

Stakeholder Perspectives on Research Enrollment at End of Life

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Researchers and clinicians frequently ask families to enroll their children in early phase clinical trials or palliative care research at the end of life (EOL); however, these decisions are rarely easy. Research burden, ethical concerns, and therapeutic misconception all must be considered. The question is often asked, should these vulnerable families be recruited for EOL studies?

The current systematic review by Hasan and colleagues helps to answer this question, summarizing the perceptions and experiences of children, parents, and health professionals regarding EOL research enrollment ([10.1542/peds.2020-003780](https://doi.org/10.1542/peds.2020-003780)). The authors identify 24 published manuscripts utilizing a mix of both qualitative and quantitative methods and focusing on stakeholder experiences in this area. Following thematic analysis and synthesis, primary themes are concisely described in the text. I encourage you to go directly to the article to learn about each of these eight themes.

In addition, specific quotations provided by the authors from these studies further illustrate the identified themes and highlight notable differences in perception/experience by child, parent, and health professional report. For example, the authors highlight the delicate balance between family and provider perception of "wanting choices." Notably, they contrast a) parental belief that EOL of life research enrollment is the only option to b) provider belief that multiple choices are offered, including palliative care. Given AAP's recent endorsement of the Clinical Practice Guidelines for Quality Palliative Care,^{1,2} EOL research enrollment may be a critical transition point in the disease trajectory, ripe for palliative care involvement.

The question of whether we should enroll children in research at the end of life is not an easy one. By providing the voice of the patient, family, and health professional, the authors of this study may help providers better understand how families weigh EOL research enrollment and how we can better support families in making these difficult decisions.

References

1. Clinical Practice Guidelines for Quality Palliative Care. *Pediatrics*. 2019;143:e20183310.
2. National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: *National Coalition for Hospice and Palliative Care*, 2018; <https://www.nationalcoalitionhpc.org/ncp>.

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