

**\*\*\* CALL FOR PARTICIPATION – Deadline: 19 September 2019 \*\*\***

## **Empowerment and Decision-Making at the End of Life**

*An interdisciplinary workshop for doctoral candidates*

### General information

This half-day workshop on 24 October 2019 (9.15-12.45) is part of the conference „[Die Macht des Patienten](#)“ (The Power of the Patient), which will take place in Berne in the afternoon of the same day (13.30-17.30). Venue: University of Bern, University Main Building (Hochschulstrasse 4), room 028.

### Participants

Primary target audience: doctoral candidates of all disciplines, especially medicine, law, ethics, philosophy, theology, history, literature and other humanities, advanced MA students and postdocs welcome. Limited number of admittance: 20-30 persons. Priority is given to doctoral candidates from the Universities of Basel, Bern and Zurich. Accepted participants get their travel expenses refunded and are offered a free lunch bag. They are strongly encouraged to stay on for the afternoon conference.

Please send a few lines about your motivation in attending this workshop to the contact person/address below. Deadline: **19 September**.

The subsequent conference „Macht des Patienten“ (The Power of the Patient) in the afternoon is the third in series dedicated to „Macht und Medizin“ (Power and Medicine), organised by the standing committee „Medical Humanities“ of the Swiss Academy of Humanities and Social Sciences (SAGW) and the Swiss Academy of Medical Science (SAMW).

### Organisers and contact

The workshop is jointly organised by Dr. Tobias Eichinger, Center for Medical Humanities, University of Zurich, and Dr. Manuela Rossini, European Society for Literature, Science and the Arts, University of Basel.

In addition, the event is supported by: SAGW, SAMW, University of Bern (Institute of Systematic Theology, Prof. Dr. Mathias Wirth).

**Contact address:** Dr. Manuela Rossini, [manuela.rossini@unibas.ch](mailto:manuela.rossini@unibas.ch)

The workshop will be followed up by another two-day workshop on „European Cultures of Palliative Care“, taking place in Zurich at the Villa Hatt, 25-26 October 2019, organised by [Dr. Anna Elsner](#) (SNF Marie Heim-Vögtlin Research Fellow, Institute of Romance Studies and Center for Medical Humanities, University of Zurich)

## **Empowerment and Decision-Making at the End of Life**

*An interdisciplinary workshop for doctoral candidates*

Chairs: [Dr. Tobias Eichinger](#), [Dr. Manuela Rossini](#)

Speakers:

[Dr. Michael Rost](#) is a postdoctoral researcher at the Institute for Biomedical Ethics at the University of Basel, Switzerland. He has recently completed his PhD on “Palliative Care in Pediatric Oncology: Ethical Considerations Surrounding Shared Decision-Making” which dealt with children’s inclusion in decision-making at the end-of-life and barriers to their involvement. His main research interests include maternal autonomy in intra-partum decision-making, decision making in pediatric oncology, and health-related social media use among adolescents and young adults with cancer. He has profound expertise in both qualitative and quantitative research. In 2015, Michael Rost was appointed member of the Ethics Council of the Systemic Society Germany in Berlin where he advises the executive board in cases of complaints against members of the Systemic Society.

[Dr. med. Jürg Streuli, PhD](#), is a senior research and teaching assistant at the Institute of Biomedical Ethics, University of Zurich, a consultant for clinical ethics, vice-president of the clinical ethics committee at the University Children’s Hospital of Zurich and board-certified pediatrician with focus on pediatric palliative care at the Ostschweizer Kinderspital. In his research and clinical work he focuses on practical implementation of concepts such as best interests and shared decision-making in complex and life-limiting medical conditions. In his publications, he shed light on the power of health care professionals in “shaping” parental / patients decision-making and developed new concepts such as shared optimum approach to conciliate the demands of best interests and shared decision-making.

[Claudia Stühler](#) is the Academic Coordinator of the doctoral program “Law and Change” (“[Recht im Wandel](#)”) at the Law Faculty of the University of Basel. She is completing her doctoral thesis on euthanasia, focusing on the lawfulness of deactivating life-sustaining implants. Claudia graduated with distinction from the Ludwig-Maximilian-University of Munich in 2016, where she also worked as research assistant with Professor Satzger who holds a chair for International Criminal Law. As part of her legal education, she studied for a year at the University of Verona, Italy. Since 2018, she has worked in Basel as research and teaching assistant to the chair for Legal Theory and Life Sciences Law, Professor Fateh-Moghadam. From January to September 2019, she is a guest researcher at the University of Oxford, supervised by Professor Jonathan Herring. During her doctoral studies, she developed a strong interest in interdisciplinary research and attended lectures in Theoretical Philosophy, Practical Philosophy and in Philosophy of Technology, and is implementing these approaches in her research.

Respondents: t.b.a.

