

Publication

From choiceless to hard choices: views of parents and oncologists on decision-making in pediatric oncology in two European countries

Journal Article (Originalarbeit in einer wissenschaftlichen Zeitschrift)

ID 3673752

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Year 2016

Title From choiceless to hard choices: views of parents and oncologists on decision-making in pediatric oncology in two European countries

Journal AJOB Empirical Bioethics

Volume 8

Number 1

Pages / Article-Number 21-31

Background : Decision making is a highly complex task when providing care for seriously ill children. Physicians, parents, and children face many challenges when identifying and selecting from available treatment options. **Methods** : This qualitative interview study explored decision-making processes for children with cancer at different stages in their treatment in Switzerland and Romania. **Results** : Thematic analysis of interviews conducted with parents and oncologists identified decision making as a heterogeneous process in both countries. Various decisions were made based on availability and reasonableness of care options. In most cases, at the time of diagnosis, parents were confronted with a “choiceless choice”—that is, there was only one viable option (a standard protocol), and physicians took the lead in making decisions significant for health outcomes. Parents’ and sometimes children’s role increased during treatment when they had to make decisions regarding research participation and aggressive therapy or palliative care. Framing these results within the previously described Decisional Priority in Pediatric Oncology Model (DPM) highlights family’s more prominent position when making elective decisions regarding quality-of-life or medical procedures, which had little effect on health outcomes. The interdependency between oncologists, parents, and children is always present. Communication, sharing of information, and engaging in discussions about preferences, values, and ultimately care goals should be decision making’s foundation. **Conclusions** : Patient participation in these processes was reported as sometimes limited, but parents and oncologists should continue to probe patients’ abilities and desire to be involved in decision making. Future research should expand the DPM and explore how decisional priority and authority can be shared by oncologists with parents and even patients.

Publisher Taylor & Francis

ISSN/ISBN 2329-4515 ; 2329-4523

edoc-URL <http://edoc.unibas.ch/45152/>

Full Text on edoc No;

Digital Object Identifier DOI 10.1080/23294515.2016.1234519