Panels, abstracts, and bios

Illness Narrative Retold – Diversity, Temporality, and Digitization

Venue: Aarhus University, Conference Center, Fredrik Nielsens Vej 4, 8000 Aarhus C
Web and contact: https://conferences.au.dk/illness-narrative-retold

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KEYNOTE SPEAKERS

All in room: 1427-246-M2

"Illness Narrative in the Age of Generative AI: Rescripting the Clinical Encounter"

Angela Woods, Professor, Durham University

Abstract: Ten years ago, in introducing *The Edinburgh Companion to the Critical Medical Humanities*, Anne Whitehead and I described the primal scene of the medical humanities as one in which the diagnosis of cancer unfolds in the clinical encounter between doctor and patient. "First-wave" medical humanities, we observed, returned again and again to this scene to show the field's value in exploring the interpersonal, hermeneutic, affective, narrative and ethical dimensions of clinical care and of illness experience. Our call to scholars of the critical medical humanities was not to look away from the clinical encounter, but to attend to "what is potentially occluded from view – both within the scene itself and in relation to other sites and modes of inquiry."
In this paper, I return to that scene to ask how it is being reconfigured in 2026 by the presence of generative AI. I focus on two distinct deployments of large language models: "ambient scribes" that transcribe and summarise clinical interactions, and AI agents (chatbots) engaged by people in everyday contexts of illness and distress. Both are frequently described in restorative terms: technologies that give time back to clinicians, restore attention to the patient, or enable patients to recover narrative aspects of what illness has taken away.

This paper interrogates the logic of restitution that structures approaches to ambient scribes across public discourse and clinical literature, and that also underpins claims that AI agents can restore the ill person's narrative agency, cogency and value. Framing generative AI in terms of restitution serves to naturalise and domesticate these tools and to obscure their function in rescripting illness experience. Ranging from barely perceptible to markedly interventionist to outright hallucinatory, this rescripting of experience raises urgent questions the critical medical humanities is well-placed to address. How should we understand testimony, empathy and voice in the context of algorithmic bias and sycophancy? What happens to illness narrative when its retelling is partially automated, optimised and, at times, hallucinated?

Generative AI does not simply introduce new tools for narrating illness, but new conditions under which narrative is produced, authorised and circulated. "Retelling," in this context, names a process of rescripting in which human and machine agencies are entangled, reshaping the contours of the clinical encounter itself.

Bio: Woods is Professor and medical humanities researcher with research interests and expertise spanning three linked areas: the interplay between clinical, experiential and cultural-theoretical accounts of voice-hearing and psychosis; narrative and its role in understanding health; and the dynamics of interdisciplinary and collaborative research. She is the Director of Durham's Institute for Medical Humanities and the Director of the Discovery Research Platform for Medical Humanities, funded by the Wellcome Trust (2023-2030). From 2012-2022 she was Co-Director of Hearing the Voice, a decade-long interdisciplinary study of voice-hearing also funded by the Wellcome Trust.

Chair: Carsten Stage

"Metagnosis: Illness Narratives and Knowledges Retold"

Danielle Spencer, Senior Lecturer, Columbia University

Abstract: *Metagnosis* is experience of learning in adulthood of a longstanding condition. It can occur when the condition has remained undetected—such as realizing that one is colorblind—and also when the diagnostic categories themselves have shifted, as with ADHD and autism. It can also accompany surprising genetic test results pertaining to health as well as identity. Though this phenomenon has received relatively scant attention, learning of an unknown condition is often a significant and bewildering revelation.

Moreover, this experience invites *illness narratives retold*, as it can require a revised personal narrative, and also tends to subvert customary scripts and expectations. For beyond the specific new diagnostic information, the precipitative and retrospective aspects of metagnosis often unsettle the very terms of knowledge, opening towards shifting understandings of normalcy, disease, disability, and identity. These experiences also invite different "readings" and open towards multiple possible narrative outcomes. I propose that such narrative awareness promises greater empowerment in healthcare and beyond.

I will begin with a brief account of my own experiences with metagnosis, first working with musician David Byrne when he self-diagnosed with Asperger syndrome in the early 2000s, and then learning of my own longstanding undetected visual field defect, and bring into conversation with others' experiences. I explore the ways in which these revelations challenge expected illness narrative scripts and categories, and draw connections to literature and film, from Oedipus to Blade Runner. Finally, I will discuss the the current evolution of this project (conducted in collaboration with Allison Coffelt) and share excerpts from oral history interviews reflecting a diverse range of metagnostic experiences—from prosopagnosia (face-blindness) to asexuality, severely deficient autobiographical memory and beyond. These stories open towards quite existential dimensions, demonstrating the depth and complexity of illness narratives re-told.

Bio: Spencer, Ph.D., is a faculty member in the Columbia University Narrative Medicine Graduate Program. Author of *Metagnosis: Revelatory Narratives of Health and Identity* (Oxford University Press, 2021) and co-author of Perkins-Prize-winning *The Principles and Practice of Narrative Medicine* (OUP, 2017), her scholarly and creative work appears in diverse outlets, from *The Lancet* to *Ploughshares*. Spencer's research interests include retrospective diagnosis, narrative ethics, and illness narratives. She is the Editor of the Anthem Studies in Narrative and Health Humanities book series, an Associate Editor of *Literature and Medicine*. www.daniellespencer.com

Chair: Ann-Katrine Schmidt Nielsen

"Social Media of Health and Illness: Platform, Narratives and Values"

Stefania Vicari, Professor, Loughborough University

Abstract: While "health creator" is now a common term across academic work, public parlance and global health policy (e.g., WHO, 2026), as a label it directs our attention away from matters of ill health (e.g., suffering, diagnosis, recovery), overlooking the work of those who share their lived experience of illness on social media. In this talk, I will focus on these users, arguing for the importance of investigating their practices through the lens of contemporary attention economies. Social media users who create content about their ill health share personal information that can be both powerful and stigmatising. This content includes high degrees of self-exposure that is usually meant to produce positive outcomes, like that of educating and supporting others. Self-exposure, however, also makes the authors of this content vulnerable to normative commentary, which can translate into cultural narratives of ableism, regimes of shame and gendered notions of sexuality, responsibility, physical attractiveness and body propriety. This, along with the affective dimension of social media communication, leads these users to experience social media platforms as technologies of hope and despair. I argue that underlying these intertwined dynamics of "beauty" and "ugliness" is a tension between the (progressive) politics of experience and the (platformed) commodification of illness narratives. In this talk, I will draw on my work on social media narratives of hereditary cancer to unpack this tension and discuss how those sharing first-person accounts of ill health develop - or redevelop - relationships and values within existing attention economies.

