FUTURES AHEAD

Translations and Collaborations between Medicine, Social Sciences and the Humanities

15–17 June 2022

Abstract Booklet

Centre for Medical Humanities
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Preface

Most welcome!

We are very happy to welcome you to the conference Futures Ahead - Translations and collaborations between medicine, social science and the humanities, organized by the Centre for Medical Humanities and Bioethics, Linköping University, 15-17 June 2022. The conference has been postponed during the pandemic, and we are excited to finally meet and engage in conversations on shared topics of concern in the field of medical humanities, broadly understood.

The conference has attracted a range of researchers, and we look forward to research presentations and productive discussions throughout the conference. We are also most grateful for the financial support from Linköping University, as part of the work at the Centre for Medical Humanities and Bioethics, and from the Royal Swedish Academy of Letters, History and Antiquities (*Kungliga Vitterhets Historie och Antikvitets Akademin*).

Again, warmly welcome to the conference!

The conference committee: Anna Bredström, Lisa Guntram, Sofia Morberg Jämterud, Anette Wickström and Kristin Zeiler

Presentation of Keynote Lectures and Speakers

Medical Humanities and Post-COVID Futures: Understanding the Past, Interpreting the Present, Imagining the Future

Jane Macnaughton

Professor of Medical Humanities and Director of the Institute for Medical Humanities, Durham University, UK.

The COVID pandemic has revealed the deep entanglement of social, political, cultural, spiritual and historical life with the biomedical. It is the role of medical humanities to pay attention to those interactions and to examine how they play out in the human experience and potential impact of the pandemic. Using methods and examples from critical medical humanities research I will reflect upon the past and present of the pandemic, and on the role of medical humanities in shaping potential futures.

Professor Macnaughton is Director of Durham University's Institute for Medical Humanities and has been centrally involved in the development of the medical humanities in the UK and internationally since 2000. She continues to practise clinically in women's health.

Dying of Whiteness: Racial Resentment, and the Politics of the Pandemic

Jonathan Metzl

Frederick B. Rentschler II Professor of Sociology and Medicine, Health, and Society Professor of Psychiatry, Center for Medicine, Health, and Society, Vanderbilt University.

With the rise of the Tea Party and the election of Donald Trump, many middle- and lower-income white Americans threw their support behind conservative politicians who pledged to make life great again for people like them. But the right-wing policies that resulted from this white backlash put these voters' very health at risk—and in the end, threaten everyone's well-being. This lecture seeks to better understand the politics of racial resentment and its impact on public health. Drawing on systematic analysis of health data it reveals how policies have made life sicker, harder, and shorter in the very populations they purported to aid. Ultimately, it demonstrates just how much white America would benefit by emphasizing cooperation, rather than by chasing false promises of supremacy.

Professor Metzl is Director of the Department of Medicine, Health, and Society at Vanderbilt University in Nashville, Tennessee. He has written extensively for medical, psychiatric, and popular publications about some of the most urgent issues facing America and the world.

Medical Humanities at the Intersection of the Humanities, the Social Sciences, Clinical Practice and Biomedicine

Kristin Zeiler

Professor in Technology and Social Change, Department of Thematic Studies – Technology and Social Change, Centre for Medical Humanities and Bioethics, Linköping University.

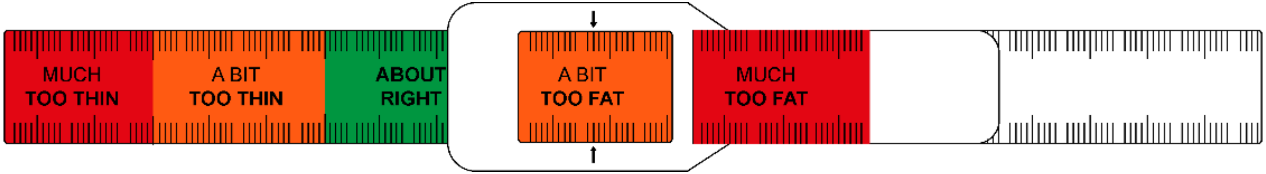
Mini keynote lecture by Professor Kristin Zeiler followed by panel conversation on interdisciplinary work with Professor Richard Levi, Region Östergötland and LiU, Professor Harald Wiltsche, LiU, Professor Ericka Johnson, LiU and Kristin Zeiler. The keynote starts in common conceptualizations of medical humanities, including more recent conceptualizations of 'Entangled Medical Humanities', 'Critical Medical Humanities' and 'Reversed Medical Humanities'. However, it also presents the project Biomedicine, Clinical Knowledge, and the Humanities in Collaboration: A Novel Epistemology for Radically Interdisciplinary Health Research and PolicyWork on Post Covid-19 Syndrome, funded by the Swedish Research Council (2022-2027), and discusses whether yet another conceptualization is needed - in order to capture aspects of the interdisciplinary work in this and similar projects.

Professor Zeiler is Director of the Centre for Medical Humanities and Bioethics, Linköping University. Her research examines subjectivity, embodiment, agency, often from hermeneutical, phenomenological and empirically philosophical perspectives, and the philosophical, ethical, and sociocultural aspects of medical technologies and practices.

Exhibition: Norm Critical Design and Medical Humanities

The exhibition will present a conversation between norm critical design and medical humanities. It will engage with some of the findings from the project A Feminist Approach to Medical Screening, funded by the Swedish Research Council. These findings have been further explored and visualised through a number of design artefacts. The exhibition discusses the performativity of questionnaires and how they (re)produce norms in a medical screening practice.

Anna Isaksson, Halmstad University
Emma Börjesson, Halmstad University
Hajar Sadequi, Halmstad University
Karin Ehrnberger, KTH Royal Institute of Technology
Malin Björklund, Malin Björklund EF



Parallel Sessions: Abstracts

(authors in alphabetical order)

The Black Box of Surgical Ethics

Kari Milch Agledahl, Finnmark Hospital Trust

Surgery is often perceived as a field of action more than one of reflection, and surgeons have traditionally shown little interest in formal ethical deliberation. Despite of this, surgery has evident moral impact: Operating on defenceless and thus extremely vulnerable patients, mutilating body parts, should make ethical reflection very present indeed. Still, many perceive surgical ethics as an oxymoron. Ethical issues have traditionally been far more prevalent in medical than in surgical literature.

There may be partly historical reasons for this omission. The Hippocratic oath specifically prohibited doctors from performing surgery and surgeons were not part of the college of physicians until the 19th century. Today, there is a growing effort from within the field of surgery to describe ethical challenges encountered in surgery. Concurrent surgery, palliative surgery, standards of excellence and surgical innovation are examples of new issues brought forward by a specific focus on surgical ethics. The topics indicate that surgical work deals with challenges and dilemmas that are not correspondingly found in non-surgical medicine, and thus warrant specific ethical reflection.

Most surgical ethics literature is, however, from a North-American context where clinical reasoning is firmly guided by laws and litigations, and the ethical discussions are deeply rooted in a specific American context that make them less useful for a broader audience. Moreover, the ethical discussions rarely focus on the work that actually goes on in the operating theatre. Attention is often limited to preoperative considerations, like patient information and consent, and postoperative care, including complications. Sometimes, surgical situations are even interpreted in a rather forced way to fit the framework of traditional medical ethics. For instance, when a question of whether or not a tired surgeon should do an elective operation is reformulated to a question of obtaining proper informed consent.

The literature of surgical ethics only rarely discusses the specific surgical activities within the operation rooms. There may be good explanations for this, as operating theatres are not readily accessible to ethicists and philosophers, but there is also reason to believe that many actions of moral consequence are conducted within that constricted area. Ethics of surgery thus constitutes a black box of medical ethics. That is, surgery is avoided or inaccurately accounted for in ethics literature so that, ethically speaking, we do not know what it contains.

The purpose of this paper is to explore the knowledge gaps of surgical ethics by analysing the literature in terms of what it covers, but also what is deliberately or unconsciously left out. Attention is also given to possible ethical reformulations that hampers formulation of a more precise surgical ethics. The aim is to identify parts of surgical work that is missing in ethics literature and expose accounts of surgical ethics that misrepresent or distort clinical work.

Interdisciplinary Uncertainties: Comparative Ethical Analysis of Genome and Epigenome Editing

Karla Alex and Eva Winkler, Heidelberg University

Current developments within genome editing research have initiated an increase in interdisciplinary discussion on conditions and possibilities of translation into the clinic. In bioethics, the debate focuses on human germline genome editing (hGGE). Although there are numerous scholarly articles and consensus statements on hGGE, the question of whether clinical research and clinical applications are ethically permissible remains unresolved. In the present paper, we analyse this ethical uncertainty with reference to scientific uncertainties. One hypothesis that needs to be discussed is: Scientific uncertainty results in moral uncertainty; to combat this process, the “only-when-it-is-safe” argument (OSA) is applied (we should do it only when it is safe, so we are safe, 'morally speaking'); however, the OSA is not sound (as it will never be safe); hence, moral uncertainty remains.

Firstly, we ask: Do differences and moral uncertainties regarding whether hGGE could be preferrable over preimplantation genetic diagnosis (PGD) result in part from scientific insecurity? This includes probabilistic uncertainty: How many embryos will be “successfully” edited by hGGE, and will embryo selection be necessary not only after PGD, but also after hGGE? Scientific uncertainty also exists regarding effectiveness and unintended medical and socio-ethical effects of hGGE, such as a change in moral attitudes among the public or increasing segregation. Moreover, uncertainties play an important role for the analysis of epigenome editing (EGE). This novel technology has so far received little attention in the bioethical discussion. EGE might present fewer scientific uncertainties regarding detrimental unintended effects because it does not change DNA sequences, but the structure of DNA to activate/deactivate certain genes. (Unintentional) inheritance can probably be excluded as well. Nevertheless, EGE still includes scientific incertitude e.g., regarding its effectiveness. Based on the results of a two-year interdisciplinary research project on ethical, legal, and societal aspects of genome and epigenome editing in medicine, we therefore, secondly, try to answer the question: Is EGE just as uncertain from an ethical perspective as hGGE or is the presumption that it is less risky than genome editing sufficient to classify EGE as ethically preferrable over other gene technologies? Addressing this issue requires consideration of different moral claims, such as prospective parents' reproductive autonomy, the presumed moral status of an embryo or fetus (fetal therapy might be necessary for some applications of EGE). And especially regarding hGGE, a debate familiar from discussions of PGD needs to take place: which diseases classify as "severe"? For a comparative assessment of genome and epigenome editing, we evaluate these often-discussed aspects from the perspective of interdisciplinary, i.e., scientific and ethical, uncertainty. This analysis includes a reference to the soundness of the OSA with implications transcending a debate on novel gene technologies. Furthermore, albeit focusing on translational medical ethics' integration of research from the natural and life sciences into analyses of applied philosophy, considerations on the translations and interdisciplinary character of uncertainty might as well be relevant for other types of collaborations between empirical and normative sciences.

Encountering Migrants when Providing Sexual and Reproductive Health and Rights Services: Experiences of Healthcare Providers in Southern Sweden

Nada Amroussia, Faculty of Health and Society, Malmö University

Introduction: Research on the encounters between healthcare providers and migrants when providing sexual and reproductive health and rights (SRHR) services tends to focus on the challenges and barriers, whereas little attention has been paid to the ways healthcare providers navigate or handle these challenges. This study examined healthcare providers' accounts of encounters with migrants when providing SRHR services to migrants in Southern Sweden. It focused on challenges and dilemmas experienced by healthcare providers, strategies used to navigate these challenges, and assumptions underlying participants' accounts.