## Workshop topic:

In this workshop, we will discuss issues of power (or the lack thereof) at the end of life. Framed by the guidelines and recommendations of the Swiss Academy of Medical Science on the [management of dying and death](#), [vulnerable patient groups](#) and [autonomy in medicine](#), we will address decision-making processes regarding end-of-life care and treatment of dying patients.

After two general inputs, two presentations zoom in on particularly vulnerable patients groups whose capacity to make autonomous decisions at the final phase of their lives becomes increasingly complex and difficult – if not impossible: children and patients with life-saving implants. These cases serve as paradigmatic examples to test current ‘best practices’ and the aforementioned guidelines in view of patients’ empowerment.

With regard to the former group, ‘power’ is framed by issues of inclusion and exclusion: should international medical guidelines be followed and to which extent, which modalities of their involvement are empowering these young patients, which ones are a barrier to their participation in the decision-making process, and which ones are rather problematic for more general reasons?

Similar controversies arise when patients have life-sustaining implants. In the era of “Medicine 4.0”, when death is no longer a metaphysical issue only but a technological problem as well: who decides when and how to deactivate those high-tech medical devices?

From a legal point of view, the key questions are whether the current criminal doctrine on euthanasia solves the novel technological challenges adequately and normative consistently or whether technological devices question the existing dogma of euthanasia and request its modification.

Such issues are not only embedded in legal, religious and ethical frameworks and driven by economic considerations but also closely connected to historical and culture-specific understandings of ‘a good life’, ‘a good death’, ‘the child’, ‘the autonomous self’ and, not least at all, to what it means to be human.

## Abstracts:

Michael Rost:

### *Shared Decision-making regarding Palliative Care in Pediatric Oncology*

Shared decision-making has become the predominant approach to pediatric medical decision-making. It involves at least three parties: health care provider, parents, patient. Involving the child in a developmentally appropriate way is unanimously recommended by international medical-ethical guidelines. Moreover, according to Swiss legislation minority per se does not deem a child incapable of judgement, it is a child’s mental ability that determines whether the child is capable of judgement and, consequently, legally competent. Empirical evidence from the Swiss pediatric oncology setting shows that (a) children’s age and gender predicted their inclusion in decision-making with girls and older children being more likely to be involved, and (b) decision-making spans from no involvement of children at all to full participation in shared decision-making with six types of how decisions are made in between. Finally, theoretical considerations warn against any reification of what it means to have decision-making capacity.

Jürg Streuli:

*Reconciling shared decision-making with best interest standard – introducing the 'shared optimum approach'*

Paediatric decision-making is the art of respecting the interests of child and family with due regard for attitudes and facts. The best interest standard (BIS) and shared decision-making (SD-M) are increasingly used in the same context but are generally believed to conflict with each other. Simply said the BIS determines what is best for a person without decision-making capacity, while SD-M is concerned primarily with how a decision is best made by someone with decision-making capacity.

Based on a extensive qualitative and quantitative data set and underpinned with examples from clinical practice in pediatric palliative care and ethics I argue that the BIS and SD-M are part of clinical reasoning not only isolated but also as a combination, further referred to as shared optimum approach (SOA). SOA separates different tasks (limiting harm, showing respect, defining choices and implementing plans) in separated dimensions and steps, based on the principles of participation, provision and protection. Subsequently, I argue against a current tendency to reduce or replace BIS by an isolated harm standard or a zone of parental discretion on one hand or misunderstand SD-M as a subset of an informed choice model. Instead, I will propose an amendment of BIS with SD-M.

Claudia Stühler:

*Smart Life-sustaining Implants at the End of Life: Patient Empowerment or Medical Paternalism?*

In the last few decades, we have merged with our technologies. Technology invades our bodies and transforms us into man-machine hybrids: “cyborgs”. It is estimated that each year 1.5 million patients worldwide receive implantable electronic devices, such as pacemakers or cardioverter-defibrillators. These smart medical implants record data, monitor bodily functions and regulate physiological processes using decision-making algorithms. What do these developments signify for the fundamental right to self-determination over our own bodies? Does the technological “upgrade” lead to individual empowerment, or are we confronted with a “paternalism by technological design” since we will not be able anymore to overrule automated decisions? Concerning end-of-life decisions, the fundamental question arises whether patients have the right to decide to deactivate a life-sustaining implant or whether the physician who implements such a decision would be guilty of murder. Does deactivation qualify as an instance of illegal active euthanasia, or as the legal ending of an ongoing life-sustaining treatment? It is highly controversial whether through implantation the device becomes part of the body and, therefore, has to be treated like a natural organ. A legal precedent concerning the lawfulness of turning off medical implants is yet to be established.

### Recommended reading

Guidelines «Management of dying and death», SAMW, 2018 (pdf)

A list with further reading suggestions will be sent to all accepted participants at the end of September.