

## Research Project

### Competency and Autonomy of Children and Adolescents in Pediatric Oncology decision making processes. Comparative research study between Switzerland and Romania

#### Third-party funded project

**Project title** Competency and Autonomy of Children and Adolescents in Pediatric Oncology decision making processes. Comparative research study between Switzerland and Romania

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**Organisation / Research unit**

Ethik / Bio- und Medizinethik (Elger)

**Department**

**Project Website** <http://ibmb.unibas.ch/research/>

**Project start** 01.01.2012

**Probable end** 31.12.2015

**Status** Completed

Research topic and study objective :

Given existing research results published so far surrounding decisions making in pediatric oncology, the study will investigate parents' and health care providers' attitudes and motives concerning minor's autonomy and inclusion in pediatric oncology decision making, as well as if and how they differ across countries. By using a mixed methods approach, the project aims to examine and compare the reality of a minor's autonomy in Romania and Switzerland. It is relevant to understand how and whether minors are included in medical decisions, as they may already be aware of their condition and probable prognosis and wish to be involved, especially in end-of-life situations. Being the ones experiencing the symptoms of the disease may make them feel entitled to this knowledge. Therefore, comparable data from Switzerland and Romania can only contribute more to fully understanding and learning about attitudes, motives and barriers concerning ethical decision making in pediatric oncology centres in Switzerland and Romania.

State of research:

For decades end-of-life decision-making has been spurring controversies worldwide, bringing to focus ethical issues and lack of consensus among actors involved in these decisions. Decision making towards the end-of-life is often difficult , dominated by uncertainties around medical treatment, illness' progression, the capacity of the patient to exert or continue to make autonomous decisions and not least, the complexity of judgments in acknowledging the patient's transition to an end-of-life state. Such decisions are influenced by many factors: age, capacity to consent, disease, and how, when and by whom should the decision be made. This might differ among countries, due to cultural differences, socio-economic aspects, and it is particularly difficult to assess when it comes to children and adolescents.

It is clear that end-of-life decision making for minors is fraught with uncertainties. Studies concerning inclusion of children in decision making about cancer research and end-of-life preferences, to name a few, have mostly been carried out in either Europe (the Netherlands, Belgium) or in the United States, with most being conducted in the US. Cultural sensitivity varies when it comes to paternalism and attitudes toward end-of-life issues among and between countries and cultural groups. To the best of researcher's knowledge, research exploring minors' autonomy and end-of-life decision making has not been done in

Switzerland and Romania. Within Europe, few studies have been carried out on this issue and so far it can be appreciated that none explored differences among countries on this issues.

Study significance :

Study results are expected to provide longitudinal insight into decision making (look at processes from diagnosis to end-of-life) for minor patients living with cancer and to investigate the possibility of including these minors in end-of-life decision-making processes. By employing mixed methods: quantitative (surveys) and qualitative (interviews) the study will help gain novel and important quantitative data on the inclusion of children in end-of-life decisions and factors influencing these choices and the decision-making processes. The qualitative data will highlight reasons for including/NOT including minors in end-of-life decision making from 2 perspectives: oncologists and patients' parents. Due to the unique diversity within the study sample: recruitment from two culturally distinct countries: Romania and Switzerland and given the potential significant differences between the German, French and Italian speaking parts of Switzerland, the study results are expected to reveal the influences of guidelines, local factors and traditions on paediatric oncology end-of-life decisions. This will add to the existing literature, providing a double perspective regarding actual decisions in pediatric oncology.

#### **Financed by**

Foundations and Associations

#### **Add publication**

##### **Published results**

1542004, Bdru, Domnica Oana, Conflict of interest in international public health research : Case study: Trovafloxacin study in Kano, Nigeria, 2224-9680, Publication: Discussion paper / Internet publication

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)

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)

#### **Add documents**

#### **Specify cooperation partners**

<b>ID</b>	<b>Kreditinhaber</b>	<b>Kooperationspartner</b>	<b>Institution</b>	<b>Laufzeit - von</b>	<b>Laufzeit - bis</b>
1016834	Elger, Bernice Simone	Kühne, Thomas, Prof. Dr. med., Co-Referee	Onkologie/Hämatologie, Universitäts-Kinderpita l beider Basel	01.06.2011	31.12.2014
1544173	Elger, Bernice Simone	Dragomir, Monica, Associate Professor	"Prof. Dr. Al. Trestioreanu" Oncology Institute, "Car- ol Davila" University of Medicine and Pharmacy, Bucharest.	01.10.2012	30.12.2014
1544174	Elger, Bernice Simone	Colita, Anca, MD	Fundeni Clinic Institute "Carol Davila" University of Medicine and Pharmacy, Bucharest	01.10.2012	30.12.2014