Bio: Stefania Vicari is Professor in Digital Media and Society at Loughborough University. Her work investigates social media practices and their intersections with advocacy, activism and lived experiences of health and illness. Her research has been funded by the British Academy (2012), Wellcome Trust (2013; 2016), Leverhulme Trust (2022) and UK Research and Innovation (2018, 2025). She is an Associate Editor of *Information, Communication & Society* and the author of *Digital Media and Participatory Cultures of Health and Illness* (Routledge, 2021).

Chair: Ann-Katrine Schmidt Nielsen

“Narrative Wreckage and Redemption: Selves, their Stories, and Typologies”

Arthur Frank, Professor Emeritus, University of Calgary

Abstract: Narrative wreckage occurs when people find themselves unable to tell a story that adequately represents what they feel themselves going through but cannot yet articulate. They lack *narrative resources*, which include all we learn about storytelling from the stories we know: what character types are available to us, what we think a plot is, our capacity for metaphor, and much more. The condition of narrative wreckage is alienation, an additional layer of suffering.

The complement to narrative wreckage is narrative redemption. When we can tell a story that does represent our situation, we can then claim what we call *experience*: we can know ourselves and feel known by others. *Redemption* is a heavily loaded word to be used cautiously. Making a situation narratable does not make it pleasant or even acceptable, but narrative can redeem life from imposed silence. That chaotic silence also has its complement: a stillness made possible by narration but surpassing it.

Narrative resources coalesce in *types* of narratives that people have available to fabricate stories and to understand them. In my past writing, I proposed three types of illness narratives; my present writing proposes a fourth. The dilemma in both fabricating stories and understanding them is that humans need types to reduce the complexity of what we confront, but types can be all too effective at assimilating the specific to generalized characteristics. We can’t live without types, but we use them at the risk of reifying them. Types are useful devices for making recognizable, but they are only a beginning, not an end in themselves.

Bio: Arthur Frank is professor emeritus at the University of Calgary, Canada. Since retirement in 2013, he has been Professor II at VID Specialized University in Oslo, visiting professor in the Program in Narrative Medicine at Columbia University, and Francqui Fellow at the University of Ghent. His books on illness experience, ethics, clinical care, and narrative include: *At the Will of the Body* (1991/2003), *The Wounded Storyteller* (1995/2013), *The Renewal of Generosity* (2004), *Letting Stories Breathe* (2010), and most recently, *King Lear: Shakespeare’s Dark Consolations* (2022; paperback Summer 2026), in Oxford’s “My Reading” series. He is an elected Fellow of the Royal Society of Canada and winner of the Society’s medal in bioethics. His other recognitions include the lifetime achievement award from the Canadian Bioethics Society. His next book, *A Quieter Illness*, is scheduled for publication in Fall 2027 from University of Chicago Press. www.arthurwfrank.wordpress.com

Chair: Carsten Stage

SPOTLIGHT PANELS W/ INVITED PANELISTS

Spotlight panel 1: Gender and Illness Narrative	
Room: 1427-246-M2 Chair: Amanda Karlsson	**1. “Illness Narratives on Instagram: Sharing and Retelling the Experience of Endometriosis”** **Ida Melander** Abstract: Traditionally, illness narratives have been approached through patient records or researcher-elicited interviews. However, recent shifts in health communication have made it possible to share the experience of being ill with much wider audiences. Consequently, illness has become an increasingly public topic – discussed, shared, and retold across a multitude of digital settings. In this presentation, I draw on previous work on Instagram narratives about the chronic disease endometriosis (Melander, 2019, 2022). Despite its high prevalence, endometriosis remains surprisingly unknown; many of its symptoms are frequently dismissed as a ‘normal’ part of female life (e.g., painful menstruation), leading to normalization and significant diagnostic delays.

In the presentation, I will specifically focus on endometriosis narratives on a shared, activist Instagram account with the explicit aim of raising awareness about the disease. Here, the multimodal affordances of social media format, combined with the co-tellership (cf. Ochs & Capps, 2001) found on the account – where multiple posters share the space yet tell their stories in separate textual units – create an innovative form of storytelling. As a shared social space, these Instagram narratives further raise critical questions regarding which particular illness experiences are deemed tellable in such a setting, and who gets to tell their story within this specific endometriosis community. From a discourse analytical perspective, exploring these shared stories can highlight the workings of health discourse and gendered experiences of illness more generally, and connect personal experiences and the self to the social and activist functions of sharing illness narratives.

Bio: Ida Melander, PhD, is a Senior Lecturer in Swedish language at the School of Humanities, Education and Social Sciences at Örebro University, Sweden. Her research interests include digital meaning making, discourse analysis, narrative analysis and health communication.

2. ““Service Due”: Masculinity, Biopolitics, and Affect in Nordic Men’s Cancer Prevention Campaigns”

Karen Hvidtfeldt

Abstract: This paper examines how contemporary Nordic men’s cancer prevention campaigns reconfigure illness and risk through gendered imagery and commonsense reasoning. Using contemporary cases from Denmark, Sweden, and Norway, I show how the male body is made actionable in familiar scenes and through a persistent car inspection frame: service, scheduled checks, preventive maintenance. By leaning on what “everyone knows” about keeping a vehicle roadworthy, prevention becomes a recurring obligation; illness is renarrated as ongoing monitoring, calibration, and compliance rather than crisis and cure.

The analysis draws on technologies of embodiment (Garlick, 2016) to argue that masculinity is performed through a technological relation to bodies and nature, freedom as anticipatory control, and on biopolitics and the somatic individual (Foucault, 2007; Rose, 1999, 2007) to unpack decision architectures (risk segmentation, home tests, periodic reminders). In dialogue with notions of vital masculinity (Eriksen & Hvidtfeldt, 2020) and capacity/debility (Puar, 2017), I show how appeals to authenticity (tools, camaraderie, outdoor competence) translate into bodily capacity: men are urged to “do something about it,” meaning book the check, send the sample, and follow up.

