



## SCIENTIFIC FINAL REPORT

### Two- and three-year projects and postdoctoral projects

Regnr Östersjöstiftelsen: 2017-0004

Project manager: Fredrik Svenaeus

Project title: The Role of Existential Philosophy in Health Care: The Cases of Germany, Denmark, and Sweden

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

The three most important results of the project consist in phenomenological characterizations of three existentially charged types of situations in health care, meeting with and caring for: 1) Patients receiving information about chromosomal abnormalities in early pregnancy and having to decide if to have an abortion. 2) Patients receiving information about chronic and/or life-threatening illness having to make hard life choices in everyday life. 3) Patients in end-of life-care reflecting upon how they want to spend their last days and how they want to die.

With the help of such phenomenological characterizations, it becomes easier for health-care professionals to discern the existential aspects of such situations and maneuver in this extra-medical ethical terrain to find their role as professional guides. The studies in the project have been carried out as combinations of scholarly-conceptual and qualitative-empirical studies, focusing on health care professionals in the three mentioned types of situations and the way they approach their task. Important phenomenological concepts have been suffering, empathy and personhood, further developed from previous studies to fit the pattern of pregnancy-abortion, chronic-illness, and end-of-life issues listed above.

As concern early pregnancy, chromosomal abnormalities and abortion issues, a phenomenological characterization of the different phases of embryo and fetus development in terms of pre-personhood stages have been developed. The model combines the first-person perspective of experiencing pregnancy in different stages, including midwifery care and technological mediations of fetal life in the form ultrasound investigations and genetic tests, with third-person medical information about the stages of development of the fetus. The model can be used to highlight existentially significant phases of going through pregnancy to be used by health-care professionals in bringing up matters relevant to abortion ethics.

As concerns patients receiving information about chronic and/or life-threatening illness, the project has focused upon the situation of cognitive tests for early dementia in which medical staff has to face patients in explaining and preparing for future disease, and the situation of receiving information about the soon to come necessity of renal dialysis care in which medical staff has to prepare patients for a radically changed life pattern. In both



cases existential issues are central, the professional having to combine the role of medical expert with facing and getting to know the person who is undergoing the disease process. In our analysis we have attempted a phenomenological grounding of the often-used term and ideal “person-centered care”.

As concerns patients in end-of life-care reflecting upon how they want to spend their last days and how they want to die, the project has addressed the debate on physician-assisted suicide, marrying the much-debated ethics to an existentially deepened account of human suffering and authenticity making it possible to navigate in a more robust way. We have also explored the political context of this phenomenological analysis by addressing the debates on assisted dying in countries that have implemented such laws and in countries which have (yet) not done so (including Sweden, Germany, and Denmark). The understanding of the political context on a national level has also been an issue in the two other types of health-care encounters explored in the project.

The main conclusion of the results of the project is that there is much to gain by providing medical ethics with a phenomenological founding ground, bringing in issues of embodiment, being-in-the-world, and life narratives in cases of existentially charged situations and encounters in health care. This makes it possible to provide more substance and content to much embraced but surprisingly thin ideals in health care ethics, such as patient autonomy, professional empathy, and person-centered care. Health care providers and organizers need to ensure a structure where professionals in the three types of situations we have investigated have sufficient training and time to be able to understand and explore the existential suffering of patients and help them to make good choices.

## **2. The project’s contribution to the international research frontline**

The project has contributed to research on the international frontline by way arranging international conferences and publishing the results in top line scientific journals in philosophy of medicine and medical ethics. In the articles, phenomenological-existential analyses of concepts such as existential suffering, empathy, personhood, dialogue, and professional responsibility have been delivered. The project members have also been invited to present this research at international conferences and professional meetings.

## **3. The contribution of the research to the knowledge of the Baltic Sea Region and Eastern Europe**

The comparative studies in the project, as concerns the three mentioned existentially charged situations in health care, have been hampered by the corona pandemic bringing lock downs and restrictions in Germany, Denmark, and Sweden. This development made it practically impossible to access health-care environments for empirical studies 2020-22. Most of the empirical studies in Sweden were carried through in 2018-19 before the pandemic hit, but the studies in other countries could not be carried through as planned but had to be substituted with studies of published works, on-line documents, mail conversations and digital interviews. Despite this we were able to map and reflect upon similarities and differences in the way in which fetal screening, health care coordinator



work, and physician assisted dying have been addresses and solved in the different countries (see articles on care coordinators and end of life issues in articles listed below).

