

Publication

Parents' and Physicians' Perceptions of Children's Participation in Decision-making in Paediatric Oncology: A Quantitative Study

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The goal is to present how shared decisionmaking in paediatric oncology occurs from the viewpoints of parents and physicians. Eight Swiss Pediatric Oncology Group centres participated in this prospective study. The sample comprised a parent and physician of the minor patient (<18 years). Surveys were statistically analysed by comparing physicians' and parents' perspectives and by evaluating factors associated with children's actual involvement. Perspectives of ninetyone parents and twenty physicians were obtained for 151 children. Results indicate that for six aspects of information provision examined, parents' and physicians' perceptions differed. Moreover, parents felt that the children were more competent to understand diagnosis and prognosis, assessed the disease of the children as worse, and reported higher satisfaction with decision-making on the part of the children. A patient's age and gender predicted involvement. Older children and girls were more likely to be involved. In the decision-making process, parents held a less active role than they actually wanted. Physicians should take measures to ensure that provided information is understood correctly. Furthermore, they should work towards creating awareness for systematic differences between parents and physicians with respect to the perception of the child, the disease, and shared decision-making.

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