Methods: Qualitative thematic analysis was used to analyze 31 interviews with healthcare providers working in youth clinics and women healthcare clinics. The analysis was guided by a theoretical framework combining person-centered care approach, Foucault's concepts on power and knowledge, and theories to navigate diversity in healthcare setting: cultural competency and cultural humility.

Results: The study findings illuminate the complex relations between person-centered care, culture, and power when providing SRHR services to migrants. Participants viewed person-centered care and cultural considerations in

healthcare setting as not always compatible. Some participants understood person-centered care as individualized care where the influence of culture on the encounter should be ruled out or de-emphasized, whereas others tended to highlight this influence. The influence of culture on the encounters was often reduced to effects of migrants' cultural background and viewed as a source of different dilemmas and challenges. Participants' strategies to navigate these perceived challenges and dilemmas oscillated between practicing cultural humility and seeking cultural competency. In addition to culture, power emerged as an important aspect of the encounters with migrants as illustrated by the tension between encouraging patient involvement and adopting evidence-based knowledge as a regime of truth.

The study findings also show how participants viewed the encounters with migrants as not only dyadic interactions healthcare provider-patient. They placed their experiences in a broader organizational and social context. In doing so, participants highlighted several organizational challenges to encountering migrants and discussed dilemmas stemming from the interplay between migrants' structural and individual disadvantages. Participants framed these challenges as not only a difficulty in their work, but also as a source of unequal care for migrants.

Conclusions: This study contributes to the understanding of healthcare providers' experiences of encountering migrants when providing SRHR services. It highilights the complexity of implementing person centered care approach in a culturally diverse setting. It also shows how the culture of biomedicine might constrain adopting some core components of person centered care approach, namely patient involvement and shared decision making.

Dialogues of Disorder; a Conversation with Mel and Nicky

Dr. Thomas Baugh, Falmouth University, Cornwall, UK and Karen Abadie, University of Plymouth, UK.

Keywords: Subjectivity, intersubjectivity and the lived experiences of embodiment, illness, pain, pregnancy, birth, and dying

Our proposal for the Futures Ahead conference at Linköping University will be to screen the filmic projection *'Dialogues of Disorder; a conversation with Mel and Nicky'*. This artistic, socially engaged contribution will be screened in conjunction with a paper that aims to visualize, and further understand what is to be embodied by a lived experience of obsessive-compulsive disorder [OCD] and self-injury [SI].

The short film, which is approximately 10 minutes in length and employs projection and associated narrative to articulate subjectivity and visualize inter connections between the body, as object and the body as subject. The film is part of a wider project currently taking place in the South West of England which aims to re-think the concept of disorder, and diagnosis, and is in collaboration between Falmouth University, Plymouth University, Live-well South west and the NHS, Plymouth, UK. By screening *'Dialogues of Disorder; a conversation with Mel and Nicky'* and delivering an accompanying paper we will interrogate the complicated and irregular strands of embodied behavior associated with both OCD and SI, through the lens of the protagonists Mel, and Nicky. Moreover, by laying bare the characteristics through a visual narrative, the contribution will provide the audience at the conference with an equivalence of both disorders, which aims to expand current methods of experiencing subjectivity. By that we mean the film aims to provide an audience with the space to interpret strands of consciousness connected to OCD and SI, and how these may affect a sufferer, as it encourages one to reflect upon one's own perceptual experiences through techniques that can be associated with structural film. Furthermore, the paper will review experiences of dissociation and, how the embodied mind of someone who has experience of OCD, and SI is affected, and is shaped by internal and external perceptions, and will reveal how their disorders are embedded and affected by public and private spheres. This project is set against a backdrop, which aims to help people understand their mental health experiences, and enable them to make changes, or accept who they are, by adopting the hypothesis that it is better to see ourselves as people with particular individual and shared human attributes. Moreover, *'Dialogues of Disorder; a conversation with Mel and Nicky'* aims to provide health professionals with an expanded knowledge of both disorders, and a vision which debates the concept of disorder. The screening at the conference will begin to examine how this practice serves to strengthen the research, which currently exists in medical fields surrounding these two mental disorders, and aims to contribute to new methods of diagnosis, in that the aim of the film is to support the design of new interventions that are accessible; encounters that aim to provide a conceptually sound basis for researchers from across disciplines to investigate mental health, support decisions within the key clinical and non-clinical settings and contribute to reduction of the stigma and the miss-representation, which currently surrounds both disorders.

Uses Of Narrative: the Introduction of Narrative Medicine in Scandinavia

Katarina Bernhardsson, Associate Professor in Literary Studies, Lecturer in Medical Humanities, especially literature and medicine, Lund University

In the interdisciplinary work of medical humanities, one of the places for intersections between disciplines is the narrative. There are several ways narratives and narration have come to play a role, two of them being the act of narrating seen as an important part of clinical practice, and the personal illness narrative seen as a way for a narrator to make sense of his or her own suffering and for others to gain a more multifaceted understanding of that suffering.

The term narrative medicine, which encompasses these strands as well as others, has been introduced in Scandinavia during the past decade, e.g. by the creation of Svensk förening för narrativ medicin, the research network Nordic Network for Narratives in Medicine, and by the introduction of narrative medicine as a subject at Syddansk University's medical school. The teaching of medical humanities at Lund University, which I am coordinating, is also closely connected to narrative medicine.

In this paper, I want to discuss what narrative medicine has come to mean in the Scandinavian setting. Drawing on sources like different descriptions of the teaching (at medical school and in continuing education), the creation of a society and events aimed at clinicians, as well as my own experiences of establishing the subject in medical school, I will discuss how narratives are used to create a meeting point between different knowledge paradigms, and the limitations and possibilities of the work.

Positioning History of Medicine within the Medical Humanities

Maria Björkman, Ph.D., Associate Professor. IKOS, Linköping University

For historians of medicine, the Corona pandemic has demonstrated an increased demand on historical perspectives on medicine. Questions about how past societies managed pandemic disease have often been used as a backdrop in contemporary discussions on how to best handle Covid-19.

The uses of history of medicine have also been actualized within the field of medical humanities, not least in the last few years in Sweden when several new centers for medical humanities have been established nationally. Both the pandemic, and the growing field of medical humanities have re-actualized that history of medicine needs to find new positions in how to navigate between public need of historical perspectives on health and disease, interdisciplinary- and cross-faculty collaborations, and the discipline's own needs of a stringent development of a research field. My paper will outline possible ways to take, based on examples from other European countries.

Monitoring Menopause

Dr. Marjolein de Boer, University of Tilburg, The Netherlands

Over the last decade, self-tracking health technologies have become increasingly popular. These technologies range from apps for mobile phones to wearables, and cover a broad range of aspects of health. A substantial amount of these self-tracking technologies are geared towards women and their physical functionality and changes: from menstruation tracking apps, to feminine weight loss apps, to pink Fitbits. Accordingly, a growing body of research study the usage and impact of these devices.

However, self-tracking in menopause – a bodily change that every women will go through – is largely taken for granted in the literature. Besides from the irregulation and eventual cessation of menstruation, menopause may involve a wide range of bodily changes: hot flashes, night sweating, a dry(er) vagina, high blood pressure, insomnia, or heart palpitations. As such, there is a broad spectrum of potential technologies that menopausal women may use to track this bodily transition, namely specifically tailored menopause apps (e.g., Menopro; Hot Flash Sister), apps for tracking sexual functionality (e.g., SAA app; Vaginal Dryness), sleep apps (e.g., Sleep cycle), Fitbits, and digital heartrate meters.

By drawing on the findings of my empirical–philosophical study to women's experiences of self-tracking in menopause, I will (1) describe whether and how women in menopause use self-tracking technologies and (2) analyze on how this usage influences and shapes their bodily experiences within this life phase. In doing so, this paper not only shows how self-tracking technologies may be understood as mediating women's experiences, but also function as a hermeneutic way of interpreting their (embodied) selves in menopause. That is, it is revealed that monitoring the menopausal body through technology heavily bears on the ways in which women's pursue their identity work – and thus, eventually, how they come to see themselves as, for example, women, partners, or employees.

Given this constructive power of using self-tracking technologies in menopause, this paper ends with an ethical reflection on how the design of these kind of technologies and their usage-guidelines could be tailor-made in order to best assist women in their identity work.

Interactive Drama Workshops as Intervention and Research Method in Clinical Settings – A Reflection

Jelmer Brüggemann, Associate Professor, Linköping University

I will start by situating this presentation in a project I worked in some years back, that focused on situations in which care professionals identify patients being neglected, offended, or abused. In that project, interactive drama workshops with care professionals, building on "forum play" (Brüggemann & Persson, 2016; Österlind, 2011), were organized in collaboration with a hospital clinic. These workshops work with local understandings and participants' collectively explored courses of actions in what they together define as problematic situations relevant to the workshop topic. The workshop series was organized with a twofold aim. First, together with the clinic management, it was designed as an educational intervention that would offer care professionals individual and collective insights in what can be at stake in these types of situations, and how they can be prevented or dealt with in constructive ways. Second, the workshops were used to collect ethnographic material that enabled analyses of relevant processes and strategies. A result of these analyses was the development of "navigation work" as a useful concept to grasp professionals' work in problematic, potentially abusive care situations (Brüggemann, Persson, & Wijma, 2019).

As a reflection upon this work, I will in this session discuss a few methodological aspects related to the use of interactive drama in studies of care. I ask questions such as: How does interactive drama about complex care situations relate to everyday care practices? How do observations of interactive drama differ from observing care professionals in clinical settings or talking about their work in interviews? And how can interactive drama, as intervention and research method, contribute to the improvement of care?

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A for Artificial or A for Augmented? AI Challenges in Healthcare Co-Production

Anna Clareborn, Oxford University

Significant advances in artificial (or augmented) intelligence are taking place in the context of healthcare, and we find ourselves on the cusp of what will doubtlessly be a far-reaching reimagining and restructuring of the field. This has raised numerous ethical, legal and societal issues, not least regarding healthcare co-production and co-creation. On the one hand, it has been suggested that AI could contribute to the enhancement and stimulation of co-production activities, for instance through automation and cost reduction. On the other, it has been argued that automation in in itself is not necessarily a catalyst for positive change, and that focusing too much on cost reduction could lead to a deterioration of quality in the long term.

During 2020 and 2021, the organizations ATMP Sweden, Biobank Sweden and Genomic Medicine Sweden have pursued *Towards a Culture of Equal Partnership*, a collaborative, innovative Patient and Public Involvement (PPI) pilot project together with a core team of patient and next of kin representatives. The end goal has been to find viable strategies for sustainable, long-term collaboration in the fields of biobanking and personalized medicine. Over the course of the pilot project it has become clear that true partnering requires frameworks supporting far-reaching changes in terms of culture, as well as tools for measuring outcomes and managing feedback. Through the implementation and evaluation of individual case studies, all three organizations have identified significant payoffs in terms of co-production activities and PPI.

The value of truly equal partnerships – rather than just superficial engagement with patient- and next of kin representatives – is clearly considerable, but where does AI fit into the picture? Taking the results of the *Culture of Equal Partnership* pilot project into consideration, we want to discuss the impact of AI on co-production and co-creation in healthcare, with a particular focus on (bio)ethical issues like risk management, trust and trustworthiness.

