



SCIENTIFIC FINAL REPORT

Regnr Östersjöstiftelsen: 2014-0004

Project manager: Fredrik Svenaeus

Project title: The Phenomenology of Suffering in Medicine: Explorations in the Baltic Sea Region

1. Purpose of the project

The purpose of the project has been to analyze and better understand the phenomenon and concept of suffering as it is encountered and understood in medicine and biomedical ethics. This has been carried out by way of three interconnected studies all making use of ideas and theories found in the phenomenological tradition. The aim of the first subproject was to explore how the understanding of suffering in medicine and the medical ethical discussion could possibly be enriched by a philosophical investigation of the embodied and narrative aspects of this phenomenon. The aim of subproject two was to explore and reflect upon how the phenomenon of suffering is approached and understood in medical ethics teaching at five medical faculties in the Baltic Sea region. The aim of subproject three was to explore how a selected group of Swedish health care professionals approach and understand patients who are suffering from severe and stressful medical conditions. The three subprojects were to be connected by relating and comparing the levels of philosophical analysis, pedagogical approach and professional understanding by way of a phenomenological analysis of suffering and neighboring concepts.

2. The three most important results of the project and what conclusions can be drawn from them

The three most important results of the project were the development of a) a general phenomenological theory of what illness suffering consists in and how it relates to other main concepts in biomedical ethics, b) a phenomenological theory of professional empathy as a necessary capability to be taught and exercised in medical education and practice, c) a phenomenological analysis of how embodied selfhood and life narratives are necessarily integrated in the suffering of severe illness, exemplified by a study of how professionals in psychiatric care encounter depressed patients. The conclusions to be drawn from these results are that a phenomenological analysis of suffering opens gateways for focusing upon



the issues that really matter for ill persons in their lives, how the suffering is manifested in the clinical encounter, and could be better understood by physicians, nurses and other health care professionals in their work. If suffering is not merely a bodily sensation or a cognitive state, but a bodily mood overcoming a person and engaging her in a struggle to remain at home in the world in the face of the loss of meaning and purpose in life, medical professionals need to focus their attention and efforts to help accordingly. Empathy becomes a necessary mean to establish contact with the suffering person and the world she inhabits. Empathy, in turn, must be understood phenomenologically as feeling-based, face-to-face attempt to imagine the situation of the patient as a person with a life-story that has broken down. In medical ethics education this could be exemplified and practiced by way of models that are less focused on autonomy and informed consent measures and more focused upon interpersonal understanding and shared decision making. A more phenomenologically developed model of the way suffering and empathy are to be focused upon in medical practice is particularly relevant in the cases of mental illness and end-of-life palliative care.

3. The project's contribution to the international research frontline

The research activities of the project have from the very start formed part of international front line research as concerns the philosophy of suffering in medicine and the proper focus of medical ethics teaching. We have arranged four project workshops on selected themes with invited scholars and one international conference on phenomenology of medicine and bioethics, by way of which we have engaged in dialogue with front line researchers in the Baltic Sea Region and from the rest of the world. The results have been published in the form of a monograph published by Routledge, a dissertation at Södertörn University, a thematic section of an internationally renowned journal, a scientific report, 18 articles in international peer-reviewed journals and 8 book chapters. The monograph *Phenomenological Bioethics: Medical Technologies, Human Suffering, and the Meaning of Being Alive* (Svenaesus) has received international acclaim, led to many invited lectures at universities abroad and been the subject of a book seminar at an international conference. The project members have also presented their thoughts and results at around 30 international conferences and Nordic-Baltic network-meetings during the project time (not including separate invitation for lectures and seminars at universities and medical institutions). The phenomenological theories of illness suffering and professional empathy,



including the way these concepts are to be situated in medical ethics as a whole, have consequently contributed to front line research in philosophy of medicine and biomedical ethics by way of academic discussions and publications in leading journals.

4. New research questions that the project has led to

A major research question evolving in the course of the project has been the existential dimensions of the phenomenology of suffering as it occurs in the life of severely ill persons. The focus on existential dimensions – What makes life worth living for a person? and How does a person perceive her personal identity in the process of falling ill and possibly becoming chronically ill or facing death? – has led to the development of a separate, overlapping research project funded by The Foundation for Baltic and East European Studies: “The Role of Existential Philosophy in Health Care: The Cases of Germany, Denmark and Sweden” in which the situations of foetal diagnosis, health-care coordinators, and end-of-life care issues are currently focused upon from an ethnographic, professional and existential-philosophical perspective. Yet a research question which has emerged in the course of the project, and which will lead to the development of future projects, is the one concerning the many meanings of the terminology of health. Health is increasingly focused as a more inclusive and expansive concept than the mere absence of diseases, such as is the case when using the terminology of “mental (ill)health” or “existential-“ or “philosophical health”. What do we mean by such concepts and what potential gains and dangers lurks around the corner if we change our focus on what health and illness mean and contain accordingly?

