

## Research Project

### Attitudes and motives concerning end-of-life decisions: competency and autonomy of children and adolescents in paediatric oncology

#### Third-party funded project

**Project title** Attitudes and motives concerning end-of-life decisions: competency and autonomy of children and adolescents in paediatric oncology

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**Organisation / Research unit**

Ethik / Bio- und Medizinethik (Elger)

**Department**

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**ETHICAL ISSUES OF END-OF-LIFE DECISION MAKING:** End-of-life decisions involving minors incorporate difficult choices that demand a complex and holistic approach from medical, social, ethical and legal perspectives. Research exploring the autonomy of children or adolescents in these situations is scarce. In many cases, minor's competency to refuse treatment at the end-of-life is questioned. Such treatment decisions for minors are made by their parents and/or physicians who refer to the best-interest of the minor. Although many believe that children and adolescents who live with chronic illnesses are able to understand their condition and the outcomes of an end-of-life decision, they are rarely given the option to voice their concerns and make their own choices.

**STUDY PURPOSE:** The purpose of this mixed methods study is to investigate the possibility of including a child or adolescent living with cancer in his or her end-of-life decision making processes and to examine associated motives and attitudes behind such decisions. In the study, quantitative data obtained will paint a reliable picture of general aspects associated with decision making in Swiss paediatric oncology situations and qualitative one-on-one interviews will help evaluate motives and attitudes of parents, primary oncologists and minors themselves when making these very difficult choices.

**STUDY METHODOLOGY:** Participants will be recruited from the Swiss Paediatric Oncology Group (SPOG) affiliated paediatric centres in Aarau, Basel, Bern, Bellinzona, Geneva, Luzern, St. Gallen and Zurich. The quantitative data will be captured on each case of childhood cancer diagnosed and/or treated during the study period. This data will be gathered from physicians and residents of the participating SPOG centres, and corresponding parents of the patient. They comprise our survey study participant (SSP). Data will be collected at three time points, the first T1 at diagnosis or first treatment and two follow-ups (T2 and T3, where possible).

In-depth information on this topic will be obtained using 60 interviews from our interview study sample (ISP). Twenty interviews will be held with children/adolescents aged 9 - 17, suffering from severe and possibly life threatening cancer. Half of our patient ISP sample will be recruited at the time of diagnosis from the SPOG centres and the other half from those who are in a stage of palliative care. The remaining 40 interviews will include the minors' parents (n=20) and primary oncologists (n=20). Participants will be interviewed using a semi-structured interview guide and a short closed-ended questionnaire. The semi-

structured interview will decipher various concerns, values and attitudes concerning end-of-life decision making and the extent of the child's or adolescent's involvement in such decision making processes. Study results will be analysed both quantitatively using SPSS and qualitatively using basic qualitative techniques and Atlas.ti.

**IMPORTANCE AND IMPACT OF THE STUDY:** We expect that the findings of this study will contribute significantly to the field of end-of-life decision making. The study will improve our understanding and assessment of children's and adolescents' autonomy, delineate the extent to which a minor could be integrated into a decision making process, provide a much needed well rounded data on the issue thereby becoming a critical informational source for practitioners, researchers, ethicists and policy makers. Finally, we hope the study will be a stepping stone for future research and contribute to the political and social discussions concerning autonomy of a minor in health care decision making, nationally and internationally.

**Keywords** Ethics, informed consent

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## Add publication

### Published results

2362370, Ruhe Katharina M; Badarau, Domnita O; Elger, Bernice S; Wangmo, Tenzin, End-of-life decision making in pediatrics: literature review on children's and adolescents' participation, 2329-4515, AJOB empirical bioethics, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

2745760, Badarau, Domnita O.; Nast, Rebecca L.; Shaw, David M., The vulnerability of the individual benefit argument, 1526-5161, The American journal of bioethics, JournalItem (Kommentare, Editorials, Rezensionen, Urteilsanmerk., etc. in einer wissensch. Zeitschr.

2779938, Ruhe, Katharina M.; Wangmo, Tenzin; Badarau, Domnita O.; Elger, Bernice S.; Niggli, Felix, Decision-making capacity of children and adolescents : suggestions for advancing the concept's implementation in pediatric healthcare, 1432-1076, European journal of pediatrics, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

3659206, Wangmo, T.; De Clercq, E.; Ruhe, K.; Beck-Popovic, M.; Rischewski, J.; Angst, R.; Ansari, M.; Elger, BS., Better to know than to imagine: Including children in their health care, 2329-4515 ; 2329-4523, AJOB Empirical Bioethics, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

3659208, Ruhe, KM.; Wangmo, T.; De Clercq, E.; Badarau, DO.; Ansari, M.; Kühne, T.; Niggli, F.; Elger, BS, Putting patient participation into practice in pediatrics-results from a qualitative study in pediatric oncology., European Journal of Pediatrics, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

3659210, Ruhe, KM.; De Clercq, E.; Wangmo T.; Elger BS., Relational Capacity: Broadening the Notion of Decision-Making Capacity in Paediatric Healthcare., The Journal of Bioethical Inquiry, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

3659213, Badarau, D. O.; Ruhe, KM.; Kühne, T.; De Clercq, E.; Anca, C.; Elger, BS.; Wangmo, T., Decision making in pediatric oncology: Views of parents and physicians in two European countries, 2150-7724 ; 2150-7716, AJOB Empirical Bioethics, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

