

**SLSAeu Conference 2017 EMPATHIES, University of Basel, 21-24 June**  
[www.empathies2017.com](http://www.empathies2017.com)

**Empathy and Ethics at the End-of-Life – A Perspective from the Medical Humanities**

A workshop for doctoral candidates and Postdocs

Wednesday, 20 June, 9.00-18.15 | Place: Englisches Seminar, Nadelberg 6, first floor, 13

**SCHEDULE**

The workshop will be divided into a morning and an afternoon session.

The morning session will have a more literary and philosophical, the afternoon a more medical perspective, while interdisciplinary debate is encouraged throughout.

09:00 – 10:30	<b>Part I: AUTO/THANATOGRAPHIES</b>	<b>Marion Coutts Ivan Callus</b>
10:30 – 11:00	Break	
11:00 – 13:00	4 presentations by doctoral and postdoctoral researchers	Joseph Wood Caitlin Stobie Manya Hendriks Tanja Petrovic
13:00 – 14:00	Lunch	
14:00 – 15:30	<b>Part II: END-OF-LIFE CARE</b>	<b>Seamus O’Mahony Anne Hudson Jones</b>
15:30 – 16:00	Break	
16:00 – 18:00	3 presentations by doctoral and postdoctoral researchers	Riana Betzler Elodie Malbois Isabelle Wienand
18:00 – 18:15	Wrapping up and short break	
18:30 – 19:00	Performance (for the larger public also)	HORA

**After the performance food and drinks served in the courtyard – courtesy Bioethics Zurich.**

## ABSTRACTS

**Marion Coutts**, Goldsmiths College, University of London | m.coutts@gold.ac.uk

### *Reading and talk*

Marion Coutts is an artist and writer. She works with a range of material forms: found objects, digital video, film, drawing, sound, text and photography. Her first book, *The Iceberg*, won the Wellcome Book Prize 2015. She is currently a Senior Lecturer on BA Fine Art and History of Art at Goldsmiths College, University of London. She writes occasionally on Art for *Intelligent Life* and has been invited to speak on panels that explore topics like medicine and disorders of the self alongside oncologists, biochemists, neurosurgeons and poets.

**Ivan Callus**, University of Malta | ivan.callus@um.edu.mt

### *Impossible Empathy: Autothanatography, or Nearly*

La Mort mode d'emploi, or in English translation Death: A User's Manual: it seems morbid to replace like this the word vie, life, in the title to Georges Perec's novel. Or perhaps it is merely comic. Everybody who has ever lived has done death very effectively and completed the task without fail; there really is no need for help. In fact, however, there is a cultural expectation that there ought to be guidance in death, or rather in dying. This paper looks at representations of that guidance in literature, finding them not in any palliative texts positionable as further therapies in palliative care (though these exist and will be mentioned), but in texts that by dwelling on death and dying paradoxically end up affirming ... what it is, exactly, that they might be affirming is the question that this paper seeks to explore.

Reference will be made to mythology, Homer, Dante, Shakespeare, Milton, and Poe: this framing move is obligatory, as is the nod toward thanatology and that seemingly inarticulate discourse, autothanatography. All of that will be kept brief, however, for the sake of the main focus, which involves reflections on Henry James's *Terminations* (1895) and Alice Oswald's *Falling Awake* (2017).

Ivan Callus is Professor of English at the University of Malta. He is the founding co-editor of *CounterText: A Journal for the Study of the Post-Literary*, launched with Edinburgh University Press in 2015. The journal's focus is on literature's evolving identities and its directions in contemporary culture, a focus that complements his commitment to posthumanism: he is co-editor of the *Critical Posthumanisms* book series with Brill and co-director of the *Critical Posthumanism Network*. He is also a member of the Humanities and Medical Science Programme at Malta.

