

Publication

Cancer care in Romania: challenges and pitfalls of children's and adolescents' multifaceted involvement

JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

ID 3661781

Author(s) Badarau, Domnita O.; De Clercq, Eva; Wangmo, Tenzin; Dragomir, Monica; Miron, Ingrid; Kühne, Thomas; Elger, Bernice S.

Author(s) at UniBasel [Elger, Bernice Simone](#) ; [Badarau, Domnita](#) ; [De Clercq, Eva](#) ; [Wangmo, Tenzin](#) ;

Year 2016

Title Cancer care in Romania: challenges and pitfalls of children's and adolescents' multifaceted involvement

Journal Journal of medical ethics

Volume 42

Number 12

Pages / Article-Number 757-761

Communication about diagnosis and medical treatment for children suffering from life-threatening illnesses is complex. It is a primary step in involving underage patients and families in care and lays the foundation for obtaining parental permission and patient assent for treatment. In practice child participation in care is often difficult to obtain due to patients' different and sometimes fluctuating preferences, but also parents' protective strategies. Physicians may be susceptible to parental wishes to limit information and feel uncomfortable discussing issues related to uncertainty of cure with patients. A qualitative study in Romanian paediatric oncology units was conducted to explore children's involvement from the perspectives of parents and oncologists. Interviews with participants discussed 18 patient cases. Data were transcribed and thematic analysis was used to interpret and mine patients' involvement during treatment. Different facets of patient participation were identified: restricting, widening and enhancing involvement. A fourth category, unintentional involvement, occurred for all patients due to children's observations during long-term hospitalisations and access to Internet. Uncertainty overarched parental attitudes regarding the extent to which children should be included. Physicians usually complied with parental wishes to limit involvement, but together with parents involved patients at least in a practical way. Adults' protective attitude may backfire, as adolescents' online searches often expose patients to worse-case scenarios. Further research should acknowledge the hazards of restricted diagnosis disclosure and develop clinician tools to support families in communicating with patients. This should be paralleled by physician efforts to elicit patients' needs regarding participation.

Publisher BMJ Publishing Group

ISSN/ISBN 0306-6800 ; 1473-4257

edoc-URL <http://edoc.unibas.ch/44974/>

Full Text on edoc No;

Digital Object Identifier DOI 10.1136/medethics-2016-103418

PubMed ID <http://www.ncbi.nlm.nih.gov/pubmed/27697792>

ISI-Number WOS:000388977100002

Document type (ISI) Journal Article