‘Learning to Listen to Your Body’: The Embodied Experiences of People Following a Weight-Loss Trajectory in a Dutch Obesity Clinic

E.I. Doeschot, PhD-Candidate, Tilburg University

People who are considered obese are increasingly resorting to weight-loss surgery in order to reach what is supposed to be a healthy weight. A growing number of clinics are offering a counselling trajectory alongside surgery in order to help patients adjust their lifestyle accordingly and keep the lost weight off. Patients following this counselling trajectory are taught and/or attempt themselves ‘to listen to the body’. The underlying assumption is that the body gives signals which, when correctly interpreted, can support them in adapting to a new lifestyle and regulating their weight. The imperative of ‘listening to the body’ as it is used in practice, seems to refer to singular, individual experiences and does not make explicit what it is in the body exactly that needs listening to. By drawing on a series of observations and interviews with patients and professionals at an obesity clinic in the Netherlands, I will elaborate on how patients following a weight-loss trajectory ‘learn to listen to the body’, in what ways they (come to) understand it, and the role professionals play in the patients’ understanding. In my presentation, I want to paint a more detailed picture of the diversity in embodied experiences of people following a weight-loss trajectory.

Keywords: embodiment, obesity clinic, phenomenology, ethnographic research, weight-loss trajectory

Orientating Affectivity. Embodiment, Feeling and Affectivity in The Practice of Running Therapy for Depression

Sanne van Driel, Tilburg University

In the Netherlands, a practice called running therapy is establishing itself from the premise that running helps improve mental health and both physiologically and psychologically activates depressed bodies. Situated on the border of (mental) health care and lifestyle interventions, running therapists operating from different professional backgrounds (physical therapy, psychology, sports, coaching) offer participants various skills and techniques to learn to run sustainably. Drawing on my findings based on participatory observations and conversations with running therapists, the focus and aim of the practice are to generate positive experience, better mood and recovery from stress. In this paper I will explicate how this is done with the use of conceptual tools from both critical phenomenology and Deleuzian affect theory.

The notion of orientation has been developed by Sara Ahmed (*Queer Phenomenology*, 2006) in critical relation to traditional phenomenology, shifting attention to the social and material situatedness of embodied subjectivity and the normativities that shape bodies. Understanding the practice of running therapy in terms of social and bodily orientation allows us to account for how normativities around health, feelings, mood and ability are enacted in the practice, co-shape bodies and enable or inhibit them to extend in space. This critical phenomenological approach offers an embodied, embedded and situated understanding of depression in movement, moving beyond a mind-body binary, while adding a critical, social-political dimension to the phenomenology of illness literature (Fuchs 2003, 2005, 2013; Svenaeus 2013; Ratcliffe 2014; Ratcliffe et al 2014; Aho 2013). However, engaging with the language of physical and physiological processes used in the field of running therapy, I turn to the Deleuzian-Guattarian understanding of bodies, affectivity and agency as put forward in the concepts of desiring-machines (*Anti-Oedipus*, 2004/1972) and assemblages or *agencements* (*A Thousand Plateaus*, 2004/1980). Bodies appear then as sites on which affects flow, organized such that they enable or inhibit flow and affective connections. This will allow for an affirmative understanding of the practice of running therapy as a way of moderating feelings, moods and affects, opening up the question of how affectivity might be done differently. Going back to Ahmed's notion of orientation, we can then ask what a critical embodied and affirmative affective -future- approach to treating depression might look like.

The Phenomenological Interview in the Medical Humanities

Hans-Georg Eilenberger, Tilburg University and Jessica Stanier, University of Exeter

People's lived experiences of illness and health form a crucial field of exploration for the medical humanities. A number of methods and theories have proven particularly attuned to this concern, including qualitative interviewing and the philosophical framework of phenomenology. While there have been many attempts to marry up these two approaches (see, e.g., de Boer et al. 2015, de Haan et al. 2013, Legrand & Ravn 2009), the epistemological, methodological, and ethical implications of their union remain underexplored. Phenomenological philosophers who integrate qualitative interviewing in their studies generally note the methodological importance of embodiment in the encounter with research participants (see Høffding & Martiny 2016). What embodiment exactly contributes, however, is not spelled out in any detail.

We take feminist epistemology as the starting point of our investigation into embodied interviewing. In her well-known essay on situated knowledges, Donna Haraway (1988) challenges the doctrine of disembodied scientific objectivity and contrasts it with response-able, partial, and localized ways of knowing. Attending to embodied experience, as we understand it, is one way of situating knowledge production in a web of worldly intersubjective relations. The aim of this investigation, then, is both methodological and ethical: to develop resources for self-reflection that further enhance the integrity and rigour of the phenomenological interview. We pursue this aim by asking the following question: how does an embodied encounter with the other *ground* the phenomenological interview, in the sense of inaugurating a situated way of knowing?

We approach the above question by means of a dialogical phenomenological analysis. Our analysis is based on an ongoing exchange of reflections regarding our respective experiences as interviewers. Through this practice of joint sense-making, we are able to describe the interview encounter in terms of basic phenomenological concepts. Echoing the interview situation, the dialogical format blends the content and the form of our analysis. It also promotes self-reflectivity by forcing us to progressively re-interpret our experiences and to regard them from different positions.

In our contribution, we focus on the methodological and ethical implications of understanding the interview as an inter-corporeal encounter. This aspect is captured most succinctly by the notion of the *other who does not leave me*. We are left by the other with a feeling of abiding commitment to them as a research participant, which situates the practices of interviewing and data analysis between the academic possibility of co-creating new meaning and the ethical call of the other. Tracing 'the other who does not leave me' through various refractions of lived experience—the interview itself, the transcription, the phases of analysis—we explore how in each instance bodily proximity and ethical response-ability are enacted.

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Enacting Diabetes: A Story of Everyday Life of Managing Chronic Illness with Wearable Technology

Lisa Engström, Senior lecturer, Lund University, Department of Arts and Cultural Sciences

Fifteen years ago, a stressed doctor at the local healthcare unit told me the shocking news, while staring at his computer screen: "You probably have diabetes". Unfortunately, he was right. The diagnosis of type 1 diabetes (T1D) has informed almost every aspect of my life ever since. T1D is a serious autoimmune disease in which the pancreas stops producing the essential hormone insulin. It means that I and other affected individuals require treatment with synthetic insulin to stay alive, and we need to monitor our glucose levels to be able to properly adjust the amount of insulin. To accomplish this, medical wearable technology is part of my everyday life. For example, a sensor is attached to my upper arm continuously measuring my blood glucose level. The data from the sensor is transmitted to an insulin pump I recently attached to my body. The pump inserts insulin in small doses via a tube that penetrates the skin. The utilisation of continuous glucose monitoring (CGM) and insulin pump therapy (IPT) makes me a rather ordinary person with diabetes in Sweden since most of us use CGM and about half of us use IPT (Eeg-Olofsson et. al 2020). This point to the fact that the treatment of T1D to a large extent is practised via self-care with wearable technologies (Øversveen 2020, p. 864).

I explore the managing of chronic illness from an information studies perspective. The practice of self-managing T1D highlights *the information work* of living with chronic illness, including information *about* the body (in medical texts, consultations with health professionals, etc.), information *of* the body (data from the body processed through technology), and information *from* the body (sensations and emotions) (cf. Charmaz and Rosenfeld 2016, p. 38).

The utilisation and experience of wearable medical devices that allows, encourage, and request lay people with chronic illness to get quantifiable data from their bodies and act upon it is central to this research project. Autoethnographic notes on my own experiences, reflections and emotions are used as empirical material in the study in which the treatment of type 1 diabetes is used as a case. The aim is to contribute to a profound understanding of the juncture between bodily information processed through wearable technology on one hand (information of the body), and sensory information on the other hand (information from the body), and how this information informs the sense-making and enactment of illness and health. I investigate both the opportunities the wearable technologies bring and the expectations and responsibilities they implicitly carry. The research takes its departure in my own living body, but it reaches into existential relations of body and technology, illness and health, individual and society, and the mundane and the life-changing.

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How to Empathize by Objectifying

Anthony Fernandez, University of Southern Denmark

In the literature on empathy in medicine, it's common to contrast empathic openness with an objectifying attitude. In empathic openness, the clinician perceives the patient as an embodied subject expressive of intentions, desires, and emotions. In an objectifying attitude, on the other hand, the clinician perceives the patient as a mere body or as an organism with a physiological dysfunction. Beginning with the phenomenological studies of Drew Leder and S. Kay Toombs, and continuing through the present discourse in the field, phenomenologists have typically argued that clinicians should avoid objectifying their patients because it's harmful, dehumanizing, and undermines effective care. I argue that these popular phenomenological characterizations rely on an oversimplified understanding of the relationship between empathy and objectification: The empathic and objectifying attitudes should not be understood as fundamentally opposed because, in some cases, fully empathizing requires that the empathizer partially objectify the empathee. Using an example of interacting with someone with Tourette's Syndrome, I demonstrate how objectifying certain aspects their movements actually facilitates rather than impedes empathic understanding. Following this, I outline how this kind of philosophical research can provide a theoretical foundation for future empirical qualitative studies with the potential to inform clinical practice.

Alignment Work in Medical Practice

Jenny Gleisner and Hannah Grankvist, Linköping University – Centre for Medical Humanities and Bioethics

In this paper, we want to bring a sensibility for the work associated with applying and maintaining standards to studying the movement of knowledge. We build on the notion of alignment work to draw analytical attention to the continuous work that, we argue, is an integral part of resolving tensions between different communities and thus a prerequisite for moving knowledge between them. Based on examples from antenatal care and occupational health we connect and develop the questions about, for example, complex collaborations across different epistemic cultures, the affective aspects of expertise, and making knowledge relevant to (potential) recipients.

Keywords: knowledge, medical practice, standards, tensions, alignment work, antenatal care, occupational health

Appropriating a Prosthetic Device: Insights From a Collaborative Research Project Between (Non-)Users, Healthcare Professionals and Researchers about Prosthesis Abandonment

Valentine Gourinat, Paul-Fabien Groud, and Lucie Dalibert. S2HEP, University Claude Bernard Lyon 1, France

In this presentation, we will introduce our ongoing research « Improving prosthetic devices appropriation: (non-)uses of amputees, practices of healthcare professionals and experiential knowledge (APADiP) ». This 3-year project (2020-2023), which is carried out in France, aims to understand the reasons why upper and lower limb prostheses tend to be abandoned by their users after a couple of years (Taylor et al, 2005). While known to healthcare professionals who refer to such phenomena as the "cupboard prosthesis," the abandonment of one's prosthesis and of prosthetic use has received very little attention from medicine and the social sciences and humanities. Yet, ceasing to use a prosthetic device can have a serious impact on one's life (Østlie et al, 2012). At stake in APADiP is, therefore, 1) to understand the mechanisms of (non-)use and (non-)appropriation of prostheses, and 2) to use these analyses as a basis for suggesting ways to improve patients' long-term appropriation of prostheses in order to facilitate their daily activities.

To understand how people with lower or upper limb amputations learn to use their prosthesis and do, or do not, manage to appropriate it, our research is based on an active collaboration between 1) the main amputee association in France, ADEPA, 2) (para-)medical teams from two rehabilitation centres and 3) social science and humanities researchers. Indeed, prosthesis abandonment or rejection is an issue that cannot be approached exclusively from a medical perspective. In fact, the causes of prostheses' abandonment, rejection or non-use are also often related to social and personal dimensions involving the user (Bidiss & Chau, 2007). Furthermore, abandonment does not take place within the rehabilitation circuit: rather, the progressive non-use of the prosthesis occurs within daily life — outside the medical field. Therefore, it cannot be observed nor addressed solely by healthcare teams, all the more so when there is not always regular long-term follow-up of patients. It is here that the social sciences and humanities can offer a complementary contribution to medical research and build a fruitful analytical collaboration.