I discuss how affective strategies such as humor and lightness can lower thresholds for “belowthebelt” conversations and counter stigma, while also considering potential moralizing drifts and examine whether the carinspection frame may overpromise control, obscure uncertainties (false positives, overdiagnosis), or stigmatize nonparticipation. Considering also how its alignment with Nordic welfarestate infrastructures shapes both its reach and its blind spots, I reflect on who might be left out and whether playful repair logics sufficiently prepare audiences for the possibility of a positive test result.

Bio: Karen Hvidtfeldt is Professor of Cultural Studies at the Department for Culture and Language, University of Southern Denmark. Her research examines cultural understandings of health and illness, reproduction, gender, and age across audiovisual, digital, and literary media. She is Principal Investigator of *Medicine Man: Media Assemblages of Medicalized Masculinity* (DFF 2018–2026) and, together with Charlotte Kroløkke, coleads *Endocrine Economies: The Cultural Politics of Hormones* (VELUX 2021–2027). She currently holds a Carlsberg Foundation Monograph Fellowship for a book on cancer, body, and gender in the Nordic welfare state.

3. “Read Like a Man: Narrative Medicine in Practice”

Peter Simonsen

Abstract: My paper presents findings from a project where we practiced shared reading with men aged +65 on or on their way into retirement. Men in this age group are at greater risk than women of experiencing loss of meaningfulness in their lives as they feel their identity is disrupted by lacking attachment to employment and, for them, meaning in life. Health research knows this decrease in experienced life quality leads to worse physical and mental health conditions which result in shorter lives.

We asked: can works of great artistic literature, distributed through shared reading where a reading guide chooses texts (and thus decides what is 'great' literature), reads them out loud and involves the small-group participants in an open dialogue about how the texts affect them, in a relatively short time-span of an hour and a half, in any way affect their health condition in positive ways, at least in the short run; long term effects are very difficult to ascertain?

I will briefly sketch how we recruited the men and then zoom in on what happened in the room after the door was closed and we sat there, total strangers, and I started to read out loud from Danish short stories and poems about old men on retirement. Did they like this? Did it work? Can illness narratives generate health? How to move the practice of narrative medicine from the classroom of teaching into other scenarios?

Bio: Peter Simonsen. Professor of European Literature, Department of Culture and Language, University of Southern Denmark. Research focuses on questions of age and ageing in literature and culture and an interest in how literature can be and has been *used* to make things happen in the world.

Spotlight panel 2: Diversifying Illness Narratives

Room: 1427-246-M2
Chair: Karen Hvidtfeldt

1. "Life as an Experiment and Narrative Delirium as Truth: The Case of Ernesto Dalgas"

Lasse R. Gammelgaard

Abstract: This presentation revisits theory about illness narratives by probing interrelations between treating your life as an experiment and using madness material from your life as a source of inspiration in your fiction writing. The source material comes from a case study of Ernesto Dalgas from my cultural heritage project on 'Aesthetic madness in the long 19th century'. Dalgas who lived in the second half of the 19th century was admitted twice to psychiatric hospitals before he committed suicide at the age of 27. Living in the age of nervousness and anxiety and being deeply influenced by positivist philosophy and by Søren Kierkegaard and his stringent demands on life choices, Dalgas devoted his life to thought and the search for life goals of the highest order. The strenuousness of these self-imposed demands in addition to a hereditary madness (his sister also spent time in psychiatric hospitals as did his grandfather on his mother's side, who also committed suicide) finally broke him at a young age.

The patient charts and records from his time at the asylums are powerful tools that tell one story of Dalgas as a psychiatric case study. In this presentation, I'll argue that his vast production of philosophical and fictional writing – of which only two brief books was published in his own lifetime – can be viewed as one collective illness narrative, where binary oppositions like life and fiction, reality and hallucinations cease to be easily distinguishable and instead inform phenomenological truths. His life and works seen as illness narrative, thus, provides a counter narrative to the medical trends of his time.

Bio: Lasse R. Gammelgaard is an associate professor at Aarhus University. He is editor of *Madness and Literature: What Fiction Can Do for the Understanding of Mental Illness* (Exeter UP 2022) and co-editor of *Fictionality and Literature: Core Concepts Revisited* (Ohio State UP 2022). He is director of the research group Health, Media and Narrative at AU and is currently leading a cultural heritage project on *Aesthetic Madness in the Long 19th Century* funded by the Augustinus Foundation.

2. “Already Working from Home: Narrative Fragments and Modalities of Crip Embodied Experience”

Maria Bee Christensen-Strynø

Abstract: In this paper, I revisit a lecture delivered a year ago, entitled *Already Working from Home: The Crip Embodied Resilience of Persisting Black Mold*, to ask how a crip embodied researcher positionality challenges the narrative conventions through which illness and disability are allowed presence within academic institutional contexts.

The point of departure is an embodied account of a moment of institutional rupture: the temporary closure of a building at my former university workplace due to black mold contamination. While, at the time, this event was widely experienced as a sudden crisis, prompting comparisons to COVID-19 lockdowns and widespread disruption of academic routines, I situated it within a longer trajectory of working from home shaped by disability-related chronic pain and fluctuating bodymind capacity.

Revisiting this asymmetry, I draw on *cripistemology* (Johnson & McRuer 2014) and *crip spacetime* (Price 2024) to show how disabled ways of knowing and working unsettle normative expectations of productivity and presence. Rather than narrating a trajectory of breakdown and recovery, the paper lingers with the slow non-linearity and recursivity of academic labor as experienced from a crip embodied position, and as forms of thinking and writing that may not register as work within dominant frameworks of institutional life (Ahmed 2012).

Looking back at this event while also considering how such experiences travel beyond the moment of their telling, I reflect on the narrative modalities through which such experiences can be told. The original lecture performatively combined script, voice, visuals, and pacing as ways of staying close to embodied rhythms. In this paper, I consider whether multimodal and performative approaches might themselves be understood as part of cripping narrative forms of academic knowledge-making by creating space for fragmentary and sensorily attuned ways of knowing. Ultimately, I propose that crip-informed storytelling practices do not merely represent disability differently but actively reconfigure the epistemological and aesthetic conditions under which illness and disability can be shared and valued within academic spaces and beyond.