#### **4. New research questions that the project has led to**

In association with the studies on chronic illness and end life issues in the project a major subject for an extended existential-phenomenological analysis has come up: ageing. We perceive the need for a more substantial conception of the lived experience of ageing, not least as concerns the different cultural environment of the countries in the Baltic Sea Region. As a result of improved health care and better living conditions we become older and older but are not always prepared to deal with changed life circumstances. Two major ideas and corresponding movements have been formulated by researchers to achieve a good life for old people: healthy ageing and anti-ageism. A phenomenological analysis of ageing would rather proceed from the handling inevitable life-losses, such as: the death and disappearance of close others, the decline of one's physical and mental capabilities, the loss of meaningful activities, the loss of a social network and the loss of a cultural influence. The importance of such an alternative becomes obvious by highlighting a peculiar form of expertise which must be developed to live well in old age despite such happenings: the capability of handling life-losses. How can we develop such an expertise and what can we learn from old people in different cultural environments in this regard?

#### **5. Dissemination of the results of the project within and outside the research community**

The results of the project have been disseminated through four major channels: teaching, presentations to the public, conferences, and scientific publications.

##### **Teaching:**

The project members Fredrik Svenaeus and Martin Gunnarson have designed and taught 4 7,5 hp courses in existential philosophy within the education "Det existentiella samtalet" organized by Centre for Studies in Practical Knowledge 2021 and 2022: <https://www.sh.se/program--kurser/kurser/avancerad/det-existentiella-samtalet> In this way we have been able to discuss and communicate the results of the project with all in all 60 students on advanced level.

We have also contributed at advanced and PhD teaching events on the following occasion:

Svenaeus, Fredrik: Invited lecture on "Dying Bodies and Dead Bodies: The Phenomenology of Dementia and Brain Death" and seminar moderator at "Copenhagen Summer School of Phenomenology and Philosophy of Mind", one week in August 2018.

Svenaeus, Fredrik: "The Nature of Suffering and the Goals of Medicine", lecture at Ph. D. course and conference, "Suffering in Contemporary Society", University of Aalborg, March 2021.

##### **Presentations to the public and health-care professionals:**

Svenaeus, Fredrik: "Phenomenological Bioethics", invited lecture at Forum för medicin och filosofi, Oslo University, February 2018.

Svenaeus, Fredrik: "To Die Well: Phenomenology of Suffering and Medical Ethics", invited lecture in the series Medizinethik in der Klinikseelsorge, Goethe Universität, Frankfurt am Main, November 2018.



Svenaesus, Fredrik: "Människan och diagnosen i den moderna medicinen", invited lecture at the educational days "Berätta för livet", Region Kronoberg, Växjö, November 2018.

Svenaesus, Fredrik: Presentation of "Homo pathologicus: medicinska diagnoser i vår tid" during my time as invited scholar at the San Michele Foundation, Capri, Italy, September 2018.

Svenaesus, Fredrik: "Det naturliga: en kritik av queerteorin, transhumanismen och det digitala livet" presentation of new book at Humboldt Universitet, Institutet för skandinavistik, Berlin, October 2019.

Svenaesus, Fredrik: "Human Suffering and the Coronavirus Crisis", invited lecture at webinar arranged by The Faculty of Law, University of Lund, March 2021.

Gunnarson, Martin: "Opportunistisk screening för kognitiv svikt" at meeting: "Demens: kommunikation, etik och demokrati", samarrangemang mellan CEDER och CMHB, Linköping, den 26 november, 2021.

Gunnarson, Martin: "Hannah Arendts handlingsbegrepp", Filosofiska grundskolan Skarpnäck, March, 2022.

Svenaesus, Fredrik: "Medicinens hermeneutik: om grunderna för ett gott kliniskt omdöme", invited talk at workshop organized by Läkaresällskapet about "Kloka kliniska val", October 2022.