In our project, social scientists are conducting ethnographic fieldwork, both in rehabilitation centres and amputees' homes. More precisely, two researchers have spent 5 months in rehabilitation centres following patients and healthcare workers. They are currently conducting observations of follow-up consultations as well as observations and interviews at the home of the amputees they have followed during rehabilitation. Likewise, we are realising observations and interviews with « experienced » amputees and prosthetic users, who are involved in ADEPA, and we will organise focus groups with prosthesis (non-) users and healthcare professionals. What this collaboration affords is to bring into dialogue the analyses of social science and humanities researchers, the experiences of patients, the knowledge of more seasoned users, and the practices of healthcare professionals. We argue that doing so enables us to attend to an issue — prosthesis abandonment — that cannot be dealt with by the medical or the human and social sciences domain alone. Besides the collaborative dimensions of this project, it is our first findings and analyses that we will highlight in this presentation.

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Doing Bodies in Dutch Youtube Video's about Contested Illnesses

Irene Groenevelt, Sanneke de Haan and Jenny Slatman, Tilburg University

Abstract: This paper describes how bodies are "done" in (the making of) YouTube videos about contested illness. It is based on an online ethnographic study of Dutch women who use YouTube as a medium to document their contested illness experiences. During 13 months of observations between 2017 and 2019, we followed a sample of 16 YouTubers, and conducted in-depth analysis of 30 YouTube videos and of 8 interviews. Following a "praxiographic" approach to social media, and utilizing insights from phenomenological theory, the paper describes [or: distinguishes] three types of bodies that are being done: (1) inert bodies, (2) experienced bodies, and (3) moral bodies. We argue that vlogging about contested illness can be understood as a practice through which bodies are continually (re)configured, and through which the bodily "invisibility" of contested illnesses can be mitigated. Related, we argue for the need to bring phenomenological theory to the field of social media studies, with the aim of achieving a better understanding of how social media shapes our experience and understanding of our bodies.

NB this abstract is based on a paper that is currently under review at the journal Body & Society, and is authored by Irene Groenevelt, Sanneke de Haan and Jenny Slatman.

Disclosing the Person in Kidney Failure Coordination: Why Unpredictability, Uncertainty, and Irreversibility is Inherent in Person-Centred Care

Martin Gunnarson, Centre for Studies in Practical Knowledge, Södertörn University

Ever since the mid 20th century a struggle has been waged against the dehumanizing, objectifying and paternalistic tendencies of modern medicine. Although the goal of this struggle has been conceptualized in different ways – as "holistic care" and "patient-centred care" for example – its main tenet has remained the same: when caring for a patient medicine has to see and treat this patient as a whole person, not as a physiological entity affected by a discrete disease. Lately, this goal has been conceptualized in terms of "person-centred care", emphasising even more that the patient is first and foremost a person and that medical action should be centred around and adapted to this particular person.

In this paper I explore an example of such person-centred care: the work of so-called kidney failure coordinators. The empirical basis of the paper consists of qualitative interviews with kidney failure coordinators and participant observations of their interactions with patients. During my analyses of the empirical material a fundamental feature of person-centred care emerged: it has to ask *who* the patient is. If person-centred care is to be truly centred around the person it has to disclose *who* the health-seeking individual is. This is a central thesis of this paper. The aim is to argue for the plausibility of this thesis, but, more importantly, to highlight and explore its implications in the context of health care, through the example of kidney failure coordination. These implications have not been sufficiently attended to in the literature on person-centred care. By turning to the philosophy of Hannah Arendt, for whom the disclosure of who someone is, is a fundamental feature of human speech and action, my ambition is to remedy this shortcoming.

The paper shows that asking *who* the patient is entails opening up for an open-ended exploration into the question of how a particular person might live with kidney failure and face the prospect of undergoing haemodialysis or transplantation. This exploration requires speech and action, which, according to Arendt, are two forms of human activity that begin something new and insert someone new into the fabric of the world. As such, they are inherently unpredictable, uncertain, and irreversible, and therefore run counter to the ambition within medicine to achieve predictability and certainty. Consequently, if healthcare is to be person-centred it has find ways of accommodating these two counterflowing streams.

What does it take? Uncertainties, Efforts, Vulnerabilities in Uterus Transplantation

Lisa Guntram, Department of Thematic Studies and CMHB, LiU

In the medical literature, uterus transplantation has often been described as aiming to remedy the last untreatable form of female infertility. It delivers what alternatives, such as surrogacy and adoption, cannot, namely genetic and gestational parenthood. In this presentation I focus on how involved actors describe and negotiate imagined, expected, and experienced uncertainties that emerge in this innovation. Specifically, I discuss the less tangible but still substantial efforts that UTx-IVF require from those involved. To do so, I draw on the rich anthropological, social scientific, gender, and medical humanities scholars on the work, efforts, fears, in organ transplantation and in ART to demonstrate how negotiations enact certain norms and values. Doing so, I also seek to engage with the emerging discussion of "societal dimensions" and expectations in UTx-IVF ethics.

Missing Voices

Ylva Gustafsson, Researcher in philosophy at Åbo Akademi University

During the last 30 years, there has been a considerable increase in illness narratives. They have become increasingly important in medical ethics and have played a formative role in the development of person-centered care. These narratives are considered central in medical ethics because they help us understand how experiences of illness are contextually embedded. Experiences of illness are shaped by how the illness affects our life in broader terms, how it affects our family life, our social life, how it affects our ability to work etc. This has significant consequences in medical ethics concerning how to care for and treat patients in a considerate manner. Detailed personal descriptions of what it can mean to live with an illness has brought forth ethical considerations that largely have been ignored from a general medical point of view.

Despite the great importance of illness narratives, I want to suggest that there might be certain problems in the scope of experiences conveyed in this literature. Illness biographies are often written by people from a certain social and economic background. They lead economically stable lives and live in a context where writing about their experiences is a usual form of self-expression that is both appreciated and endorsed. People who live less economically stable lives may be less prone to write about their lives and may have greater difficulties getting published. One question I want to address is whether there is a risk that this leads to certain questions falling outside the general scope of illness narratives. Is there a risk that the lack of certain voices in illness narratives may create a too unitary conception of experiences of illness? Is there a risk that the lack of certain voices creates the impression that experiences of illness are basically "equal"? Another, connected, question I want to address is whether there is a risk that illness narratives create an individualistic conception of the meaning of illness where societal aspects of illness do not get enough attention?

The Humanities, Care, and the Phenomenological In-Between

Ryan Hart, MA. PhD Candidate at the University of Texas Medical Branch, Medical Humanities Graduate Program

In this presentation, I will sketch a brief reflection on the value of the humanities for disciplines of care and the enriching potential of existential phenomenology therein. Toward complementing the occasional tendency toward scientific, calculative abstraction in biomedical ideologies, a poignant value of the humanities consists as the cultivation of an intellectual quality of availability to interpretive revisions. Taken as an intellectual current pulsating through ancient sources—dialogically reverberated through writers like Plato, Cicero, and Montaigne—the humanities ensue with an inner momentum that can encourage broadened and more adaptable perspectives for its interlocuters. Of course, the flexibility of thought needed to be freed from the factual and open to the possibly otherwise demands one's release from being zoned into one technical way of seeing things. I will examine two consistent themes in the perennial dialogue of the humanities—suspicion and the question of how to live, with an eye toward their role in effecting the suspension of taken-for-granted, habitual meanings.

Of critical importance for this "possiblizing" effect of the humanities is sustained attention to the in-between fields of significance that incessantly elude the grasp of calculative abstractions. Refined attention to the dynamic, processual nature of existence is decidedly enriched by phenomenology's emphasis on the edges of experiential horizons and their possibilities. Drawing on the philosophy of Martin Heidegger and the important ways it was expounded upon by Merleau-Ponty, I will illustrate the relational nexus between self, world, and other at the fringes of being and its distinctive importance for the medical humanities. Bringing this altogether, existential phenomenology supports refined perspectives on the network of concerns between being and the world, perspectives that enrich and bring into steadier view the themes of suspicion and the question of how to live as they are implicated in the ideological influence that the humanities can offer disciplines of care.

The Artificial Medical Gaze: Understanding the Classificatory Power of AI in Medicine

Charlotte Högberg, Technology and Society, Lund University

To classify is a practice of power, whether it concerns the everyday low-stakes definition of a household item, or the politically informed decision about what category a human being belongs to. By the act of classification, an ontological claim is made regarding what something is, and what it is not. Some of these everyday classifications become formalized and standardized, having impact on large scale and with severe effects (Bowker and Star 1999). Within medicine and health care, there are agreed upon definitions of what should constitute a specific disease, and the health professionals are enacting these principles, as well as continuing to define, modify and develop them. Foucault (2003) describes the medical gaze, referring to the medical professionals' practice of seeing, valuing, selecting, and making knowledge claims about what is healthy, what is not, and what the cause, form and cure of the illness is. To increasing extent, classificatory artificial intelligence is developed to make medical diagnoses, prognoses and predictions. Either by full automation or in the form of decision support. This paper is a theoretical exploration into what happens with classificatory power within medicine and healthcare when AI enters the scene as an epistemic actor. Can frictions be identified in relation to traditional knowledge production, when the medical gaze is no longer performed by a human? This is fueled by how the patient, as material for classificatory claims, is increasingly datafied, as well as the expansion of the data gaze (Beer 2019). This detachment of data and patient could be understood as part of making data "bloodless", disguising its origins and ends (Crawford 2021). On the contrary, AI-supported personalization of medicine could also be argued to pump blood into classification, making the patient more present than ever. However, at center stage we find the big conundrum of how to understand AI's classificatory power, when systems are lacking transparency and explainability, blurring the view of their gaze.

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Common Understandings in Different Settings: Equity in Cancer Healthcare in Kenya and Sweden

Helena Iacobaeus, Linköping University, Philippa Barnes, Linköping University and Rispah Torrorey, Moi University

Equity is an important concept for the legitimacy of local democracy, especially in terms of central functions such as access to and distribution of healthcare. Equity is closely linked to equality in healthcare but differs in some respects. How this concept is interpreted and used by the political leadership has practical significance within the healthcare sector and is of academic relevance to the fields of political science, ethics and medicine. To fully comprehend this concept, we must understand the experiences and impressions of the decision-makers within the healthcare sector who play a critical role in equity policy formation. As a case study, this article aims to address the concept by asking how the political leadership in a Kenyan and a Swedish region define equity in cancer healthcare. The understanding is then positioned within the different settings, which provide diverse policy challenges to equity goals.

Reflecting on semi-structured interviews, focus groups and participant observations of politicians and high-level public servants within healthcare, the article contributes to the understanding of the concept of equity and on how shared reflection and inter-institutional learning can deepen this understanding among decision-makers. The article is based on data from an evaluation of a municipal partnership programme, focusing on a collaboration project between Uasin Gishu, Kenya, and Region Östergötland, Sweden, within cancer care.

The results indicate that the politicians and public servants in the different settings share a common understanding of the concept of equitable health as a needs-driven and fair healthcare system where factors such as

patients' place of residence, gender, age, economic status or minority affiliation are not the governing factors in the care they receive. Transparency and the prevention of corruption are also highlighted. However, although equitable health is considered a central concept it is not seen as a self-evident part of healthcare in the participants' regions today. The results problematise and show regional differences in how economic status, ethnicity and life situations can result in unfair access to cancer healthcare. The translation of equity into different policy settings which change over time remains a central challenge to both regional cases.