Bio: Maria Bee Christensen-Strynø is Associate Professor of Cultural Studies in the Department of Culture and Language at the University of Southern Denmark. Her research traverses the fields of critical, cultural, and feminist disability studies, crip methodology, visual culture, social media studies, and participatory arts-based research, with a particular focus on the ways in which processes of visual mediation, self-representation, and auto-narrativity shape and are shaped by lived experiences of disabled and crip embodiment. She has written and published widely on the cultural intersections of disability and other perspectives of minoritized bodily being, including gender, aging, and chronic neurological conditions, across contemporary art, media, and popular culture in international and Nordic journals and edited volumes

3. “Why All Norwegians Must Go Skiing: The TV Narrative about Childhood Dementia and Disabled Youth”

Nora Simonhjell

Abstract: For two seasons, the teenagers in *Team Pølsa* (NRK 2025 – 6) have charmed the Norwegian television audience. The first season had a steady 1.2 million viewers, and the numbers for the second season are just as high. Here we meet disabled teenagers who, under the leadership of former skier Øystein Pettersen (nicknamed “pølsa”), challenges the concept of being able-bodied and disabled. What is special about the series is that the young people’s own thoughts and feelings about their special life situation and its big and small challenges are expressed so clearly in their own words. What is it like to have a syndrome that has such a difficult name that it is impossible to say, how does it feel to have CF, or just a half functional heart, and what does the world look like when you have childhood dementia, already blind, and know that you are gradually only getting worse?

They are given an almost impossible task: first in the tough ski World Championship trials in Trondheim (2025) and this year they were to go biathlon in Holmenkollen. Both times in front of full stands with spectators, and a tight time margin. What does it involve being a part of a team? How does it feel to experience mastery? We follow them in their challenges and on their way to new coping strategies when the natural impulse is to say, “I can’t do this?”. Based on disability theory, I will discuss how this documentary series contribute to challenging the collective understanding of what it is like to be young and disabled, and the narrative strategies in use.

Bio: Nora Simonhjell is professor at the Department of Nordic and Media Studies at the University of Agder, Kristiansand. Her research interests are particularly related to contemporary Scandinavian literature, and its representations on demanding care relations and care experiences, more specific next of kind stories. She has also focused on dementia narratives, and trauma stories. Her doctoral thesis (2009) was related to literary representations of disability and aging. She is one of the editors of *I skyggen av sykdom. Skandinaviske pårørende fortellinger I vår tid* (2024), and was editor of *Norsk litterær årbok* (2017-2023). Home page: https://www.uia.no/om-uia/ansatte/noras/

Spotlight panel 3: Narrative in Medical Education

Room: 1427-246-M2
Chair: Anna Louise Skovgaard

1. “Narrative Medicine in Medical Education”

Anders Juhl Rasmussen

Abstract: In this paper, I will narrow my focus within the humanities and health sciences to the interdisciplinary field of narrative medicine. Modern-day medical students devote a large portion of their studies to understanding the functions and physical composition of the human body and the methods used to treat disease. This knowledge is the foundation for their ability to provide adequate healthcare to future patients. However, these future doctors also need to be able to communicate well with their patients and build a relationship of trust. Narrative medicine is the practice of medicine with narrative competence, understood as “the ability to listen to the narratives of the patient, grasp and honour their meanings, and be moved to act on the patient's behalf” (Charon 2006).

I was for six years associated with the University of Southern Denmark that since 2017 has offered a six-week-long mandatory course in Narrative Medicine for first-year medical students.

Since 2023, I am associated with the University of Copenhagen that has an elective on ethical dilemmas in the clinic in the sixth year of medical education which become a mandatory course in 2029. What lies ahead of the newly graduated doctor, is a daily life in which decisions are not made solely according to general guidelines; they are challenged by the individual patient’s situation, age, general condition, life circumstances, and wishes for a future life. The course discusses the ethical dilemmas that young physicians soon encounter daily in the healthcare system and thereby provides guidance on how to make more well-informed decisions. My point is that courses in narrative medicine and medical ethics should remain an integral part of medical education to ensure the voice, perspective, and history of the patient are respected. Literary studies provide methods for reading literary texts and for engaging in reflection through reading and writing.

Bio: Anders Juhl Rasmussen. MA in Danish and Philosophy, PhD in Danish Literature. 2017-2023 associate professor of narrative medicine at the University of Southern Denmark. Now associate professor in Danish literature at the University of Copenhagen. Member of the steering group for *Nordic Network for Narratives in Medicine*. Author of two monographs (2012 and 2018) on Danish literature; in the field of narrative medicine, he is author of several journal articles and book chapters, co-editor of two research anthologies *Narrative Medicine* *in Education, Practice, and Interventions* (2022) and *Narrative Medicine: Trauma and Ethics* (2024).

2. “An Alternative Rhythm in Clinical Practice: Integrating Narrative Medicine Education in Postgraduate Hospital Settings”

Jane Ege Møller

Abstract:
Introduction
Narrative Medicine is an established educational tradition that foregrounds narrative engagement as a source of knowledge in healthcare. Research has documented its contributions to empathy, narrative competency, and reflective capacity. At the same time, critical voices have questioned assumptions about the inherent value of narrative, arguing that not all individuals experience themselves through coherent storytelling. Relatively few studies have explored Narrative Medicine initiatives embedded directly within postgraduate clinical settings.

Methods
This study examines the integration of Narrative Medicine into postgraduate clinical practice through a programme implemented at a university hospital’s Department of Haematology. Over a nine-month period, 18 sessions were embedded into the department’s existing educational schedule following morning reports. The sessions varied in duration and were facilitated by trained instructors. Data were generated through observations of nine sessions and semi-structured interviews with trainee doctors and specialists (n = 16).

Findings
Participants described the Narrative Medicine sessions as an interruption of the fast-paced, efficiency-driven temporality of the hospital and characterized them as “mental breaks” or moments of relaxation. This temporal otherness shaped the sessions as a restorative space distinct from routine clinical pressures. The narrative texts facilitated reflection without immediate personal exposure. Additionally, the sessions strengthened a sense of community by introducing a more personal dimension to professional interactions and by enabling junior and senior physicians to participate on more equal terms. Structural conditions, e.g. leadership support, and skilled facilitation were articulated as central for making the initiative feasible.