5. The contribution of the research to the knowledge of the Baltic Sea Region and Eastern Europe

The project has explored the setup of medical ethics teaching at five universities with medical schools in Germany, Denmark, Lithuania, Finland and Sweden. By way of interviews with key teachers involved, field work and sampling of teaching material, the methods have been explored and compared with a particular focus on the presence of medical humanities approaches and the use of personal stories and empathy-based approaches in teaching. The setup of ethics teaching and its relationship to other parts of the medical program was found to be heavily dependent on the local situation as concerns 20th century history, mainly with respect to the second world war and the Soviet occupation. In the case of Germany the subject of medical history itself has been connected



to the teaching of medical ethics in the wake of Nazi war-crimes, whereas in the case of Lithuania it is rather the break with communist ideology, which has led to a rather hasty embrace of analytical bioethics in the liberal tradition. Finland and Germany have more substantial influences of the tradition of medical humanities, starting out in the 1990s, although this, as in the case of Sweden, is largely dependent on the role of individual researchers and teachers designing and working in the medical programs. The results have been put together in a report (see below) and also been used in the development of the phenomenological theories of suffering, empathy and medical ethics mentioned above and realized in the books, articles and chapters listed below.

6. The contribution of research to multidisciplinary knowledge formation

The project has been designed as a multidisciplinary effort from the very start, integrating philosophical, ethnographic and medical research traditions by way of the three sub projects and the way they have been knitted together in the output of the project. Such an approach is particularly relevant in the case of analysing phenomena such as suffering and empathy in the medical context and the way such knowledge can be used in teaching medical ethics. The project members have strived to realize this multidisciplinary endeavour not only in form of the published results of the project, but also by way of putting their analyses at work in teaching in medical schools and master and Ph. D. programs as listed below.

7. Dissemination of the results of the project within and outside the research community

Teaching:

Rolf Ahlzén: Teaching at Medical School, Örebro University, about 30 hours yearly 2015-2019 in medical ethics and medical humanities.



Rolf Ahlzén: lectures two times early 2015-19 at Lund University Medical School “The body from a humanistic perspective”.

Rolf Ahlzén: course in medical ethics at University of Iceland, Reykjavik, March 2019.

Patrick Seniuk: Teaching, 60 hours 2017-19 on Phenomenology of Perception and Literature and Suffering Master courses, Center for Studies in Practical Knowledge, Södertörn University.

Fredrik Svenaeus: Teaching about 40 hours yearly 2015-19 at Master and Ph. D. level courses on subjects related to Phenomenology, Suffering and Empathy, at Södertörn University.

Fredrik Svenaeus: “Copenhagen Summer School of Phenomenology and Philosophy of Mind”, one week in August 2018.

Supervision:

Of Patrick Seniuk’s Ph. D. project financed by the ÖSS: Fredrik Svenaeus, Jonna Lappalainen and Rolf Ahlzén.

Of 5 master theses at The Centre for Studies in Practical Knowledge with themes related to Phenomenology, Suffering and Ethics: Fredrik Svenaeus.

Organized conferences and seminars:

Project Workshop, Empathy and Medicine, Stockholm, March, 2016, 6 speakers (4 invited), circa. 30 participants in total, including healthcare clinicians and professionals.

Baltic Region Workshop: Disordered Worlds: Selfhood in Psychiatry, Södertörn University, April 2016 (in partnership with CBEES) 11 speakers (10 invited) from the Baltic region, circa. 30 participants in total over two days, including attendees from the public.

Project Workshop: Phenomenology of Suffering in Medicine and Bioethics, Stockholm, September 2016, 10 speakers (8 invited), 10 participants in total.

Project Workshop: Suffering and the teaching of Bioethics, Stockholm, September 2017, 10 speakers (8 invited), 10 participants in total.

International conference on Phenomenology of Medicine and Bioethics, Stockholm, June 2018. 40 international speakers/presenters, 5 invited keynote speakers, circa. 60 participants in total over two and a half days, including attendees from the public.

Papers related to the project presented at international conferences and workshops (excluding the one’s mentioned above organized by the project):



Rolf Ahlzén: 15 presentations 2015-19 (including The Hippocrates Lecture at the Swedish Society for Physicians, and at yearly conferences organized by: European Society for Philosophy of Medicine and Health Care, The Nordic-Baltic Network for Philosophy of Medicine, The Nordic Narrativity Net Work).