What can Prostate Health Activism Learn from Women's Health Activism?

Ericka Johnson, Professor, Department of Thematic Studies, Linköping University

This paper presents three areas where feminist health activism has made a difference for women's health, and some of the lessons this activism may be able to share with those concerned about prostate health. I will be discussing insights gathered while leading a medical humanities research project about the aging prostate, studying how prostate health is entangled with social understandings of men, masculinity, sexuality and aging. The first place for potential activism is in the approach to our material world and the normative design processes that help build it. I will discuss how a critique of the public toilet infrastructure informed by feminist movements, ability studies, and trans activism can also be useful for prostate patients. The second point is the epistemological critique brought forward by women's health collectives and activism to change regulatory regimes. The feminist epistemological critique challenged medical expertise by claiming that a patient's knowledge of their body was and is valuable; Questioned research materials and approaches by demanding that medical science include women's needs and desires; and demanded care that respects one's lifestyle, which that would allow women to use their bodies to live the way they want to, even after treatment. All three of these points could be inspiring to activists trying to reclaim and shape prostate health knowledge and treatments. Finally, I will also speak about the lessons learned from an intersectional approach – which recognizes the diversity of subjects impacted by prostate health – and the importance of acknowledging that 'man' is too broad a category to be useful analytically or for health activism.

What Can Medical Humanities Offer Future Pandemic Preparedness and Policy? A Modest Proposal

Anne Hudson Jones and Faith McLellan, University of Texas Medical Branch at Galveston. World Health Organization, Geneva

In the midst of the global coronavirus pandemic, the contributions of healthcare professionals and scientists have regularly been on view—in emergency rooms, intensive care units, and laboratories throughout the world. What medical humanities can offer public health efforts for future pandemic preparedness and policy is less visible but also of importance: historical memory and context; cultural awareness and sensitivity; narrative analysis and interpretation of the multitude of individual stories logged daily on social media and in blogs, online chats, and other virtual events. The ubiquity of these accounts means that we will likely never again be in a situation where pandemic stories are passed down only orally and in a limited way from one generation to the next. Instead, we will be facing an overwhelming amount of material related to this COVID-19 pandemic. How can we harness these views and perspectives of ordinary people and local communities to prepare better for the next pandemic? We argue that we must do so if we are to craft the best possible public pandemic preparedness and policies for the next such event. The local knowledge, and combined wisdom of those who have endured and recorded their personal experiences and thoughts in countries all over the world offer perspectives that public health and policy planners desperately need to develop better approaches for the next such event, whenever and wherever it might occur. Humanities scholars can bring their special knowledge and skills to help gather and analyze the stories that are already available from the coronavirus pandemic. We put forward our modest proposal that this conference, in collaboration with interested partners, launch a pilot project to establish a task force for this effort.

Mental Health Communication of Social Media Influencers Followed by Teenage Girls

Judith Lind and Anette Wickström, Department of Thematic Studies and CMHB, Linköping University

A majority of teenage girls in Sweden follow social media influencers, and a common topic in influencer content is how to feel good or what to do when you feel low. Thereby, influencers not only facilitate discussions of mental health issues but they also circulate and legitimise specific norms related to wellbeing and healthy living through the content they disseminate. Most influencers who post content related to mental health issues, as well as their followers, are female. As a result, they become important conversational agents and personal coaches for teenage girls' health management.

In preparation for this study we conducted group interviews with 44 girls in upper secondary school and asked them to name social media influencers, who they knew had posted mental health related content. From the list of social media influencers that were suggested to us, we selected two for our analysis, Therese Lindgren (TL) and Johanna Ottosson (JO). Both address mental health issues in their videos regularly. Both also have personal experiences of mental health problems and have claimed that they want to raise awareness about mental health problems. While TL was the pioneer influencer talking about mental health who eventually turned into a celebrity with her own brand and authorship, JO is younger, lives with her mother and has less followers. For our analysis we watched all videos published by TL and JO during 2021. Sections, in which mental health problems were addressed

– including accounts of personal experiences, advice, Q&A sessions on mental health etc. – were transcribed with notes of the visual content of the videos.

Several understandings of TL's and JO's videos on mental health issues are possible – they can be read as visual diaries that are published to an audience, as a form of health communication or awareness campaign or as part of a strategy to make a vlog commercially viable. These readings are not mutually exclusive. Rather, they serve as lenses, through which different facets of the mental health related content in TLs and JOs videos are made visible. Self-love and feel-good discourses figure alongside explicit and implicit acceptance of beauty norms, and the marketing of beauty products. Mental health advice to followers is combined with demonstrations and accounts of mental unwellness. In conclusion, this paper, by closely examining the fine-tuned balancing of intimate accounts of mental health problems, entertainment, information and sponsored content in TLs and JOs videos, sheds new light on the contradictions or tensions inherent in the mental health communication that can be found in influencers' videos.

Contradictions in The Provision Of Swedish Health Care - A Historical Perspective

Henrik Loodin, Department of Service Management and Service Studies, Lund University

Health care currently constitute one of the largest parts of the Scandinavian welfare system, with private as well as public providers competing on a quasi-market. In order to ensure an egalitarian and safe provision of health care health care services are governed by several laws and regulations. Previous research demonstrates that health care services is regulated by processes of decommodification and defamiliarization to ensure that the delivery of health care services and level of welfare should not be dependent on family bonds or determined by the market. But this body of research does not fully discuss the consequences of organizing health care on a quasi market.

The research aim in this paper is to examine the construction of the health care system in a historical perspective. To this end, a genealogy was conducted of government reports (SOU), laws and dominating management models organizing health care in Sweden from the beginning of the 1990s to the present.

The genealogy reveals that the structural reforms of the welfare sector in the past three decades in Sweden have meant that the implementation of management models in accordance with the terms of a quasi-market, turns the sector into a competing network of different actors. In conclusion, the paper argues that the Swedish health care sector functions as a stratifying institution that polarizes patients, not based on their need for care, but on their position in the competing network. In the end, the competition challenges the egalitarian principles of the Scandinavian welfare system.

Keywords: Health care services, quasi-market, Scandinavian welfare system, health management, genealogy

Norwegian Men's Perceptions of Artificial Intelligence (AI) Prostate Cancer Diagnostics

Emilie H. Lysø, Marit Solbjør & John-Arne Skolbekken, NTNU Trondheim

Prostate cancer is the most common type of cancer among men in Norway, with approximately 5,000 cases per year. Since the '90s, the number of prostate cancer cases has increased, whilst the mortality of the disease has decreased. Due to the challenges of overdiagnosing and overtreatment of prostate cancer, the field of radiology has met new needs to develop methods that more precisely separate benign and malignant tumors to prevent invasive procedures such as biopsies. Artificial Intelligence and machine learning in radiology have emerged as technologies that some could argue will revolutionize how we diagnose prostate cancer. Affecting both patients, physicians, and health systems, several ethical questions have been raised: Will AI replace radiologists? What will the doctor-patient relationship look like if we rely on AI to make decisions for us? Or do patients trust that the AI-assisted diagnose is correct? It is important to gain knowledge about how patients view and trust new technologies to understand the potential impact that AI could have in health care and to help develop AI systems that are responsible, trustworthy, and that reflect the challenges we face in health care today. However, little is known about how patients perceive such technologies for diagnosing prostate cancer.

Drawing on a qualitative study of men's perceptions of the use of AI in prostate cancer diagnostics and concepts from Science and Technology Studies (STS), this paper will explore how these new technologies could affect their understandings of prostate cancer diagnosis and trust. The empirical analysis will be based on 10 focus groups interviews with 49 men with an age range of 54-85 years. Seven groups included men with a history of prostate cancer diagnosis, whilst two of the groups had no history of prostate cancer, and the final group consisted of men who were put on active surveillance for prostate cancer. Participants were recruited from a prostate cancer patient association, a professional association of pensioners, and through a register of a larger research project on prostate cancer and Magnetic Resonance Imaging (MRI). Preliminary results from the interviews suggest that there is a lack of knowledge and understanding about what AI is and its purpose. Questions regarding diagnostic accuracy, possibilities of avoiding biopsies, and trust in both health care services, and the diagnosis came up during the interviews. Also, the human role in validating and communicating results was discussed.

Central Position of The Doctor in Patient-Centred Medicine: The Case of Nocebo

Andjelija Milic, University of Rostock

The nocebo effect is an unwanted occurrence in both practices of primary care and clinical trials. There is still not enough understanding how neural mechanisms trigger placebo or nocebo responses in different individuals, and what triggers them (Tu et al., 2018, etc.), but there has been some inquiry into the prevention of nocebo which doctors can influence (Howick, 2020). All this becomes even more important when we ask how much medicine is oriented towards the wellbeing of patients. Therefore, I will argue that putting the doctor in the focus of attention in the case of nocebo alleviation exhibits how even indirect addressing of side-effects mechanisms is a substantial promotion of the patient-centred paradigm in the long run.

The relationship between nocebo and focus points in medicine sheds light on another meaning in the spectrum of paternalism in this domain, showing that certain types of ignorance can cause nocebo which could have been averted. In clinical trials, there is fear that doctors' care can cause biases. In primary care, that is fear of lessening the autonomy of the patient. Doctors' over-restraint, or inadequate approach to reassuring the patient the side-effects are harmless and worth tolerating can lead to patients dropping out of the study, or refusing therapy. On the other hand, affect attunement has been accepted as a functional notion incorporating empathy as the crucial part of clinical procedures (Adler, 2007; Blasini et al., 2018). It directly influences triggering of positive or negative psychobiological mechanisms responsible for placebo or nocebo effect.

Parallel occurrence of these two phenomena shows inconsistency between understanding nocebo theoretically and addressing it practically. I will demonstrate this is due to medicine not being actively patient-centred, and that approaching it as such directly mends various negative occurrences in the following cases: According to the sum of reviews, the most common causes of nocebo are: 1) expectations, 2) conditioning, and 3) anticipatory anxiety. (Chamsi-Pasha et al., 2017): 1) Expectations usually present perceptions of increase or reduction of pain, or of overall improvement of health, but they are shown to be not necessarily and not primarily correlated with personality traits. (Corsie & Colloca, 2017) That is a ground where doctors' influence can be direct. 2) Conditioning, on the other hand, much like 3) anticipatory anxiety, does in major part depend on previous life and medical treatment experiences, but making the patient at least aware of those neuro-psychological mechanisms (Blasini et al., 2017, Benedetti, 2007., etc.) is what makes a big practical difference in relation to treatment or clinical trials. (Barsky, 2002; Evers et al., 2018).

In the narrower scope, the results of this paper will show the real possibilities for making medicine more patient-centred, starting from the case of nocebo. In the broader scope, the results will also have a bearing upon reassessing the notion of the "(expert) patient", for whose practical employment there still are many soft-skills obstacles. (Kaisler et al., 2021).

Philosophical Health? Personal Philosophies of Persons Living with Spinal Cord Injury

Dr Luis de Miranda, Uppsala University, Professor Richard Levi, Linköping University Hospital, RÖ and LiU, Dr Anestis Divanoglou, Department of Rehabilitation Medicine, RÖ

In this presentation we will discuss the methodological and theoretical framework of a pilot study with people living with spinal cord injury (SCI) in Sweden, as a partnership between Uppsala University and Linköping University Hospital (ethical approval Dnr 2021-04898). Clinical experience shows that paraplegic and tetraplegic people with similar objective functional limitations may show significant variation in their sense of general wellbeing, well-belonging or meaningfulness. If subjective factors play a role in the post-traumatic rehabilitation process, we wonder if the person's philosophical beliefs or conception of life help to overcome the personal and social challenges of a *dis-ability* condition, such that this new condition may appear, for example, as one of possible *expand-ability*.

