

## Publication

## End-of-life decision making in pediatrics: literature review on children's and adolescents' participation

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**Background:** Pediatric guidelines recommend that children and adolescents participate in a developmentally appropriate way in end-of-life decision making. Shared decision making in pediatrics is unique because of the triadic relationship of patient, parents, and physician. The involvement of the patient may vary on a continuum from no involvement to being the sole decision maker. However, the effects of child participation have not been thoroughly studied. The aim of this literature review is to identify studies on end-of-life decision making in pediatrics to explore patient participation and to assess the effects of such participation.

**Methods:** Five databases—PubMed, PsycInfo, Medline, CINAHL, and Sociological Abstract —were searched for empirical studies on end-of-life decision making in pediatrics. Selected articles fulfilling the criteria were assessed for type of decision, participants' characteristics, reports on participation of the minor patient, and outcome.

**Results:** Fifty-seven articles on end-of-life decision making in pediatrics were identified. The majority of papers (n = 43, 75%) investigated parents' and clinicians' perspectives, while only 14 articles (25%) included perspectives of children and adolescents. Twenty-two articles (39%) reported some details on various forms of children's participation (e.g., receive information, plan care details, consulted before or after a decision was made). Positive (e.g., respect for patient's preferences) as well as negative (e.g., conflict due to diverging opinions) effects of children's participation in end-of-life decision making were reported.

**Conclusions:** This systematic review highlights the need for research to identify factors that contribute to a favorable participation of minors in decision making processes as well as strategies to solve possible conflicts. More research should take into account the dynamics in the triadic process of decision making and emphasize children and adolescents' perspectives. A better understanding of how to meaningfully involve children and adolescents in end-of-life decision making could facilitate the practice of patient participation in pediatrics.

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