Discussion
Rather than producing changes in empathic behaviour or narrative competence in patient encounters, Narrative Medicine functioned primarily as a temporal and experiential intervention, creating a resonant space within an accelerated clinical environment and supporting physicians’ well-being. The presentation concludes by outlining the expansion of the initiative to three additional hospital departments and the development of materials enabling physicians to facilitate Narrative Medicine sessions in clinical settings.

Bio: Jane Ege Møller, MA, PhD, is an Associate Professor at MERU, Medical Education Research Unit, Department for Clinical Medicine at Aarhus University, Denmark. She serves as the Academic Lead for the Post-graduate Communication Skills Training for Residents in the Central Denmark Region. She is the Chair of tEACH, the teaching subcommittee of EACH, the International Association for Communication in Healthcare. With a background in literature, communication, and philosophy, she has over 20 years teaching and research experience in the fields of post-graduate medical education, narrative medicine and health communication.

3. “Long-Term Aims of Literature, Storytelling, and Narrative Medicine in Medical Education”

Katarina Bernhardsson

	Abstract: The inclusion of literature and narrative medicine in medical education has a long history. At Lund University, this has been part of the curriculum for the past fifteen years, on the one hand in an elective course in Medical Humanities for a subset of students, and on the other hand integrated into various modules, such as psychiatry, pathology, and professional development, for all students. Drawing on this experience, as well as fifteen years of course evaluations and a 2023 survey directed at alumni of the elective course, I want in this paper to reflect on what lies beyond the texts and the stories themselves, and instead focus on what the seminars lead to: what we achieve in the room, what the students take with them, and how they report that this affects them in the longer term. Aspects include encountering and sharing experiences, reflecting on experiences and perspectives, and increasing the ability to verbalize thoughts and feelings. The alumni in the survey emphasize the importance of open-ended seminars, where they could discuss both everyday matters and more complex issues with fellow students and teachers. I will discuss how, in a professional programme that offers only limited space for articulating experience, narrative medicine's potential to both invite responses to stories and encourage the creation of stories gives students an opportunity to process and integrate thoughts and emotions, and to remind them (in the words of one student) of "who I want to be as a doctor." Bio: Katarina Bernhardsson is associate professor in literary studies, senior lecturer in medical humanities, and assistant director for Birgit Rausing Centre for Medical Humanities, all at Lund University. Since her PhD thesis *Literary Ills. Portrayals of illness in contemporary Swedish fiction* (2010) she has continued to work at the intersection of humanities and medicine. Her research interests include illness narratives and narratives by next of kin, the reading method shared reading, and medical humanities and narrative medicine in medical education. Currently, she is leading a five-year project in narrative medicine which includes both theoretical and empirical dimensions.

PANELS

Panel 1: Time, Narrative, and Illness: Lessons across Media and Genres	
Room: 1427-246-M2 Chair: Lasse Gammelgaard	This panel analyzes a set of compelling illness narratives in order to open up conversations about the diverse and complex relationships among time, illness, and narrative. Temporality is a central concern in each of the three papers, but each panelist explores what's distinctive about its treatment in the illness narratives they choose to analyze. James Phelan, in his paper on the remarkable ending of Paul Kalinithi's *When Breath Becomes Air*, will explore how Kalinithi efficiently and provocatively intertwines temporality with ethics and with his address to multiple audiences. Antonio (Joey) Ferraro, in his paper on the radically different but equally consequential conceptions of time in Carson McCullers's 1961 novel *Clock without Hands* and in the 2025 serial television show, *The Pitt*, will argue for a "temporal pluralism" in the assessment of illness narratives: let's not seek an ideal conception of time, illness, and narrative but recognize the value of multiple conceptions. Catherine Belling, in her paper on "the post-trauma plot," will compare psychiatry's standard accounts of traumatized memory with forms of analepsis in PTSD memoirs. She will contend that some of those memoirs, including Jamie Hood's *Trauma Plot: A Novel* challenge psychiatry's efforts to contain trauma and its temporal effects. Taken together, then, the papers on this panel seek to both deepen and diversify our understanding of the interconnections among temporality, illness, and narrative.

1. “Time, Ethics, and Audience in *When Breath Becomes Air*: A Rhetorical Reading of Its Last Ten Paragraphs”

James Phelan

Abstract: A dying Paul Kalanithi and his readers come to the end of his memoir, *When Breath Becomes Air,* knowing that the rapid advance of his metastatic cancer prevents him from completing the narrative as he’d hoped. Nevertheless, I shall argue, he finds a powerful way to connect the real-time extratextual experience of his advancing illness to the formal construction of his narrative. In so doing, he constructs a rare kind of illness narrative, one that provides satisfactory closure without completeness and that simultaneously accepts and pushes back against death. I shall analyze how Kalanithi achieves those effects by focusing on his handling of three interacting rhetorical resources: time, ethics, and audience. With time, he shifts from the past to the present tense, a move that leads to the convergence of the narrating-I, the experiencing-I, and the constructing-I. In addition, Kalanithi offers explicit thematic reflections on time that call back to some of his earlier thematizing of time in the memoir. With ethics, Kalanithi not only offers some explicit reflections on his values but also implicitly invites readers to consider the unusual ethics of his telling: he has chosen to use his final days writing the pages we have been reading. With audience, Kalinithi shifts in the final paragraph from addressing an uncharacterized public narratee to addressing his eight-month old daughter, Cady. In that address, he layers time in new ways, as he imagines her future self taking a retrospective glance at her life and urges her to know how much he values her at the time of the telling. I will close with some of my own reflections on time in illness narratives.

Bio: James Phelan, Distinguished University Professor of English at Ohio State University, directs Project Narrative and the Medical Humanities there. He has devoted his research to thinking through the consequences of conceiving of narrative as rhetoric. He served as editor of *Narrative* from its inception in 1993 until 2025. His books include *Somebody Telling Somebody Else: A Rhetorical Poetics of Narrative* (2017) and *Narrative Medicine: A Rhetorical Rx* (2023). Phelan is a member of the American Academy of Arts and Sciences (2025) and the Norwegian Academy of Science and Letters (2016). Aarhus University granted him an honorary PhD degree in 2013.