**Joseph Wood**, King's College London, UK | joseph.wood@kcl.ac.uk

### *Empathy in Cicely Saunders' 'total pain' and two recent narratives of dying*

This paper will introduce the modern hospice pioneer Cicely Saunders' concept of 'total pain' to an audience interested in empathy and medical humanities by exploring it through readings of two recent auto/thanatographies: Tom Lubbock's *Until Further Notice, I Am Alive* and Marion Coutts' *The Iceberg*. These texts echo Saunders' understanding that terminal pain is not limited to an individual's physical suffering but extends to include 'her emotional and mental suffering, her social problems and her spiritual need for understanding and security'. Such an appreciation of a person's 'total pain' elicits empathy by urging us to understand another's pain as inextricably bound up with the rest of his or her life-story and the fact of its ending.

As such, 'total pain' assumes that there is always more to be done to help a person and so encourages an (empathetic?) confidence in the blurred connection between the individuated dying body and the continuing world beyond it. As Coutts and Lubbock demonstrate, this is achieved through acts of presence that include making space for narrative acts of listening through the timelessness of the hospice environment but also non-verbal interaction such as touch and 'watching with' the dying. As such 'total pain' is part of Saunders' wider lexicon of mystery and excess which gestures beyond boundaries or limits towards the infinite and the interpersonal in a way that can be understood as a form of medical empathy that flies in the face of clinical detachment.

Joseph Wood is soon to be a PhD candidate at the University of Glasgow with a project examining the legacy of Cicely Saunders' concept of total pain. He completed a Wellcome Trust-funded MSc in Medical Humanities at King's College London. His doctoral research is funded by AHRC and affiliated with both Glasgow's Medical Humanities Research Centre and the interdisciplinary End of Life Studies Group based in Dumfries.

**Manya J. Hendriks**, University Hospital and University Zurich, Switzerland (co-author: **Andrea Abraham**, Interdisciplinary Institute of Ethics in Health Care, Zurich, Switzerland & Institute of Social Anthropology, University of Bern, Switzerland)

*Perinatal Loss and Loneliness: Narratives of Late-Term Abortion Decisions*

*Background:* Across the globe, advancing technologies for selective reproduction place increasing numbers of women in situations where they must make excruciating decisions about the outcomes of their pregnancies. This article hones in on the choices pregnant women and couples face and their needs and experiences related to late-term abortion decisions when confronted with a prenatal diagnosis.

*Methods:* We focus on the narratives of two women, one couple, and one male partner regarding their late-term abortion decisions at 18 to 24 weeks of pregnancy due to the prenatal diagnosis of a fetal anomaly at a Swiss University Hospital in the years 2013-2015.

*Results:* The narratives hinge on the culmination of existential feelings around birth and death in a strongly compressed period of time. The narratives illustrate five themes: (1) being conflicted by emotions such as insecurity, love and guilt, (2) the loneliness of the decision, (3) the importance of giving birth to a live-born infant, (4) the social taboo surrounding a perinatal loss from a late-term abortion, and (5) the importance of attentive professional support.

*Conclusions:* Late term abortion engenders a unique, especially intense and debilitating form of grief that is often not publicly recognized or validated. This 'cultural denial' has an immense impact on the decision and aftermath of a late-term abortion. It seems surprising, given the large number of pregnancy losses and terminations, that this is not discussed publicly. Few social rituals, specifically through the care of midwives and other caregivers, aim to acknowledge fetal death and guide women and/or couples on how to handle birth, death and the aftermath of a perinatal loss.

Manya J. Hendriks is a PhD Candidate at the Institute of Biomedical Ethics and History of Medicine with an affiliation at the Neonatology Department of the University Hospital in Zurich with a background in Bioethics (MSc) and Medical Anthropology (MSc). Together with her co-worker Andrea Abraham she has worked in the SNSF-funded NRP67 Project on end-of-life decision-making for extreme preterm infants from a parental perspective.

Andrea Abraham is a medical anthropologist and the research director at the institute “Dialog Ethik” in Zurich; associated researcher at the Institute of Social Anthropology at the University of Bern, and former president of Medical Anthropology Switzerland. Andrea Abraham has worked in the SNSF-funded NRP67 Project on end-of-life decision-making for extreme preterm infants from a parental perspective.