Patrick Seniuk: 1 presentation at the Nordic Society for Phenomenology in Reykjavik, April 2016; 1 presentation at International Conference of Philosophy of Psychiatry, Oxford University, July 2017.

Fredrik Svenaeus: 30 presentations 2015-20 at international conferences and universities, including invited key note lectures and invited lectures on Phenomenology, Suffering and Medical Ethics Topics at, for instance, University of Ghent, Tokyo University, University of Maastricht, Universität Wien, University of Tromsø, University of Exeter, Riga Stradvins University, Goethe Universität Frankfurt am Main, University of Oslo, Humboldt Universität Berlin, University of Konstanz, and Book seminar on his *Phenomenological Bioethics* with commentaries at the 17th Annual Meeting of the Nordic Society for Phenomenology, Copenhagen, April 2019.

Monographs:

Seniuk, Patrick: *Encountering Depression In-Depth: An Existential-Phenomenological Approach to Selfhood, Depression and Psychiatric Practice*. Södertörn Doctoral Dissertations, 2020: <http://www.diva-portal.org/smash/record.jsf?pid=diva2%3A1460919&dswid=-8075>

Svenaeus, Fredrik: *Phenomenological Bioethics: Medical Technologies, Human Suffering, and the Meaning of Being Alive*, London: Routledge, 2018:
[https://www.academia.edu/34424609/Phenomenological bioethics Medical technologies human suffering and the meaning of being alive](https://www.academia.edu/34424609/Phenomenological_bioethics_Medical_technologies_human_suffering_and_the_meaning_of_being_alive)

Articles published in scientific journals and reports:

Thematic Issue on Suffering in *Medicine, Health Care, and Philosophy*, vol. 23, no. 3, 2020: <https://link.springer.com/article/10.1007/s11019-020-09968-x>

Rolf Ahlzén, Hilde Bondevik and Knut Stene-Johansen: Fragments of Illness: *The Death of a Beekeeper* as a Literary Case Study for Cancer. *Medicine, Health Care, and Philosophy*, vol. 19: 275-83, 2016:
https://www.researchgate.net/publication/284812540_Fragments_of_illness_The_Death_of_a_Beekeeper_as_a_literary_case_study_of_cancer



Rolf Ahlzén: Rapport av den empiriska delen av projektet The Phenomenology of Suffering in Medicine: Explorations in the Baltic Sea Region, Södertörn Working Papers 2019: 5: <https://www.diva-portal.org/smash/get/diva2:1351997/FULLTEXT01.pdf>

Rolf Ahlzén: Narrativity and Medicine: Some Critical Reflections. *Philosophy, Ethics and Humanities in Medicine*, vol. 14, article 9, 2019:
<https://link.springer.com/article/10.1186/s13010-019-0078-3>

Rolf Ahlzén: Suffering, Authenticity and Physician Assisted Suicide. *Medicine, Health Care, and Philosophy*, vol. 23: 353-59, 2020:
<https://link.springer.com/article/10.1007/s11019-019-09929-z>

Patrick Seniuk, Book Review of Ratcliffe: Experiences of Depression, *Philosophical Psychology*, 2015:
https://www.academia.edu/19785558/Review_of_Matthew_Ratcliffes_Experiences_of_Depression_A_phenomenological_study

Patrick Seniuk: I'm Shocked: Informed Consent in ECT and the Phenomenological Self, *Life Sciences, Society and Policy*, vol. 14 (5), 2018:
https://www.academia.edu/35930081/Im_shocked_informed_consent_in_ECT_and_the_phenomenological_self

Svenaesus, Fredrik: "The Relationship Between Empathy and Sympathy in Good Health Care", *Medicine, Health Care and Philosophy*, vol. 18, no. 2, 267-277, 2015:
https://www.academia.edu/26083032/The_Relationship_Between_Empathy_and_Sympathy_in_Good_Health_Care

Svenaesus, Fredrik: "The Phenomenology of Chronic Pain: Embodiment and Alienation", *Continental Philosophy Review*, vol. 48, no. 2, 107-122, 2015:
https://www.academia.edu/26082569/The_phenomenology_of_chronic_pain_embodiment_and_alienation

Svenaesus, Fredrik: "The Phenomenology of Empathy: A Steinian Emotional Account", *Phenomenology and the Cognitive Sciences*, vol. 15, no. 2, 227-245, 2016:
https://www.academia.edu/26082649/The_phenomenology_of_empathy_a_Steinian_emotional_account