2. “Time Enough: Temporal Pluralism in *The Pitt* and *Clock Without Hands*”

Antonio (Joey) Ferraro

Abstract: This paper examines the treatment of time in two radically different stories about medicine and illness. First, it explores how the popular HBO television series *The Pitt* (2025) treats time as both a formal and material resource. Time in the show’s overcrowded, understaffed hospital is a precious commodity that is spent and acquired in fits and starts, fragmenting the experience of health care and the presentation of the narrative. Carson McCuller’s final novel *Clock Without Hands* (1961) is also concerned with temporality, but unlike *The Pitt*, which focuses on presenting time as finite and fragile, the novel presents it as something deeply symbolic and enduring. J.T. Malone is a middle-aged pharmacist living in Georgia who is diagnosed with terminal leukemia. While he previously paid little attention to the racial and historical complexities of his antebellum Southern upbringing — in other words, to the legacies of his “blood”— Malone’s reckoning with his own mortality forces him to also reckon with the racist violence that shaped his community. In outlining these two different approaches to narrative time, I advocate for the value of “temporal pluralism.” Studies of time within the health humanities frequently focus on identifying the limitations and weaknesses of a given approach, and often do so, as I will argue, with the unspoken assumption that there exist more and less ideal forms of temporal representation. By contrast, I offer my analyses of time to argue for a disciplinary openness towards a wider range of temporal strategies. The goal is not to prevent genuine critique, but instead to emphasize that the nature of time as a rhetorical resource in illness narratives is, like the nature of time itself, never fully settled, and is often productively and surprisingly redefined across different stories.

Bio: Antonio J. ("Joey") Ferraro, Visiting Assistant Professor at the University of Cincinnati-Blue Ash, holds a PhD in English from the Ohio State University and currently serves as the Outreach Coordinator for the International Society for the Study of Narrative. His work has been published in *Literature and Medicine, Style*, *DIEGESIS,* and elsewhere, and his monograph *Moral Storytelling in Illness Narratives: Dialogue, Subjectivity, and Justice* is under contract with Anthem Press.

3. "The Post-Trauma Plot: Temporal Sequencing in Autobiographical and Psychiatric Accounts of PTSD"

Catherine Belling

Abstract: Psychiatry defines post-traumatic stress disorder (PTSD) by its temporality: past events invade the patient's present with involuntary mental intrusions given the cinema-derived term "flashbacks." These collisions of past and present are different from the intentional recollection of past events, though in PTSD such memories also often take unexpected forms. This paper compares psychiatry's descriptions of traumatized memory with forms of (non-cinematic) analepsis found in published narratives of PTSD, suggesting that the two discourses have been both mutually influential and contradictory in their plotting of stories about trauma. The "trauma plot" has become a somewhat disparaging term for narratives organized by withholding the details of a traumatizing event to keep readers anticipating a climactic revelation recounted analeptically. Authors can forestall the sequential narration of key events by giving the narrator and/or protagonist post-traumatic amnesia until some dramatic trigger overcomes repression. A classic example is the belated narration of Savannah and Tom Wingo's rapes in Pat Conroy's novel *The Prince of Tides* (1986), written shortly after PTSD first entered medical and popular discourse. Tom functions as his psychotic sister's "memory," and a psychiatrist facilitates his recounting and her remembering, healing both. Recent non-fiction post-trauma narratives tend to represent more complex disorderings of memory. I compare medical PTSD cases with non-fiction memoirs about sexual violence, including topical accounts by Christine Blasey Ford (2024) and Chanel Miller (2019); Roxane Gay's collection *Not that Bad* (2018); and Jamie Hood's *Trauma Plot: A Life* (2025). Hood addresses plotting directly, representing her experiences of sexual violence by recounting her own recountings of them addressed to friends, diary, psychotherapist, and readers of the book itself. She investigates accepted assumptions about how past and present interact in the recollection and reconstruction of trauma, productively challenging medicine's efforts to contain trauma and its temporal effects.

Bio: Catherine Belling is Associate Professor of Medical Education (Bioethics & Medical Humanities), at Northwestern University Feinberg School of Medicine, Chicago. Her article "Narrating Oncogenesis" (*Narrative,* 2010) won the Schachterle Essay Prize from the Society for Literature, Science, and the Arts. Her book, *A Condition of Doubt: The Meanings of Hypochondria* (Oxford University Press, 2012), won their 2013 Kendrick Book Prize. Journals where she has published include *American Literature*, *Academic Medicine*, *English Language Notes, Horror Studies*, and *Genre*. She was editor-in-chief of *Literature and Medicine* (JHUP, 2013–2018). Her current work explores connections between horror (both feeling and genre) and medicine.

Panel 2: Illness in Graphic Novels and Comics

Room: 1421-118-M1.1
Chair: Camilla Bruun Eriksen

1. "You're Not Broken. Joy in Finnish Health and Illness Comics"

Noora Raiskio

Abstract: Zines Comics can help shape the ideas we have of our wellbeing – and further, of ourselves. Drawing oneself in autobiographical comics is often a powerful experience that can help the artist to make sense of their life. As a combination of words and images, comics provide a medium where expressing an altered and often traumatic state of an ill-fallen body or mind can be explored in rich and unique ways. Furthermore, in self-published comics zines, the difficult, amorphous and ugly sides of illness can be shown freely and without the constraints of traditionally published comics. My analysis focuses on the unlikely feeling of joy in health and illness comics zines. As illness stories are often understood through war metaphors, or as crises to be endured through, I will investigate stories where a trait traditionally constituted as an ‘illness’ is redrawn as a source of joy. I analyse Eve Kajander’s *Homon elämäni epäonnistuja* (2025), Mitja Mikael’s *2007: A Trans Odyssey* (2021) and elppidraws and ellumir’s *you don’t know how to love.* (2023). Kajander’s comic is about asexuality, Mitja Mikael offers a transgender coming-of-age story and elppidraws and ellumir’s zine discusses aromanticism. Each comics zine is autobiographical and engages in societal discussion about what is, what should, and what should not be categorised as ‘illnesses’. Through these examples I show how joy can act as a rebellion against medicalisation, and how it is often paired with marginalized experiences. I analyse the different stylistic choices in comics zines and map the ways these zines talk back or talk with the healthcare institutions. I argue that self-published comics zines can give marginalised people valuable tools to make sense of their ‘illness’ and become essential in making one’s experience a valid one.