**Caitlin Stobie**, University of Leeds, UK | [ences@leeds.ac.uk](mailto:ences@leeds.ac.uk)

*Representing Life, Death, and Abortion: Embodying Empathy and Ethics in Yvonne Vera’s Butterfly Burning*

Written after the ‘birth’ of postcolonial Zimbabwe in 1980, but set in colonial Rhodesia during the 1940s, Yvonne Vera’s 1998 prize-winning novel *Butterfly Burning* tells the story of a rural woman who self-induces an abortion. She reaches this decision after realising that a pregnancy would threaten her studies, and potential career, in nursing. The text is littered with references to death: from workers who are killed in an oil explosion early in the narrative, to the protagonist’s decision to commit suicide in the closing chapter after she falls pregnant for a second time. This paper argues that the novel utilises natural elements to figure for ethical – and political – anxieties about terminating a potential life. Vera focuses on affect and agency as being intrinsically linked to interconnected material systems; creative forms which manifest in her work include human, animal, vegetal, elemental, or textual participants in ecosystems. For example, inorganic forces like lightning are imbued with the same level of autonomy as non/human animals. Instead of discussing reproduction in anthropocentric or hyper-medicalised terms, then, the novel approaches Karen Barad’s conception of the foetus as a phenomenon which includes the zygote, the maternal environment, *and* the broader ecologies in which both are situated (2007: 217). After contextualising my analysis with an overview of the roles that empathy and metonymy play in literary realism, I perform a close reading of the primary abortion scene, paying attention to how organic and inorganic forces serve as metonyms for affect. Next I utilise this postcolonial posthumanist methodology to analyse the protagonist’s second terminated pregnancy. The final chapter of the novel resonates with various earlier appearances of non/human subjectivities throughout the text. Analysing empathetic intra-actions between actants in the two abortion scenes, I conclude by considering postcolonial feminist representations of embodied exchanges and the ethics of ending lives.

Caitlin Stobie is a PhD candidate in the School of English at the University of Leeds whose research interests include posthumanism, literature and biology, and critical animal studies. She is an intern on the AHRC-funded project “The Risks of Childbirth in Historical Perspective”, director of the Leeds Animal Studies Network, and an editor of [EPIZOOTICS!](#). Her work has been published (or is forthcoming) in *The Vegan Studies Reader*, *Interdisciplinary Studies in Literature and Environment (ISLE)*, *Green Letters*, and *Scrutiny2: Issues in English Studies in South Africa*.

**Tanja Petrovič**, AMEU, Slovenia | tanjuska31@yahoo.ie

*Empathy and Ethics of Care*

In my presentation, I would like to shed light on Empathy in the context of Healthcare, and Care Ethics.

Michael Slote is an interesting author in the field. His notion on Ethics, with strong emphasis on Empathy, is positioned into the sphere of Virtue Ethics, an Aristotelian person-based Ethics, particularly in Ethics of Care. This “branch” of Ethics is focused on a caregiver-patient relationship, and practical aspects of Care (taking care of a person in need). As a »moral sentimentalist«, Slote exposes the importance and role of Empathy in Ethics of Care. Sentiment rather than reason is the source of morality. A motive for moral action stems from Care and from Empathy as its constitutive element.

Many questions do emerge. Is Empathy a skill, can it be learned, practised? Is it evolving through cycle of human life? Is it mainly a fixed category, or a fluent one, and socially – culturally, gender - dependent? Slote sees differences in the sustainability and development of Empathy, but takes distance from a feminist approach. Slot's concept has been challenged by others of Ontology of Care, for instance »Deep Caring« by van Hooft.