Through in-depth dialogue (interpretative phenomenological analysis) with individuals with lived experience of SCI as well as with health professionals with expertise in SCI rehabilitation, and in partnership with the non-profit organization RG Aktiv Rehabilitering, we plan to collect, unveil and clarify philosophical stances, philosophical shifts or life conceptions associated with life with a SCI. Our results will, we hope, be relevant in contributing to a general discussion about the role of philosophical cognition in coping with such a disability. Philosophical cognition and its potential health effects is a much under-studied phenomenon, compared for example to creative cognition (how creativity impacts the mind) or religious cognition (how religious spirituality impacts the mind). Our general project is to explore philosophical health as a complement to physical and psychological health (https://philosophical.health).

If in the future we gain evidence that a given philosophical mindset, a conceptual constellation of meaning or any other form of philosophical cognition, can have an impact in expanding the domain of possibilities within a condition of disability, we might be able to contribute to enrich and improve the non-physical aspects of the rehabilitation process, usually more or less neglected.

Responsible Subject Positioning in Preconception Expanded Carrier Screening

Sofia Morberg Jämterud, Postdoc, Department of Thematic Studies & CMHB, Linköping University, Sweden

A preconception expanded carrier screening (PECS) test is a test a couple can take before trying to get pregnant to see whether both of them are carriers of the same autosomal recessive disease and therefore at risk of conceiving a child with that disease. Technological advancement has recently made possible PECS for many hundred genetic diseases in the general population, without previous indication, such as family history or belonging to a high-risk group (Holtkamp et al. 2017; Delatyckiet al. 2020). Since all humans are carriers of one or more hereditary diseases, all are at risk of passing on genetic disease to prospective children. Such knowledge –that one can be a carrier of genetic disease–can have reproductive implications.

The practice of PECS creates new questions of importance for ethical reflection, such as: which norms and values are connected to 'carriership' and what responsibility is placed on 'a carrier' in a moral sense? In this paper I will present my results from an empirical bioethical study where I have examined 'carriership' from the theoretical perspective of biomedicalization (Clarke et al, 2003). The empirical material consisted of semi-structured interviews with Dutch PECS test specialists.

Drawing on my results I will present descriptions of different forms of responsibility in relation to the PECS test, for example views on 'moral carriership'. Furthermore, I will unpack a discrepancy within the discussion on PECS, namely that on the one hand, PECS supports and enhances reproductive autonomy which is a free choice shielded from undue pressure, but on the other hand –at least to a certain extent–there is accusatory rhetoric vis-à-vis couples who would not choose to consider taking the PECS test. The latter position of inaction is accompanied with ideas of irresponsibility (Monteleone, 2020), and is framed in the context of a presumed notion that the couple could have prevented suffering.

This research is part of the research programme 'A Feminist Approach to Medical Screening', funded by the Swedish Research Council.

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Race in Clinical Trials: Testing the Limits of a Post-Racial Sweden

Shai Mulinari Lund University and Anna Bredström, REMESO and CMHB, Linköping University

The post-racial liberal ideology of many Western countries proclaims the insignificance of race and a society beyond racism. Critical scholars have revealed its falsity and showed that race persists in new disguises, albeit often below the surface. This paper problematizes the central narrative that race as a concept and category has been abolished from official, public, and academic discourses. We do this by analyzing the routine registering of patient race in clinical trials in Sweden, an example of a self-proclaimed post-racial country. We explain how international regulatory and medical standards used by pharmaceutical companies, regulators, and doctors direct the categorization of patients by race and how this standardized use travels to Sweden. We argue that the disjunction between post-racial ideology and medicine's racialist practice has implications for social science debates about race and, based on our evidence, we suggest that the critique of the post-racial ideology should be further developed to grasp the emergence of a new reality where a biological race concept can figure in the midst of an official denial of its existence.

Complexities Matter – Some Thoughts about How to Handle the Diversity of Existing Understandings of Health

Pelle Pelters, Stockholm University

What is health? The answer to that question appears to be extremely complicated, turning the achievement of a comprehensive, general answer into an at least very brave, if not impossible aspiration.

There are the proponents of medical philosophy like Boorse, Nordenfelt, Svenaeus, Brülde etc. who negotiate the best theoretical approach to describe health. Then there are the behavioural theories in health psychology like the health belief model, the transtheoretical model or the theory of planned behaviour which try to provide insights into what affects and creates people's health-related behaviours in order to bring those people's behaviours into line with the aim of promoting (a certain kind of) health. That health often turns out to be of physical or physiological nature but might also refer to a different dimension, e.g. mental, social, spiritual/existential etc., even here revealing a multitude of perspectives. And then of course, the so-called 'lay persons' themselves interpret health in a variety of ways, including (but not limited to) health as absence, balance or resource for living. Not to mention that different concepts may be appealing to people at different points in time and in different social context…

In a time, in which conceptual diversity is easily accessible through a variety of media sources and communicative opportunities for attitude exchanges, it appears to be unrealistic to expect everybody to adopt a single understanding of health. Hence, instead of trying to find the one suitable and all-encompassing theory or model of health, I argue for adding a focus on investigating possibilities for an acceptable ‘variety management’ or, if you will, a meta-theory of health for practical (and pragmatic) use in the ‘health system’ (in a broad sense). As someone educating and researching within the field of health education, a field in which medical, educational and sociological (and assumingly some more) understandings meet, I would like to start that investigation by discussing the usefulness of three approaches in my paper: the concept of complexity (using Osbergs, Biestas and Chilliers’ thoughts [2008] as point of departure), the notion of orientation (based on Ahmed, 2006) and the psychological construct of ‘ambiguity tolerance’ (see e.g. Yurtsever, 2000 or Valutis, 2015).

Translating Informed Consent in Maternity Services

Jenny Patterson (Edinburgh Napier University) and Şebnem Susam-Saraeva, University of Edinburgh

The paper will report on the preliminary findings of an ongoing RSE-funded project on informed consent during pregnancy, labour and birth in the case of parents with limited English-proficiency (LEP) in Scotland (e.g. refugees and asylum seekers who have recently arrived at the country).

Background: It is often difficult for LEP parents to access adequate information in their own languages during perinatal care and this greatly contributes to poor maternal outcomes. Informed consent is integral to maternity care. No care, action or intervention should be provided during labour, birth or the postnatal period without explicit consent from the pregnant person or parents (limited exceptions exist in extreme emergency situations or where there is limited capacity). Pregnant or birthing people are regularly required to provide either verbal or written consent throughout their maternity care. The informed aspect of consent is key in this study. For birthing people or parents with LEP, giving consent without full understanding of the English medical language can be a significant issue, especially when the decisions taken have far-reaching consequences for the health of the mother and the baby. Evidence shows that perinatal outcomes for women and birthing people from minority ethnic backgrounds are much poorer than for those from white backgrounds.

Objective: The main objective is to understand the issues surrounding informed consent when engaging with birthing people or parents with LEP from an interdisciplinary perspective of midwifery and translation & interpreting studies. By bringing together the perspectives of different people who support and look after birthing people, this project hopes to encourage inter-disciplinary and cross-professional conversations, which are currently limited in practice due to time restrictions and sometimes poorly perceived expectations and prejudices.

Participants and methodology: This project brings together diverse participants: midwifery and translation studies researchers; healthcare providers; and interpreters. Data will be collected through expert focus groups and interactive workshops. Conversations will be audio recorded and transcribed verbatim. Qualitative methods including Framework Analysis will be used to analyse the data and identify key themes that arise.

Results and discussion: The results will help us to understand the multidisciplinary factors that help or hinder language barriers so that care provision can be improved for birthing women, people or parents with LEP, in particular with regard to giving information about their own wellbeing or needs, understanding the information provided, and providing consent. We hope this improves maternal outcomes in these populations.

Robotic Cats in Triad Action: A Qualitative Study of Meaning-Making Practices between Humans and Robots on Dementia Care

Marcus Persson, Linköping University, David Redmalm, Mälardalen University and Clara Iversen, Uppsala University

Research on robots in care settings has been criticized for being either technophobic or technophilic. While some researchers raise ethical questions regarding the risk that the introduction of robots in care settings may increase older people's social isolation and entail a dehumanization of patients, others argue that robots can play social, assistive, or therapeutic roles by interacting with individuals who face difficulties in maintaining social relationships. The sole focus on the dyadic patient-robot relation contributes to this binary view on robots by excluding a key part of the relation: the caregiver. The aim of this paper is therefore to study meaning-making practices when using robots in dementia care by examine the verbal and corporeal interaction between caregivers, residents, and robots.

We understand the social order into which humans are integrated and which is, at the same time, a product of human activity. Technical artifacts must be treated not only as engineering constructions but also as social constructions, and social formations must be examined in the context of the technical relations that stabilize them. Our research in this regard focuses on the process of action—that is, the performance of the deployment of social robotics. Technical artifacts are "objects in action" that require interpretation.

Based on qualitative field work conducted at four dementia care facilities in Sweden, the data consists of transcripts from 35 semi-structured interviews with caregivers and observational field notes from over 20 visits. All the participating facilities use the same robot model – a robotic cat developed by Hasbro. This robot mimics a real cat with pressure sensors under the fur which makes it react to touch. When patted, the robot can move its upper body, head, and a paw, as well as give off purring and mewing sounds.

The findings account for the detailed interaction between caregivers, residents, and robots, focusing on sequences of physical and verbal actions. These sequences of actions are categorized according to recurrent patterns of interaction, which forms specific practices, and analyzed in relation to the theoretical approach. The identified physical practices are: Strategic positioning, activation in passing, holding, and patting; and the verbal practices are: Creating the unexpected, confirmation, and nicknaming. We will empirically account for each practice, but also discuss the importance of interplay of different practices. Depending on how the caregivers act upon these practices, and on how the resident is responding, will guide the outcome of the interaction.

Empirically, the study generates knowledge about how robots are acted upon by caregivers and residents in dementia care and contributes with concrete practices of how to create meaningful interactions. The paper will also provide a theoretical contribution of how meaning is created through action, and attributed to, the triadic relationships between users and robots in a dementia care context. The significance of the caregiver's role in the triad to create a meaningful interaction is unique in dementia care, due to the cognitive impairment of the residents, and is discussed in the end of the paper.

Practices of Sedation: Doing Palliative Care in a Hospital Ward

Julia Rehsmann and Eva Soom Ammann, Bern University of Applied Science, Department of Health Professions

Palliative Care historically emerged from the hospice movement. One of its main claims is to alleviate suffering at the end-of-life. Following hospice pioneer Cicely Saunders' terminology, Palliative Care is striving to ease 'total pain' with 'total care'. As a countermovement to high-performance curative medical care in hospitals, Palliative Care has developed considerable expertise regarding end-of-life care. As a health care specialty, Palliative Care is currently on its move back to the mainstream healthcare system, in Switzerland exemplified by the establishment of specialized units in hospitals.