Bio: Noora Raiskio is a doctoral researcher in literature studies from Tampere University, Finland. Her doctoral dissertation combines graphic medicine, narratology and health humanities on researching Finnish graphic medicine comics zines. They are especially interested in how self-published zines can democratise health and illness narratives and how they can talk back or talk with the healthcare systems’ power structures. She has stitched herself into the comics researcher community, offered her expertise on the national comics prize Comics Finlandia, and has organised the Finnish comics festival Tampere Kuplii’s academic track since 2024. They document their research in zine form.

2. “Illness in Graphic Novels for Young Audiences. The Case for (Not) Teaching Children about Health and Illness”

Henrik Johnsson

Abstract: This presentation examines contemporary graphic novels written in the Scandinavian languages for younger audiences that address themes of illness and death. It argues that children’s illness narratives can be considered a distinct literary genre, one with notable historical antecedents and characterized by recurring tropes and techniques. The aim of the presentation is to promote the entanglement of children’s and young adult literature and the medical humanities. These fields have only infrequently been made to work together in university settings in the Nordic countries. The presentation highlights theoretical and methodological challenges involved in designing courses, in particular aimed at students enrolled in teacher education programs, who may have limited familiarity with the medical humanities. Drawing on my experience teaching and supervising students who explore illness narratives for young audiences in their theses, the presentation discusses some of the benefits and pitfalls I have encountered when combining two distinct fields. My source materials include contemporary graphic novels dealing with ill health and, in some cases, death and bereavement. In order to trace the contours of a lineage of children’s illness narratives, several contemporary graphic novels – such as Jens Mattsson and Jenny Lucander’s *Vi är lajon!* (We are Lions, 2019), Daniele Evelin Alves’ *Inni mamma* (Within Mom, 2016), and Maja Lunde’s *Snøsøsteren* (The Snow Sister, 2018) – are presented alongside classics of the genre, including Astrid Lindgren’s “I skymningslandet” (In the Land of Twilight, 1949) and Tove Jansson’s “Berättelsen om det osynliga barnet” (The Invisible Child, 1962). Framed in relation to the Norwegian national curriculum LK20, the presentation argues that children’s illness narratives should be taught in classroom settings. The presentation concludes with a counterargument addressing why they should not.

Bio: Henrik Johnsson is Professor of Nordic Literature at Østfold University College, Norway. He holds a PhD in the history of literature from Stockholm University. He is the author of two monographs on the oeuvre of August Strindberg and is co-editor of the anthology *The Occult in Modernist Art, Literature, and Cinema* (Palgrave, 2018). His most recent monograph is *Ibsen and Degeneration: Familial Decay and the Fall of Civilization* (Routledge, 2024).

3. “Representing the Spiritual Aspects of Illness and Death in Narratives: Countering “Disneyfication””

Lisbeth Frølunde

Abstract: The presentation raises critical questions about the ethical and narrative challenges of representing illness and its spiritual aspects. “Disneyfied” narrative templates involving illness, death, and spiritual beliefs, risk glossing over, or sanitizing complex experiences. Illness narratives that invite multiple interpretations as catalysts for acknowledging mortality – counteracting death as taboo subject or discourses on death as a medical failure rather than a natural part of life. Theoretically I draw on Arthur Frank’s dialogic "wounded storyteller" concept (1995) about his own transformative experiences following serious illness, which he framed in relation to self-healing and to furthering the academic study of illness narratives. Frank encourages attention to unique narrative qualities and narrative tropes. I explore spiritual perspectives of illness represented in two empirical sources, tracing birds as tropes - agents of change with symbolic multiplicity.

The first source is curated from the collaborative research project “Dancing with Parkinson’s”, 2019-22, and the graphic novel “Moving Along” (Frølunde et al 2022) with stories developed between people with Parkinson’s, carers, me and colleagues. I reflect on my dual roles as researcher / family carer (my husband had Parkinson’s and Alzheimer’s).

The second source stems from my recent artwork on bird-women which led to inquiries into the “psychopomp” (Greek for "guide for souls"). These figures, deities, or spirits, such as Isis, Sirens, Valkyries, recur in mythology, religion, and folklore as escorts for deceased from the world of the living to the afterlife. Bird-women figures can be attributed various meanings including psychological transition. Birds as narrative tropes exemplify meaning reconfiguration, pointing to concepts of non-linear time, liberation, or attunement with magical transcendence in ancient myths and religious tales. The discussion reviews the challenges of representing illness with perspectives on keeping stories messy as alternatives to sanitized Disneyfication tendencies, especially regarding spiritual aspects.

Bio: Lisbeth Frølunde is an artist and Associate Professor Emeritus in visual communication at Roskilde University, Denmark. She was one of three researchers behind the project “Dancing with Parkinson’s” funded by the VELUX Foundation (2019-2022). Her transdisciplinary research explores bodily, sensory experience, arts, illness and health. She draws on critical visual culture, feminist narrative inquiry, and arts-based research based in dialogic, pragmatist approaches to aesthetic experience. Current interest is how visual storytelling evolves e.g. cave art, ancient myths, animation film, graphic medicine, feminist art and popular media. She is preparing an illustrated manuscript about the shifting meanings of winged goddesses.

Panel 3: Co-narrating the Clinical Encounter

Room: 1420-234-M2.2
Chair: Matilde Nisbeth Brøgger

1. “Finding Narrative Form for the Uncertainties of Critical Care: The Case of the Intensive Care Patient Diary”

Cindie Maagaard

Abstract: Intensive care is a situation of extreme illness and suffering, characterized by great uncertainty and unpredictability for patients and health professionals about the course of illness and the outcome, including whether the patient will survive. Due to illness, trauma, and medication, it is common for patients to lack awareness of what they go through. They often experience nightmares, hallucinations, and delirium, or they may remember very little about their time in intensive care – all of which can lead to post traumatic stress and impede physical and psychological recovery (Jones et al. 2001). As an intervention, some Scandinavian and Central European hospitals have implemented the practice of nurses writing patient diaries to fill in the gaps of knowledge for the patient. Designed to be read after ICU, the diary seeks to help the patient understand “what really happened” (Storli and Lind 2008, p. 46).

Yet how does a nurse create a narrative from within the precarious situation of intensive care? How does the lack of an ending affect the activity of narrative emplotment as it is undertaken from shift to shift? How does the limited temporal horizon come to expression in narration, and how does the diary reflect the ambiguous ownership of the narrative of critical illness? Based on collaboration with Odense University Hospital, my paper addresses these questions through the theoretical perspective of the diary genre, showing how it offers a resource for nurses to “sculpt” experience (Lejeune 2009) and find a form for the uncertainties and ambiguities of critical illness.