Furthermore, what is a benchmark of a »normal«, »natural« human Empathy? Is there something like an experience of Empathy “overdose” or its deficiency? We can speculate that too much Care and Empathy can lead to unbalanced relationship. On the side of deficits, we can learn a lot about mechanism of Empathy from different pathologies, in Mental Health Disorders, such as Dementia (Alzheimer etc.), Schizophrenia, Autism, and others. There can be deficits in Cognitive Empathy or Affective or on both components.

Tanja Petrovič is a PhD candidate, in AMEU, Slovenia, in The Humanities Programme. In her Thesis, she explores Empathy and Ethics of Care. She is affiliated with National Health Insurance Institute, Slovenia. Her background is in Anthropology (MSc.), Business Administration (BBA), Comparative Literature and Literature Theory (BA).

**Anne Hudson Jones**, University of Texas Medical Branch at Galveston | ahjones@UTMB.EDU

*Ethics after End of Life: Narratives of Mourning*

Much attention in the past few decades has been given to ethical issues at the end of life, but little attention has been given to ethical issues *after* end of life for those who survive the loss of beloved family members or friends. The profound effects of grief on the human body and psyche are well known but less well researched and rarely addressed in discussions of empathy and ethics. As the field of trauma studies has developed in the past few decades, the plight of holocaust survivors and of combat veterans (especially in the United States of Viet Nam war veterans) has received clinical attention, but that of individual survivors of deaths of a family member or friend has not. In this short presentation I'll focus on selected recent narratives of widows whose husbands died suddenly, discuss physical and mental effects these women experienced afterwards, and consider what ethical implications there may be for clinicians and others. I will argue that raising awareness of the health risks of the recently bereaved is an important and often neglected aspect of medical care and that personal narratives of mourning are excellent resources for education of health professionals.

**Anne Hudson Jones** is Professor and Harris L. Kempner Chair in the Humanities in Medicine, in the Institute for the Medical Humanities and the Department of Preventive Medicine and

Community Health of the University of Texas Medical Branch at Galveston, where she is also on the faculty of the Graduate School of Biomedical Sciences. She was a founding faculty member and is currently Director of the Medical Humanities Graduate Program, which offers the only Ph.D. in medical humanities in the United States. She was also a founding editor of the journal *Literature and Medicine* and its editor-in-chief for more than a decade. She has published widely in humanities and biomedical journals on topics related to literature and medicine, narratives of illness, ethical issues in biomedical publication, and narrative ethics. Her current research interests focus on narratives of medical catastrophes and narratives of mourning.

**Seamus O'Mahony**, Cork University Hospital, UK | Seamus.OMahony@hse.ie

*Why the dying need compassion, not empathy*

In this talk, I will explore the difference between empathy and compassion. Empathy might be defined as the ability to feel what someone else is feeling. This ability has been the subject of much feverish neurobiological speculation, and has become the putative solution for all our societal woes. Compassion, on the other hand is a combination of kindness, honesty, courage, competence, and the mysterious quality which I call "bottom". I will argue that empathy is often a barrier to good care, and that the current drive to "teach" empathy to medical students, doctors and nurses is misguided.

Seamus O'Mahony is a consultant gastroenterologist at Cork University Hospital. His academic interest is in the Medical Humanities and has published widely in this area. His book *The Way We Die Now* is a plea for dealing more humanely with the very natural process of death, calling for a demedicalisation of death and dying. He is associate editor for Medical Humanities of the *Journal of the Royal College of Physicians of Edinburgh*, and is a regular contributor to the *Dublin Review of Books*.

**Riana Betzler**, Konrad Lorenz Institute, Klosterneuburg, Austria | riana.betzler@kli.ac.at

*The Empathic Ideal and Decision-Making at the End of Life*

Empathy is widely, and largely unreflectively, considered to be important in medicine and the helping professions more generally. Enrichment of interpersonal skills and of empathy are among the objectives of medical education set forth by the Association of American Medical Colleges. The Cambridge-Calgary guide to the medical interview, which is used widely in UK medical training, likewise lists empathy as an objective. And many medical schools around the world have worked to develop empathy training programs for their students. In modern medicine, empathy is held up as an ideal for facilitating the doctor-patient relationship, although this was not always the case.