As part of an interdisciplinary research project, Settings of Dying (sterbesettings.ch, 2020 – 2023), we are currently exploring end-of-life care in one of these units in a city hospital in Switzerland. The project is driven by a design perspective, focusing on how dying emerges as a socially constructed phenomenon at the intersection of practices, material things and narratives in the setting of Palliative Care. Our perspective in this project is focusing on nursing care practices, and we are exploring this perspective with a 'classical' ethnographic strategy of long-term participant observation.

One of the issues emerging from participant observation is the practice of alleviating suffering by sedation and its symbolic and interpretative meanings. The object of the analgesia pump will be at the centre of this presentation. Field observations and ethnographic talks around the use of analgesia and sedative substance pumps will be discussed to sketch interconnections between everyday practices on the ward and Palliative Care narratives stressing e.g. self-determination of the dying or alleviation of pain and suffering as a field of professional expertise.

The ‘proper’ use of analgesic (e.g. morphine) and sedative substances is one of the key fields of expertise in Palliative Care, but also one of its most controversial topics due to its closeness to euthanasia. Analgesic and sedative substances are applied for pain management, to ease respiratory distress, and to achieve continuous deep sedation until death. A central technology in practices of sedation in the clinical setting of Specialized Palliative Care is the pump, which allows for machine-controlled dosage and administration of analgesia and sedative substances. Pumps allow not only for handing over control from professionals to technology, but for strengthening the agency of patients, as the mainstream technical term for this device, the PCA Patient Controlled Analgesia pump, indicates. Handing over the control from the professional to the patient, at least to some degree, however, is a tricky thing in Palliative Care since patients usually lose (or: withdraw from) some of their capacities to act as a self-determined subject at the end-of-life. Moreover, the interpretation of when and how much pain must be alleviated to which degree needs to be negotiated between various actors involved in patients’ care – the patients themselves, their relatives as well as various professionals on the ward. Therefore, pumps allow for a sophisticated management of agencies. For us, they seem to be a fruitful point of departure for an exploration at the nexus of health care practices, medical technologies, and moral implications of agency.

Channelling the Voice of the Patient: Using Qualitative Research Methodology to Explore the Subjectivity of Freud's Patient Anna Von Lieben

Hilda Reilly, Glasgow University

This project is inspired by the work of Roy Porter (1985), who draws attention to a patient-shaped gap in medical history, and Rita Charon (2006), who emphasises the need to bring the patient's narrative to the fore in the practice of medicine. The principal aim was to devise a means of accessing the lived experience of a patient who is no longer alive in order to gain an understanding of her narrative. Anna von Lieben was identified as a suitable subject as she wrote a substantial quantity of autopathographical poetry suitable for analysis and her status as Freud's patient makes her a person of significant interest to the history of medicine.

The poems, previously not in the public domain, were analysed using Interpretative Phenomenological Analysis (IPA), an idiographic and inductive qualitative research method, based on Heideggerian hermeneutic phenomenology and committed to illuminating first-person experience. It combines a hermeneutics of empathy with a hermeneutics of questioning to interpret a text in its own terms rather than by applying an existing analytical framework (eg, psychoanalytic, feminist) imported from outside.

The main findings of the IPA study reveal that Anna suffered a long period of ill-health, starting in adolescence. The discovery of additional family documentation, in particular her husband's diaries and family correspondence, enabled me to contextualise and add substance to those findings. I then identify a number of comorbidities and show how those could be responsible for much of the symptomatology identified by Freud as 'hysteria' On this basis, and using a process of Bayesian reasoning, I outline a fourfold set of hypotheses as a more plausible explanation of Anna's condition.

The project overall highlights the way in which qualitative research methods in combination with historical methods can contribute to the furtherance of narrative medicine and, in this case, restore the dignity of a victim of epistemic injustice. Moreover, as it presents a three-stranded account of the illness and treatment of one of Freud's patients, combining and contrasting the narratives of the patient herself, her husband, and Freud. the study is likely to be the first of its kind.

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Scenes of Shame and Stigma during COVID-19

Arthur Rose and Luna Dolezal, University of Exeter

Shame and stigma have been prominent features of the COVID-19 pandemic. Stigma, in particular, has been identified as an urgent issue related to COVID-19 by health organizations worldwide, including Public Health England, the CDC and the WHO. Both stigma and shame negatively impact on health seeking behaviours, cause personal and social harm, and exacerbate existing social and health inequalities. The first months of the COVID-19 crisis demonstrated that instances of shame, shaming, stigma and discrimination are related to, and often arise from, public health interventions (e.g., the "Lepers of Leicester" resulting from the UK's first local lockdown or the on-going shaming of individuals for the use/non-use of face masks). This is of particular concern when considering the uneven distribution of social power, resources and health for Black, Asian and Ethnic Minority communities in the UK and the US who are disproportionately impacted by COVID-19, and how these inequalities are, in turn, intimately related to experiences of stigma and shame.

In this presentation, we establish four sites or "scenes" where shame and stigma came to be "weaponised" during the first 12 months of the COVID-19 pandemic: the domestic, the medical, the political and the social. We argue that distinct forms of shame and stigma erupted in each scene, which constitutes their differentiation. But, we conclude, it is precisely insofar that each scene fed into the others that makes the consideration of shame and stigma so essential to public health responses.

Intersecting Social Determinants in Sexual and Reproductive Health and Rights (SRHR) among Young People

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Malin Lindroth, Malmö University

Introduction: Gender is the primary social determinant used in today's sexual and reproductive health and rights (SRHR) policies to explain vulnerability in relation to SRHR among young people. Using intersectionality theory and methodologies, we aim to explore how gender interacts with other social determinants and impacts vulnerable positions and health outcomes among young people (16-29) in the area or SRHR.

Methods: The data comes from a population based, cross-sectional SRHR study conducted in Sweden in 2015. The total population aged 16-29 were included in the sampling frame. 29,997 young people were selected, and 7,755 responded (response rate 26 %), which was consistent with the power estimates. Social stratification was used to explore the material in a stepwise intersecting inequality configuration. Sexual identity, transgender experience, perceived economy, being foreign-born, and having received social aid were predictor variables. Outcome variables were unsafe sex ex against one's will and transactional sex.

Results: We found that gender interacts with other social determinant variables in the generation of vulnerable position. Such positions for females can be found at the intersections of being female, bisexual, or a social welfare recipient. The intersection of being male, homosexual, or bisexual or having transgender experience exposes males to vulnerability.

Conclusions and Implications for Policy: In respect to SRHR, gender mainstreaming policy must be supplemented by an intersecting awareness how vulnerable positions are formed. In doing so, policy can guide practice addressing vulnerable positions among women and men by identifying the intersections of sexual minorities and transgendered people, and social assistance recipients.

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Capturing Epidemics: Making Sense of The World through *Fixture* in Medical Science, Historical Collections, and Photography

Helene Scott-Fordsmand, University of Cambridge

This paper will take point of departure in the exhibition "Capturing epidemics" (11.2020-05.2021, Copenhagen) displayed at *Medical Museion*, a university museum in Denmark, at the end of the first year of the Covid-19 pandemic. The exhibition was a response to the on-going pandemic; to the loss of control and the societal bewilderment by experts that didn't yet have answers, and the public awareness of the complexity of health and disease management that societal measures brought with it. The exhibition was the result of a collaboration between artists, historians, philosophers, and conservators. It contained photographs of medical objects from the museum collection and displayed moments in medical history where scientists had found themselves in similar struggles: attempting to make sense of complex and overwhelming realities in moments when epidemic disease raised havoc and challenged the limits of their knowledge.

While the exhibition is itself an example of an interdisciplinary project, and of ways in which medical work was translated into various layers and disciplinary elements of a cultural project, the paper will also address the conference topic by using the exhibition as an occasion to reflect on the challenge of working with complex and contentiously unfolding health issues – such as the pandemic.

In a three-layer parallel, the exhibition revealed a shared strategy for making sense of a chaotic situation between medical science, historical collections, and photography: *fixture*. In the face of new territory, medical science 'captures' bacteria, tissue, infection rates, or even people. Museums dig into collections, and try to capture histories – in this case, histories of medicine – by storing objects that encapsulate the epidemic moment. And finally, photographs freeze moments in time, so that we will not forget – famously 'capturing' their subject. In all these examples, *fixture* – I will argue – is a response to a dilemma between openness and focus, inquiry and manipulation. Drawing lessons from the exhibition, I will show how this strategy is similar across the disciplines; reflect upon the variations of it; and more broadly discuss how the need for *fixture* may be a decisive element in establishing interdisciplinary collaborations around unsettled health questions.

The Particular Sadness of Lemon Cake: Mirror-Touch Synaesthesia Between Magical Realism and Neuroscience

Nadine Sigalov, University of Glasgow

The importance of cross-fertilisation between literature and neuroscience has been unequivocally highlighted in recent years. For example, Paul Armstrong elucidates various processes related to reading, text interpretation and intersubjectivity, and relates them to brain research, emphasizing the importance of going back and forth between the discourses and opting for an explanatory interaction between these two fields. Synaesthesia – a neurological condition in which stimulation of one sensory modality (for example vision) automatically triggers a perception in a second modality (for example audition) in the absence of any direct stimulation to this second modality, resulting in a union or mixing of senses – has both been extensively studied in the neuroscientific context and widely explored in literature.

A particular type of synaesthesia I shall focus on is mirror-touch synaesthesia in which the observation or imagination of somatosensory stimulation (notably touch or pain) in another person or object can induce similar somatosensory experience in oneself, thus obfuscating the boundaries between self and other. I will propose that mirror-touch synaesthesia on the one hand, and autistic spectrum disorders on the other, can offer illuminating interpretive frameworks to read Aimee Bender's novel The Particular Sadness of Lemon Cake (2010), while the reading of the novel can elucidate ongoing scientific debates regarding central issues involving these neuroatypical phenomena. Specifically, the novel can shed light on an ongoing debate regarding the relationship between mirror-touch synaesthesia and empathy. Currently, two opposing groups of scientists insist on two contrasting views of this relationship: while one claims this condition is related to increased emotional empathy to others and better ability to read facial expression of emotion, the other asserts instead that mirror-touch synesthetes have reduced aptitude for social situations and empathy, scoring higher on a standardized test measuring autistic traits. I shall show that Lemon Cake may elucidate this scientific disagreement and offer a complex, non-binary solution to the question.

Another relevant and related framework I shall employ focuses on finding and implementing embodied ways of communicating with others and one's physical surroundings in an attempt to bridge the gap between self and the world. Like synaesthesia, embodiment can be seen as the middleman between the humanities and sciences, as the focus on materiality and bodily experience has lately permeated both disciplines. Lemon Cake explores the themes of isolation and alienation, on the one hand, and their opposite – interconnectedness, reciprocity and intersubjectivity – on the other, through the characters' relationships with others and the physical world around them, with objects often serving as potential intermediaries in the relationships between people. Neuroscientific findings involving embodiment will help illuminate these themes and shed a light on their relationship with mirror-touch synaesthesia and autism.

Another facet of the literature-neuroscience relationship will be inspected through the apparently magical elements in Bender's novel, which are, as I shall show, in fact grounded on neuroscientific and neurological principles which are extended, expanded, and, many times, taken to an extreme.