3669344, Wangmo, Tenzin; Ruhe, Katharina M.; Badarau, Domnita O.; Kühne, Thomas; Niggli, Felix; Elger, Bernice S.; Swiss Paediatric Oncology Group, Parents' and patients' experiences with paediatric

oncology care in Switzerland—satisfaction and some hurdles, 1424-7860 ; 1424-3997, Swiss medical weekly, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4021478, Rost, Michael; Wangmo, Tenzin; Niggli, Felix; Hartmann, Karin; Hengartner, Heinz; Ansari, Marc; Brazzola, Pierluigi; Rischewski, Johannes; Beck-Popovic, Maja; Kühne, Thomas; Elger, Bernice S., Parents' and Physicians' Perceptions of Children's Participation in Decision-making in Paediatric Oncology: A Quantitative Study, 1176-7529 ; 1872-4353, Journal of Bioethical Inquiry, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4082980, De Clercq, Eva; Rost, Michael; Pacurari, Nadia; Elger, Bernice; Wangmo, Tenzin, Aligning guidelines and medical practice: Literature review on pediatric palliative care guidelines, 1478-9515 ; 1478-9523, Palliative & supportive care, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4021472, Rost, Michael; De Clercq, Eva; Wangmo, Tenzin; Elger, Bernice S., The Need for a Shared Understanding: Domains of Care and Composition of Team in Pediatric Palliative Care Guidelines, 1522-2179 ; 1539-0705, Journal of Hospice & Palliative Nursing, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4348492, Rost, Michael; Acheson, Elaine; Kühne, Thomas; Ansari, Marc; Pacurari, Nadia; Brazzola, Pierluigi; Niggli, Felix; Elger, Bernice; Wangmo, Tenzin, Palliative care in Swiss pediatric oncology settings: a retrospective analysis of medical records, 0941-4355 ; 1433-7339, Supportive Care in Cancer, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4487017, Rost, Michael; De Clercq, Eva; Elger, Bernice, Arno Gruen's understanding of autonomy in children: Experiencing and integrating one's own feelings and needs, 1424-7860 ; 1424-3997, Swiss medical weekly, JournalItem (Kommentare, Editorials, Rezensionen, Urteilsanmerk., etc. in einer wissenschaftl. Zeitschr.

3868205, De Clercq, E.; Ruhe, K. M.; Rost, M.; Elger, B. S., Is decision-making capacity and "essentially contested" concept in pediatrics?, 1386-7423 ; 1572-8633, Medicine, Health Care and Philosophy, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4112818, De Clercq, Eva; Elger, Bernice Simone; Wangmo, Tenzin, Missing life stories. The narratives of palliative patients, parents and physicians in paediatric oncology, 0961-5423 ; 1365-2354, European Journal of Cancer Care, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4487111, Rost, Michael; Wangmo, Tenzin; Rakic, Milenko; Acheson, Elaine; Rischewski, Johannes; Hengartner, Heinz; Kühne, Thomas; Elger, Bernice S., Burden of treatment in the face of childhood cancer: A quantitative study using medical records of deceased children, 0961-5423 ; 1365-2354, European Journal of Cancer Care, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4511105, De Clercq, Eva; Rost, Michael; Rakic, Milenko; Ansari, Marc; Brazzola, Pierluigi; Wangmo, Tenzin; Elger, Bernice S., The conceptual understanding of pediatric palliative care: a Swiss health-care perspective, 1472-684X, BMC palliative care, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4513892, Rost, Michael; De Clercq, Eva; Rakic, Milenko; Wangmo, Tenzin; Elger, Bernice, Barriers to Palliative Care in Pediatric Oncology in Switzerland: A Focus Group Study, 1043-4542 ; 1532-8457, Journal of Pediatric Oncology Nursing, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4514438, Badarau, D. Oana; De Clercq, Eva; Elger, Bernice S., Continuous Deep Sedation and Euthanasia in Pediatrics: Does One Really Exclude the Other for Terminally Ill Patients?, 0360-5310 ; 1744-5019, Journal of Medicine and Philosophy, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4488815, Cheng, Brian T.; Röst, Michael; De Clercq, Eva; Arnold, Louisa; Elger, Bernice; Wangmo, Tenzin, Palliative Care Initiation in Pediatric Oncology Patients: A Systematic Review, 2045-7634, Cancer medicine, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

**Add documents**

**Specify cooperation partners**

ID	Kreditinhaber	Kooperationspartner	Institution	Laufzeit - von	Laufzeit - bis
1016834	Elger, Bernice Simone	Kühne, Thomas, Prof. Dr. med., Co-Referee	Onkologie/Hämatologie, Universitäts-Kinderpital beider Basel	01.06.2011	31.12.2014
1544131	Elger, Bernice Simone	Niggli, Felix, Prof.	University of Zurich	01.06.2011	30.04.2015
1544132	Elger, Bernice Simone	Wilfond, Benjamin, Prof.	University of Washington School of Medicine, Seattle	01.06.2011	30.04.2015
1544133	Elger, Bernice Simone	Ross, Lainie, Prof.	The University of Chicago Medicine, Chicago	01.06.2011	30.04.2015
1544177	Elger, Bernice Simone	Ansari, Marc, MD	Pédiatre FMH Oncologue et Hématologue, Hôpital Cantonal de Genève	01.05.2012	30.04.2015
1544183	Elger, Bernice Simone	Hengartner, Heinz, MD	Ostschweizer Kinderspital St. Gallen	01.05.2012	30.04.2015
1544191	Elger, Bernice Simone	Rischewski, Johannes, MD	Onkologie, Kinderspital Luzern	01.05.2012	30.04.2015