

## Publication

## Putting patient participation into practice in pediatrics-results from a qualitative study in pediatric oncology

**JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)****ID** 3661785**Author(s)** Ruhe, Katharina Maria; Wangmo, Tenzin; De Clercq, Eva; Badarau, Domnita Oana; Ansari, Marc; Kühne, Thomas; Niggli, Felix; Elger, Bernice Simone; Swiss Pediatric Oncology Group (SPOG)**Author(s) at UniBasel** [Ruhe, Katharina](#) ; [Badarau, Domnita](#) ; [Elger, Bernice Simone](#) ; [Wangmo, Tenzin](#) ; [De Clercq, Eva](#) ;**Year** 2016**Title** Putting patient participation into practice in pediatrics-results from a qualitative study in pediatric oncology**Journal** European Journal of Pediatrics**Volume** 175**Number** 9**Pages / Article-Number** 1147-55

Adequate participation of children and adolescents in their healthcare is a value underlined by several professional associations. However, little guidance exists as to how this principle can be successfully translated into practice. A total of 52 semi-structured interviews were carried out with 19 parents, 17 children, and 16 pediatric oncologists. Questions pertained to participants' experiences with patient participation in communication and decision-making. Applied thematic analysis was used to identify themes with regard to participation. Three main themes were identified: (a) modes of participation that captured the different ways in which children and adolescents were involved in their healthcare; (b) regulating participation, that is, regulatory mechanisms that allowed children, parents, and oncologists to adapt patient involvement in communication and decision-making; and (c) other factors that influenced patient participation. This last theme included aspects that had an overall impact on how children participated. Patient participation in pediatrics is a complex issue and physicians face considerable challenges in facilitating adequate involvement of children and adolescents in this setting. Nonetheless, they occupy a central role in creating room for choice and guiding parents in involving their child. Conclusion: Adequate training of professionals to successfully translate the principle of patient participation into practice is required.

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