1), 168-175.

Ethical advantages of this approach include clearer communication with research participants, and a richer understanding of the palliative benefits and limitations of neurosurgery.

• Funding agencies, IRBs, DSMBs, and manuscript reviewers should request clarification when palliative outcomes are not clearly defined.

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