Despite the widespread enthusiasm for empathy, some scholars have raised important worries about the lack of conceptual clarity surrounding the meaning of "empathy" in medicine. There are many concepts of empathy floating around in the literature and it is sometimes unclear which notion of empathy a particular measurement or training technique tracks. Failure to keep track on the relevant notion of empathy leads to adverse consequences. In this paper, I begin by arguing that we need to pause and scrutinize the contemporary empathic ideal before moving forward with empathy training programs for medical students. Taking empathy to be an ideal obscures the distinction between the various aims that calls for empathy seek to achieve, such as: (1) to facilitate communication;

(2) to aid in decision-making; and (3) to foster a sense of goodwill, kindness, or tenderness in the doctor-patient relationship. While these various aims may work together, they may also come apart and yield different recommendations about the sort of behaviour physicians should cultivate in a given situation.

I then think through how these issues play out with respect to end-of-life care in particular. I consider how certain forms of empathy—especially empathy taken as “the ability to understand and share the feelings of another”—face special challenges in the context of end-of-life care. First, it may be especially difficult to imagine oneself in the situation, or “in the shoes” of a dying individual. Second, end-of-life care often involves taking into account and understanding the perspectives of multiple individuals, including both dying individual and their family members. Can empathy, defined in this classical way, handle such situations in which multiple individuals are involved? I suggest that this classically-defined form of empathy may not be best for such end-of-life situations—and may even confuse decision-making—but that other more communicatively-oriented forms may be better.

Riana Betzler did her undergraduate degree in psychology at Yale University and then moved to Berlin to deepen her knowledge of philosophy, history, and literature at the European College of Liberal Arts (now Bard College Berlin). She then went on to do an MPhil in History and Philosophy of Science as well as a PhD at the University of Cambridge. Her dissertation *Why Empathy? The Pernicious Consequences of Conceptual Confusion in Empathy Research* investigated the sources of the conceptual confusion that plagues empirical research on empathy, and argued that this confusion is not benign but instead leads to significant problems for projects that seek to put empathy to work in social and political domains. She is currently a research fellow at the Konrad Lorenz Institute in Austria where her project on genealogical approaches and the origins of empathy seeks to extend her PhD work by looking for ways of moving beyond conceptual confusion in the case of empathy. She has also become increasingly interested in the role of empathy (and the emotions more widely) in the medical context.

**Elodie Malbois**, University of Fribourg, Switzerland | [elodie.malbois@unifr.ch](mailto:elodie.malbois@unifr.ch)  
*Empathy at the end of life: advocating availability*

It has been established for years that the satisfying and efficient caring relationship is an empathic one (Reynolds and Scott 1999). However, what empathy is remains unclear and there are almost as many definitions as there are papers on the topic. On one side of the scope, empathy is taken to be an emotional phenomenon. A carer is empathic if she experiences emotional resonance with her patient. But there is concern too much emotional involvement might lead to compassion fatigue and burnout (Decety 2012). One might also worry that it is not an attitude one can control, leaving it to nature or other external factors whether one is a good carer or not. On the other side, empathy is understood as a behavioural or cognitive ability which consists in understanding the patient’s perspective and communicating it to her (Mercer and Reynolds 2002). The worry is that with (almost) no emotional involvement, the carer-patient relationship becomes cold and dehumanised. In this paper, I argue for a type of empathy, availability, that is minimally emotionally engaging for the carer while still safeguarding the quality of the caring relationship. I first describe availability and then explain why it is the optimal attitude for both the carer and the patient, especially dying ones. A carer is available if she pays attention to and tries to understand her patient because she is interested in her for her own sake and wants her wellbeing. This attitude is mainly cognitive, making it easier to control and elicit it. The emotional involvement is also minimal – the carer only needs to desire her patient’s

wellbeing-, hence preserving the carer. At the same time, the carer is genuinely interested in her patient and cares about her wellbeing, which seems to be what patients want most (Anderson, Barbara, and Feldman, n.d.).