Svenaesus, Fredrik: "Self and Other", *Journal of Phenomenological Psychology*, vol. 47, nr. 1, 83-103, 2016:
https://www.academia.edu/26082674/Review_Article_Self_and_Other_by_Zahavi



Svenaesus, Fredrik: "Cultural Ontology of the Self in Pain", *Journal of Indian Council of Philosophical Research*, vol. 33, no. 3, 515-518, 2016:

https://www.academia.edu/27707573/Review_article_Cultural_Ontology_of_the_Self_in_Pain

Svenaesus, Fredrik: "Human Suffering and Psychiatric Diagnosis", *Bioethica Forum*, vol. 11, no. 1, 4-10, 2018: [http://www.bioethica-](http://www.bioethica-forum.ch/docs/18_1/02_Svenaesus_BF11_01_2018.pdf)

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Svenaesus, Fredrik: "Edith Stein's Phenomenology of Sensual and Emotional Empathy", *Phenomenology and the Cognitive Sciences*, vol. 17, no. 4, 741-760, 2018:

<https://link.springer.com/article/10.1007/s11097-017-9544-9>

Svenaesus, Fredrik: "How Medical Technologies Shape the Experience of Illness", with Björn Hofmann, in *Life Sciences, Society and Policy*, vol. 14, no. 3, 2018:

https://www.academia.edu/35949720/How_medical_technologies_shape_the_experience_of_illness

Svenaesus, Fredrik: "Why Heideggerian Death Anxiety is not Truly Uncanny: Existential Feelings and Psychiatric Disorders", *Discipline Filosofiche*, vol. 28, no. 2, 43-59, 2018:

https://www.academia.edu/37695180/Why_Heideggerian_Death_Anxiety_in_not_Truly_Uncanny_Existential_Feelings_and_Psychiatric_Disorders

Svenaesus, Fredrik: "A Defence of the Phenomenological Account of Health and Illness", *Journal of Medicine and Philosophy*, vol. 44, no. 4, 459-478, 2019:

https://www.academia.edu/32533542/A_Defence_of_the_Phenomenological_Account_of_Health_and_Illness

Svenaesus, Fredrik: "The Phenomenology of Pain", *Phenomenological Reviews*,

<https://reviews.ophen.org>, 2020-07-12.

Svenaesus, Fredrik: To Die Well: The Phenomenology of Suffering and End of Life Ethics, *Medicine, Health Care, and Philosophy*, vol. 23: 335-42, 2020:

<https://link.springer.com/article/10.1007%2Fs11019-019-09914-6>

Chapters in books:

Patrick Seniuk: Soul Searching: Psychiatry's Influence on Selfhood, in *Medicine, Health and Being Human*. Ed. L. Scholl. London: Routledge, 2018.

Fredrik Svenaesus, "Hermeneutics, health and medicine", in *The Routledge Companion to Philosophical Hermeneutics*, ed. Jeff Malpas and Hans-Helmuth Gander, 550-560, 2015.



Fredrik Svenaeus, "The lived body and personal identity: The ontology of exiled body parts", in *Bodily Exchanges, Bioethics and Border Crossing: Perspectives on Giving, Selling and Sharing Bodies*, eds. Erik Malmqvist and Kristin Zeiler, Routledge, 19-34, 2015.

Fredrik Svenaeus, "Sjukdomsbegreppet i psykiatri", in *Psykiatri* (sec. rev. ed.), ed. Jörgen Herlofson et al., Lund: Studentlitteratur, 37-44, 2016.

Fredrik Svenaeus, "Psykiatrins etik", in *Psykiatri* (sec. rev. ed.), ed. Jörgen Herlofson et al., Lund: Studentlitteratur, 69-78, 2016.

Fredrik Svenaeus, "Phenomenology and Medicine" in *The Bloomsbury Companion to Contemporary Philosophy of Medicine*, ed. James Marcum, London: Bloomsbury, 205-226, 2017.

Fredrik Svenaeus, "Edith Stein's Phenomenology of Empathy and Medical Ethics", in *Empathy, Sociality and Personhood: Essays on Edith Stein's Phenomenological Investigations*, eds. Elisa Magri and Dermot Moran, Springer, 161-175, 2018.

Fredrik Svenaeus, "Heidegger's Philosophy of Technology and the Perils of Medicalization", in *Existential Medicine: Essays on Health and Illness*, ed. Kevin Aho, Rowman and Littlefield, 131-144, 2018.

Fredrik Svenaeus, "Pain", in *Routledge Handbook of Phenomenology of Emotions*, eds. Thomas Szanto and Hilge Landweer, 543-552, 2020.