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Norwegian Men's Views on PSA Screening for Prostate Cancer

Marit Solbjør, Emilie H. Lysø and John-Arne Skolbekken, NTNU

Few countries have recommended population-based screening for prostate cancer with prostate specific antigen (PSA), but the PSA-test is used extensively among men who are having it done as a blood test at their GPs. PSA screening has long been contested among professionals, not only to its lack of proven effect on mortality but to whether or not the benefit from early diagnosis outruns the negative side-effects of screening. Due to the test's low specificity, a high number of men participating in such testing would need follow up examinations, and potentially have a cancer diagnosis and treatment for a cancer that would not cause death. Unnecessary examinations include biopsies which might cause infections and sepsis, the cancer diagnosis might cause worries and anxiety, and treatment often cause incontinence and impotence. A meta-synthesis found that men's sense of masculinity diminished after being treated for prostate cancer, with impotence, incontinence, and physical changes causing stress (Alexis, 2018). Men might be reluctant to participate in PSA screening if they fear loosing their masculinity (James et al, 2017). Nevertheless, the Norwegian Prostate Cancer Association is campaigning for a population program for PSA-screening. Different norms and sociocultural assumptions about bodies, sex, and gender might contribute to how men understand prostate cancer and PSA testing. In this paper we will investigate Norwegian men's views on PSA screening.

Our data material comprises 10 focus group interviews with a total of 49 men aged 54-85 years old. In seven of the groups the men had been diagnosed with prostate cancer. One group comprised men who were under active surveillance for prostate cancer, while two groups consisted of men who had no prior experience with prostate cancer. Participants were recruited through a hospital register; from a cancer patient association; and from an association of retired professionals.

Preliminary results suggest that most of these men had a PSA test on their own initiative. Some had been offered a test at their GPs', while others had insisted on have the test despite their GPs' reluctance. The men varied in their knowledge on the contestedness of PSA screening. Many men with prostate cancer were eager to have a screening program for prostate cancer, while those without prostate cancer were more reluctant towards the benefit of such examinations. Loss of masculinity caused ambivalence but were seen as a small price to pay for saving lives. For many, it was difficult to see that a small blood test could cause any harm, and they focused on the nature of the examination rather than on negative side-effects from cancer diagnostics or treatment. Our data suggest that men experience ambivalence towards prostate testing. We will discuss if views on PSA screening relates to the prostate being a part of the body that is important for masculinity while being invisible in public discourses - both at macro and micro levels.

The Phenomenology of Objectification in and Through Medical Practice and Technology Development

Fredrik Svenaeus, Södertörn University

A major issue for phenomenological analyses in the areas of medicine and bioethics has been the danger of objectifying the patient in the medical encounter by viewing and handling her mainly or merely as a physical body to be scientifically investigated. The patient is not only a bodily specimen of a disease to be diagnosed and treated, but first and foremost an ill person to be listened to and helped. According to phenomenologists, the increasing number of different forms of medical objectification in and outside the clinic entrenches risks regarding bodily alienation. The body becomes a foreign territory rather than the patient's home ground by way of such objectifications, a development which was inaugurated already with the birth of modern medicine and what Michel Foucault famously dubbed "the medical gaze". The making visible of the insides of living human bodies was made possible towards the end of the 19th century with technologies such as endoscopy and x-rays. These were used not only in medical practice but also outside the clinic, generating feelings of surprise, astonishment, and horror among the public. The distribution and application of various forms of medical technology outside the walls of the hospital has continued to this day, including developments such as the quantified-self movement.

Objectification is no doubt a real problem in medicine and it can lead to bad medical practice or, in the worst case, dehumanization of the patient if not enveloped by a personalistic attitude. Nevertheless, objectification also plays a major and necessary role in medicine, the patient's body should be viewed as a (malfunctioning) biological organism in order to find diseases and be able to cure them. The listening to the patient's illness story should not be replaced, but, indeed, developed by the physical examination of her body searching for the causes of her complaints. Whereas phenomenologists have so far been keen on identifying the negative aspects of objectification in medicine, a more balanced strategy might be to discuss and analyze differences between medical objectifications that make the patient feel like being merely a body and the objectifications that do not deprive the patient of her subjectivity. This is what I intend to do in this paper. "Bad objectification" makes the patient feel like being a body instead of being a person, while "good objectification" makes the patient feel like a body but not in a way that is detrimental for her personhood. In some cases, which I will come back to, such good forms of objectification can even make the patient feel more at home with herself by incorporating a richer understanding of what goes on in the body.

Striking Balance: Art and Biotechnology on Aesthetic Plastic Surgery

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Since the early twentieth century, the field of plastic surgery has been strongly associated with art and aesthetics. Several past and practicing plastic surgeons have demonstrated the parallel between painting, sculpture, photography, and drawing, amongst others, with the demonstrated ability to understand and create form, proportion, and beauty. Furthemore, many plastic surgery residency programs have incorporated art lessons into their curriculums. Simultaneously, novel frontiers in biotechnology, including machine learning, artificial intelligence, and big data, among other modalities, have offered significant contributions to the practice of aesthetic plastic surgery. In particular, artificial intelligence has been proven to be effective in identifying surgical markers, guiding preoperative and intraoperative procedures, and generating 3-dimensional renderings to predict post-operative outcomes.

It is currently believed that biotechnologies will continue to advance and soon have the ability to evaluate aesthetic beauty with patient-guided inputs. In other words, technologies may soon enable patients as aesthetic designers, placing significant emphasis on patient perception and self-image. As advancements continue, the underlying foundation and principles of art, including its inherent subjectivity, may be compromised into an algorithm –consistently accumulating inputs at the sake of generating unique, averaged outputs.

Therefore, the primary goal of this paper is to evaluate the ethical potential of current biotechnologies and their impact on historically understood artistic principles that have guided aesthetic plastic surgery. Secondly, this paper will suggest how to reach an ethically sound balance between artistic principles and biotechnologies in efforts to best achieve desired patient outcomes.

Childbirth against the Norm. Recent Swedish Media Debates about the Freedom to Choose to Give Birth at Home or by Caesarean Section

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The shortcomings of maternity care in Sweden have been highly debated during the last decade. For example, the deficiencies in treating maternal birth injuries have been discussed in the media by affected women and health professionals working with maternity care and gynaecology. Midwifes have debated their dreadful working conditions, and some have quit their jobs as an action against the working conditions. Some midwives and pregnant women have also raised their voices for the right to give birth at home. At the same time, the proportion of women who want to have a caesarean section without a medical reason has increased. We think the debates and changes in preferred mode of birth are connected.

Childbirth, no matter of the mode, is paradoxical in its position as being both private and public as well as naturalized and medicalized. Different discourses are becoming visible in the debates about women's choice to give birth at home or to give birth via caesarean section without medical reason. Women's right to the freedom to choose how to give birth to their children clashes against, or are aligned with, medical professional's authority to decide what is best. The norm in Sweden for giving birth, vaginally at a hospital, also becomes visible as a discourse that other ways of giving birth is measured against.

The aim of this paper is to analyse how the argumentation about the right to choose to give birth at home or by caesarean section is debated in the Swedish media during the years 2017-2021. The material is analysed in relation to gender, professional standpoints, and medicalization versus naturalization. Questions that are explored in the material are how arguments about the different modes of childbirth are constructed, and how the arguments are connected to different positions, such as being a medical doctor, a midwife or the one giving birth.

Translation Into Biomedical Research: From Bedside to Bench

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Translational medicine came to the fore in the 1990's under the buzz-word bench-to-bedside. The movement promotes close collaboration between biomedical research and the clinic with the aim of improving prevention, diagnosis, and therapies for diseases. The movement acknowledges a gap between the epistemic aims and practices of biomedical research and clinical practice: That medical research is often concerned with specific hypothesis and seeking to understand general causal connections, and that clinical medicine is focused on treatment in practice and on individual patients. Translational medical set out to mediate between the two.

But while there has been much emphasis – as well as pressure from funders – on the translation from research to the clinic, much less attention is offered on the translation at the other end of biomedical research practice. How diagnoses and patients' bodies and experiences are translated into biomedical research.

The paper Translation into biomedical research will investigate practices at a large medical research center in metabolic disease particularly how patients' tissues and data are integrated into the research center, where they enter at the "unclean" section of the laboratories. How are the diagnoses of the patients translated into research categories and are the diagnoses questioned? The paper will be based on the initial findings from a collaboration between biomedical scientists and philosophers of medicine exploring how diagnostic categories are translated into and out of research.

Collaboration and Continuity in Women's Dementia Fiction in French

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The experience of Alzheimer's disease is gendered: women are not only more likely to experience dementia-related diseases directly – typically as a result of greater life expectancy – but they are also more likely to become the caregiver to someone with an age-related illness. Such gendered differences – particularly in advanced old age – are reflected in the works of contemporary authors who choose, in the majority, to present women as the experiencing subjects of Alzheimer's disease.

In this paper, I explore the consequences and representation of this gender divide in the novels of two contemporary French authors. In Anne Bragance's La reine nue (2003, The Naked Queen) and Caroline Vié's Dépendance Day (2015, Dependance Day), the experiences of the female protagonists affected by Alzheimer's disease are relayed and reconstructed by family members. Such 'scaffolding' (Hydén 2017) rejects the common assumption that persons with Alzheimer's disease lack a narrative self (Hyvärinen and Watanabe 2017) and challenges notions of selfhood as exclusively autobiographical. At the same time, this collaborative effort risks imbalanced assumptions about another's subjective experience that speaks to the gendered experience of disease more widely, to the alterity of the female voice and to its appropriation in times of pain and distress.

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Keywords: Alzheimer’s disease; gender; collaboration; narrative

Does Paying for Private Maternity Services Ensure Better Care? Comparing Rates of Medical Interventions During Childbirth Between Women who Did and Did Not Pay for Private Care

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The Polish maternity care is a complicated mix of private and public services. While most women give birth in public hospitals, many chose private prenatal care. In addition, over the last two decades some public hospitals started to offer private rooms or designated midwifery intrapartum care on a fee-for-service basis. Our previous research showed women access these services in order to establish personal relationships with healthcare providers to ensure "having someone on the ward" and in this way maximize their chances of getting more attentive and better care.

This paper reports on the research that follows up on the previous findings from a more medical approach and seeks to answer the explore the impact of accessing private services, particularly private prenatal care and designated intrapartum midwifery care on the medicalization of labour and birth. It is based on data collected through an online questionnaire from 10,249 women who had given birth in Poland in 2020 and 2021. Women who attended private prenatal care tended to have more medicalized birth, while women who paid for designated midwifery intrapartum care were more likely to have natural birth and fewer interventions. This shows that "having someone on the ward" indeed alters the care women receive and private services contribute to inequalities in access to quality care.

Claims in the Clinic: Tensions in Healthcare Communication about Side Effects of the Copper IUD

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A large share of health-related information is today sought and communicated via the internet, including in social media. Questions have been raised about how this may affect health perceptions and behaviors, not least by enabling the communication of claims that contradict information from established medical authorities. As an example, knowledge claims about systemic side effects of the contraceptive copper intrauterine device (IUD) have in recent years been circulating in social media. This widely used long-acting contraceptive method is here linked to a range of physical and psychological symptoms believed to be caused by an excess of copper. A Swedish Facebook group centered on this issue currently gathers around 8.500 members. Based on seven online focus groups with women recruited from this Facebook group, and six online focus groups with mid-wives and gynecologists, this paper explores how tensions between alternative and established claims about the copper IUD are expressed and negotiated in and between these groups. While gaining medical support in order to get well is a central concern to women with health issues believed to be related to the copper IUD, many report not only being unable to access help from, but not being taken seriously by, healthcare professionals. Healthcare providers, on the other hand, describe balancing between following guidelines or protocols and caring for or listening to the individual patient. We discuss such

tensions and processes of negotiating between sources of knowledge and uncertainty described by participants from both groups.