

## Publication

### Better to know than to imagine: Including children in their health care

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**BACKGROUND:** This article describes the overall attitudes of children, their parents, and attending physicians toward including or excluding pediatric patients in medical communication and health care decision-making processes. **METHODS:** Fifty-two interviews were carried out with pediatric patients (n = 17), their parents (n = 19), and attending oncologists (n = 16) in eight Swiss pediatric oncology centers. The interviews were analyzed using thematic coding. **RESULTS:** Parenting styles, the child's personality, and maturity are factors that have a great impact upon the inclusion of children in their health care processes. Children reported the desire to be heard and involved, but they did not want to dominate the decision-making process. Ensuring trust in the parent-child and physician-patient relationships and respecting the child as the affected person were important values determining children's involvement. These two considerations were closely connected with the concern that fantasies are often worse than reality. Seeking children's compliance with treatment was a practical but critical reason for informing them about their health care. The urge to protect them from upsetting news sometimes resulted in their (partial) exclusion. **CONCLUSIONS:** The ethical imperative for inclusion of children in their health care choices was not so much determined by the right for self-determination, but by the need to include them. If children are excluded, they imagine things, become more isolated, and are left alone with their fears. Nevertheless, the urge to protect children is innate, as adults often underestimate children's coping capacities.

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