References:

Anderson, Roger, Angela Barbara, and Steven Feldman. n.d. 'What Patients Want: A Content Analysis of Key Qualities That Influence Patient Satisfaction'. *Greenbranch Publishing LCC*.

Decety, Jean. 2012. *Empathy: From Bench to Bedside*. Social Neuroscience Series. Cambridge, Mass: MIT Press.

Mercer, Stewart W., and William J. Reynolds. 2002. 'Empathy and Quality of Care.' *Br J Gen Pract* 52 (Suppl): S9-12.

Reynolds, W. J., and B. Scott. 1999. 'Empathy: A Crucial Component of the Helping Relationship'. *Journal of Psychiatric and Mental Health Nursing* 6 (5): 363–70. doi:10.1046/j.1365-2850.1999.00228.x.

Elodie Malbois is a Phd student in philosophy at the University of Fribourg and at the Institute for Ethics History Humanities at the University of Geneva. She is trying to understand and describe an attitude of attention and care towards an ‚other‘ that Gabriel Marcel has called „availability“. Before taking up her doctoral studies, she studied philosophy at the Universities of Lausanne (BA) and St Andrews (MA).

**Isabelle Wienand** (co-authors: Eva De Clerq, Milenko Rakic), University of Basel, Switzerland | [isabelle.wienand@unibas.ch](mailto:isabelle.wienand@unibas.ch)

*Empathy Towards Ways of Dying: All Ways of Dying?*

‘End of Life’ has become a major issue in western ageing societies. In Switzerland researchers, health professionals and social-political actors have united their competences to offer a better, more adequate and more humane way for - mostly - elderly patients with chronic diseases to die in a dignified way. The National Research Programme 67 ‘End of life’ (NRP 67) exemplifies this conjoined interdisciplinary effort to enhance the autonomy of dying patients, that is, to help them manage their own death.

One interesting finding of a research project conducted within the NRP 67 is that many patients are either not (fully) aware of their imminent death, or are incapable to choose among the different options (e.g. palliative care, assisted suicide), or do not wish to reflect upon their own death.

Our contribution focuses upon the following question: how can health professionals take into account patients’ death wishes if patients are physically or mentally unable to voice these preferences or even refuse to accept their imminent death? Even if advance directives are in place, they are often too vague to provide clear guidance. Cultural, socio-economic and religious differences further complicate the care for the dying. How then can health professionals and relatives provide patients a dignified death? We argue that what might seem passivity, silence and surrender is one possible and legitimate way to die. There seems to be no compelling reason to think that everyone should die according to the normative ideal of a self-aware and self-orchestrated ‘good death’. It might be a prejudice of our time, after all. Dying is a highly individual and varied phenomenon. In order to respect dying persons our empathy towards them should be inclusive (open to non-autonomous ways of dying) and self-critical (we have no direct access to another’s person inner life).



Isabelle Wienand is a philosopher and postdoc researcher at the Institute for Bio- and Medical Ethics at the University of Basel. Her area of research and expertise are modern moral philosophy, medical ethics and philosophy of medicine. Her current research project deals with the autonomy of palliative care patients. She teaches medical and bioethics for medical, biology, pharmacy and nursing sciences students at the University of Basel.

Most recent Publications: Wienand I. (2016) *Wozu die Philosophie, wenn wir über Gesundheit sprechen?*; Rakic M.; Wienand I.; Shaw D.; Nast R.; Elger B.S. (2016) "Autonomy and Fear of Synthetic Biology: How Can Patients' Autonomy Be Enhanced in the Field of Synthetic Biology? A Qualitative Study with Stable Patients." *Science and Engineering Ethics*. 2016; Roodt V.; Wienand I. (guest editors) (2014) "Happiness", *South African Journal of Philosophy*.