#### **Five most important conferences in the project:**

Svenaesus, Fredrik, with Martin Gunnarson and Anna Wennergren, organizing of the international conference: "Existential, Medical Humanities", Södertörn University, November 2019. 40 participants with presentations also by the organizers.

Fredrik Svenaesus: invited book seminar on his book *Phenomenological Bioethics: Medical Technologies, Human Suffering, and the Meaning of Being Alive*, Routledge, 2017, with commentaries by Sören Overgard, Lisa Käll och Espen Dahl, at the 17th Annual Meeting of the Nordic Society for Phenomenology, Copenhagen, April 2019.

Fredrik Svenaesus: "Why do People Want to Die? The Meaning of Life from the Perspective of Euthanasia", invited plenary lecture at the conference "The Meaning of Life and the Knowledge of Death", University of Liverpool, July 2021 (online).

Fredrik Svenaesus: "The Phenomenology of Objectification in and Through Medical Practice and Technology Development", presentation at the Conference "Futures Ahead for Medical Humanities", University of Linköping, June 2022.

Fredrik Svenaesus with Martin Gunnarson organizing of the international conference: *The Phenomenology of Chronic Illness and Ageing*, Södertörn University, November 2022. 40 participants with presentations also by the organizers.

Presentations of papers by project members at round 15 more conferences and workshops (some of them online) during the project time.

#### **Publications:**

##### **Monographs:**

Svenaesus, Fredrik: *The Hermeneutics of Medicine and the Phenomenology of Health: Steps towards a Philosophy of Medical Practice* (second, revised edition), Springer, 2022.

Svenaesus, Fredrik: *Världen vaknar: Känslornas plats i människans liv*. Möklinta: Gidlunds förlag, 2023.



**Papers in scientific journals and anthologies:**

Gunnarson, Martin, Kapeller, Alexandra och Zeiler, Kristin. 2021. Ethico-Political Aspects of Conceptualizing Screening: The Case of Dementia. *Health Care Analysis*. 29, 343–359. <https://doi.org/10.1007/s10728-021-00431-3>

Gunnarson, Martin och Zeiler, Kristin. 2022. Ethico-Political aspects of clinical judgment in opportunistic screening for cognitive impairment: Arendtian and aristotelian perspectives. *Medicine, Health Care and Philosophy*. 25(3), 495-507. <https://doi.org/10.1007/s11019-022-10095-y>

Gunnarson, Martin. 2022. Det lilla och stora screeningstestet. I *Screeningens mångsidighet: dess möjligheter och utmaningar* Anette Wickström, Sofia Morberg Jämterud och Kristin Zeiler (red.). Lund: Nordic Academic Press.

Gunnarson, Martin, together with Zeiler, Kristin and Karlsson, Gunnar. 2022. Opportunistic cognitive screening in Sweden: What the tests mean and do for patients and healthcare professionals. *Dementia*. 21(1), 236-249. <https://doi.org/10.1177/14713012211035373>

Gunnarson, Martin. 2022. Disclosing the person in renal care coordination: Why unpredictability, uncertainty, and irreversibility are inherent in person-centred care. *Medicine, Health Care and Philosophy*. 25(4), 641-654. <https://link.springer.com/article/10.1007/s11019-022-10113-z>

Gunnarson, Martin, together with Zeiler, Kristin and Segernäs, Anna. Entering the Grey Zone of Aging between Health and Disease: A Critical Phenomenological Account. Submitted to *Continental Philosophy Review*.

Gunnarson, Martin. The Existential Charge of the Mundane: The Work of Care Coordinators in Germany and Sweden. Submitted to *Health Care Analysis*.

Svenaesus, Fredrik: "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.

Svenaesus, Fredrik: "Phenomenology of Pregnancy and the Ethics of Abortion", *Medicine, Health Care and Philosophy*, vol. 21, no. 1, 77-87, 2018. <https://link.springer.com/article/10.1007/s11019-017-9786-x>

Svenaesus, Fredrik: "Fenomenologia del embarazo y la ética del aborto", *Estudios de Filosofía*, vol. 15, 106-132, 2018 (Spanish translation).

