

Publication

Participation in pediatric oncology: views of child and adolescent patients

JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

ID 3401749

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Year 2015

Title Participation in pediatric oncology: views of child and adolescent patients

Journal Psycho-Oncology

Volume 25

Number 9

Pages / Article-Number 1036-42

Keywords cancer, participation, pediatric oncology, children, adolescents

The aim of the present study is to explore patient's perspectives in pediatric oncology on participation in discussions and decision-making surrounding their cancer diagnosis.; Seventeen patients between 9 and 17ăyears of age receiving treatment at centers of the Swiss Pediatric Oncology Group were interviewed for this study. Their interview data was analyzed qualitatively to identify themes with regard to participation in medical communication and/or decision-making.; Participants highlighted how their roles in health care discussions varied from direct participation to indirect involvement. Overall, there were fewer accounts of involvement in decision-making than in overall health care discussions. Challenges with regard to completely understanding the information provided and making decisions were identified. Participants also discussed situations when they were not involved in medical communication or decision-making. While they generally valued their participation, the preferred level of involvement oscillated between participants as well as within one and the same child across time.; The complex pattern of participation found in this study calls for a flexible model of involving children and adolescents in health care that accounts for the varying roles and preferences that they manifest. A patient may appreciate active involvement in some decisions while choosing to remain in the background for others. Copyright I' 2015 John Wiley & Sons, Ltd.

Publisher Wiley

ISSN/ISBN 1057-9249 ; 1099-1611 edoc-URL http://edoc.unibas.ch/41710/

Full Text on edoc No;

Digital Object Identifier DOI 10.1002/pon.4053

PubMed ID http://www.ncbi.nlm.nih.gov/pubmed/26677126

ISI-Number WOS:000385722700004 **Document type (ISI)** Journal Article