Svenaesus, Fredrik: "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.

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://lssjournal.biomedcentral.com/articles/10.1186/s40504-018-0069-y>

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](https://www.academia.edu/37695180/Why_Heideggerian_Death_Anxiety_in_not_Truly_Uncanny_Existential_Feelings_and_Psychiatric_Disorders)



Svenaesus, Fredrik: "Dying Bodies and Dead Bodies: A Phenomenological Analysis of Dementia, Coma, and Brain Death", in *Phenomenology of the Broken Body*, eds. Espen Dahl and Cassandra Falke, Routledge, 215-231, 2019.

Svenaesus, Fredrik: "A Defense of the Phenomenological Account of Health and Illness", *Journal of Medicine and Philosophy*, vol. 44, no. 4, 459-478, 2019. <https://academic.oup.com/jmp/article/44/4/459/5540416>

Svenaesus, Fredrik: "To Die Well: The Phenomenology of Suffering and End of Life Ethics", *Medicine, Health Care and Philosophy*, vol. 23, no. 3, 335-342, 2020. <https://link.springer.com/article/10.1007/s11019-019-09914-6>

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

Svenaesus, Fredrik: "Phenomenology and Embryo Ethics", *Topos: Journal for Philosophy and Cultural Studies*, no. 2, 11-26, 2020. [https://www.academia.edu/43264621/Phenomenology\\_and\\_Embryo\\_Ethics](https://www.academia.edu/43264621/Phenomenology_and_Embryo_Ethics)

Svenaesus, Fredrik: "The Phenomenology of Pain", *Phenomenological Reviews*, 2020-07-12. <https://reviews.open.org/?s=the+phenomenology+of+pain>

Svenaesus, Fredrik: "Empathy and Togetherness Online Compared to IRL: A Phenomenological Account", *Journal of Phenomenological Psychology*, vol. 52, 78-95, 2021. [https://www.academia.edu/45668336/Empathy\\_and\\_Togetherness\\_Online\\_Compared\\_to\\_IRL\\_A\\_Phenomenological\\_Account](https://www.academia.edu/45668336/Empathy_and_Togetherness_Online_Compared_to_IRL_A_Phenomenological_Account)

Svenaesus, Fredrik: "Why do People Want to Die? The Meaning of Life from the Perspective of Euthanasia", *Royal Society of Philosophy Supplements*, Cambridge University Press, vol. 90, 297-311, 2021. [https://www.academia.edu/50844414/Why\\_Do\\_People\\_Want\\_to\\_Die\\_The\\_Meaning\\_of\\_Life\\_from\\_the\\_Perspective\\_of\\_Euthanasia](https://www.academia.edu/50844414/Why_Do_People_Want_to_Die_The_Meaning_of_Life_from_the_Perspective_of_Euthanasia)

Svenaesus, Fredrik: "Health and Illness as Enacted Phenomena", *Topoi*, vol. 41, no. 2, 373-382, 2022. <https://link.springer.com/article/10.1007/s11245-021-09747-0>

Svenaesus, Fredrik: "The Phenomenology of Objectification in and Through Medical Practice and Technology Development", accepted for publication in *Journal of Medicine and Philosophy*, 2023. [https://www.academia.edu/44490935/The\\_Phenomenology\\_of\\_Objectification\\_in\\_and\\_Through\\_Medical\\_Practice\\_and\\_Technology\\_Development](https://www.academia.edu/44490935/The_Phenomenology_of_Objectification_in_and_Through_Medical_Practice_and_Technology_Development)

Svenaesus, Fredrik: "Empathy and Dialogue in Nursing Care", in *Routledge Handbook of Philosophy of Nursing*, ed. Martin Lipscomb, accepted for publication in 2023.

Svenaesus, Fredrik: "How to Wither Well: An Explication and Critique of Simone de Beauvoir's Phenomenology of Ageing", submitted to *Continental Philosophy Review*.

Svenaesus, Fredrik: "The Phenomenology of Frailty: Existentialism and Old-Age Vulnerability", in *Routledge Handbook of Contemporary Existentialism*, ed. Kevin Aho, accepted for publication in 2023.