Bio: Cindie Maagaard is an associate professor in the Department of Culture and Language at the University of Southern Denmark. She is co-coordinator of the Narrative Medicine program at her university, engaged in research collaboration with the Intensive Care Unit at Odense University Hospital, and leader of a work package on narrative authority in the project “Ignorance and Inequality in Sexual Health” funded by the Velux Foundation. She teaches and publishes research widely in intersections of narrative, multimodality, and health communication, and her current interests focus on the narration of uncertainty, narrative authority, and medical students’ development of professional identity.

2. “Merged Frames, Drawing for the Consultation Room”

Marjolein Uitham

Abstract: The increasing prevalence of chronic conditions and the mounting pressure on healthcare systems amplify tensions between biomedical and social models of health, particularly regarding how illness experiences are given meaning. Many individuals living with chronic illness report feeling insufficiently heard within prevailing clinical frameworks, which are often shaped by normative assumptions about health and quality of life. These dominant perspectives can obscure the personal meaning-making processes of care recipients. The (art-based) method Merging Frames addresses this challenge by facilitating attunement and shared decision-making between healthcare professionals and care recipients through drawing. Developed from interdisciplinary literature on communication, presence theory, language, meaning-making, visualization, narrative and (bio)graphical medicine, bodily experience, autonomy, embodied learning, and agency, the method places the subjective bodily experience at its center By posing targeted questions and visually articulating lived bodily sensations, care recipients are able to reflect on their bodily experience and may assign renewed meaning to it. In this moment of reflection, ‘renewed’ meaning can be given to lived experiences. Care recipients gain a literal and metaphorical voice within the care process. The co-creative act of drawing provides access to inner experiences that are often difficult to express verbally. This process allows the care recipient to explore and communicate bodily meaning without judgment or imposition of external frames of reference. In this moment of reflection, ‘renewed’ meaning can be given to lived experiences. As a result, a more equitable form of communication emerges one in which multiple perspectives can coexist and inform the encounter. The further development of the Merging Frames method aims to offer an empowering paradigm that stimulates reciprocal communication and supports dialogue-based shared decision-making. Ultimately, the approach seeks to strengthen the care chain by enabling healthcare professionals and care recipients to collaboratively determine what constitutes appropriate and meaningful care.

Bio: Marjolein Uitham (b. 1966) is an illustrator at Colouring Life and a drawing artist for the Drawing for Children Foundation. She is a lecturer-researcher at the Hanze University of Applied Sciences specialized in Art & Healthcare. Her research investigates how artistic skills, particularly drawing, can enhance effective and reciprocal communication in healthcare settings. Her goal is to find new ways in which art can have a positive impact on communication and interaction in this field. On the project Merged Frames, drawing for the consultation room she collaborates with Nieke Koek (1982) is an interdisciplinary artist Yke Reeder (1973) is an illustrator at -ieks- and a lecturer-researcher at the University of Applied Science Hanze / NHLStenden specialized in creativity and art in the social domain.

3. “Beyond Patient Stories: How Clinicians Position Themselves in Psychiatric Consultations”

Karen Schriver

Abstract: Psychiatric consultations are saturated with patients’ narratives. Stories of trauma, ongoing illness, or, even, assertions of not being ill at all. While such narratives are often examined for their content or for how they construct patient identities, in this talk I propose a different lens: Looking at clinicians’ responses to examine how these project professional identities and shape patient agency. Psychiatry is not a uniform field; it is a contested space where multiple professions, guidelines and philosophies of care intersect. Within this complexity, I identify four discursive positions that clinicians adopt in consultations: the objective observer, the educational gatekeeper, the comforting yet opaque priest, and the motivational supporter. Each position shapes how clinician and patient negotiate agency and authority in practice, but they also align or misalign with distinct institutional tasks and identities. By tracing these positions, the analysis illuminates how patient agency is not a single concept but multiple and often quite restricted possibilities, shaped by professional positions and institutional guidelines.

Bio: Karen Schriver is a PhD student doing research on how clinicians handle communicative challenges in inpatient, psychosis care. She has previously done research on Open Dialogue, a therapeutic, psychiatric, intervention, and has also worked in health-related NGOs as a project assistant.

Panel 4: Disability, Pain, and Injury

Room: 1421-118-M1.1
Chair: Henrik Johnsson

1. “Rethinking (Reading) Narratives of Chronic Pain”

Anna Ovaska

Abstract: In recent years, narrative and literary scholars have increasingly turned to crip theory (Kafer 2013; Patsavas 2014) to imagine alternative ways of thinking about representations of chronic pain, as well as muchtheorized narrative concepts such as voice, time, space, plot, and metaphor. Scholars have also reimagined our ways of reading, introducing practices like “episodic reading” (Wasson 2018) and “narrative sidestepping” (Lewis 2025), while offering glimpses of reading *through* pain, illness, and disability (Lanser 2018; Mellor 2023). This presentation brings together recent applications of crip theory in the study of chronic pain narratives and outlines what “crip close reading” could look like. I show how a crip perspective encourages us to rethink cultural narratives of chronic pain’s “illegibility,” “loneliness,” its “destructiveness” to the self, and the imperative of “recovery,” while simultaneously dismantling the assumption of the reader as an ablebodied and ableminded figure. Through small case studies on the works of Eula Biss (*The Pain Scale*), Christina Crosby (*A Body, Undone*), Johanna Hedva (*How to Tell When We Will Die*), and Julia Lappalainen and Ella Mettänen (*Kipeä esitys*), I focus particularly on the ways contemporary narratives of chronic pain invite readers to reflect on subjectivity and collectivity, crip temporalities, (in)visibility, and agency in pain. I argue that a crip close reading foregrounds the relationality and multiplicity of pain as well as nonnormative modes of attention.

Bio: Anna Ovaska (PhD, M. Soc. Sc.) is a senior researcher at Narrare: Centre for Interdisciplinary Narrative Studies at Tampere University, a docent in Finnish Literature at the University of Helsinki, and a coPI of the project *Words for Care: Literature, Healthcare and Democracy* (Kone Foundation 2024–2026). Her research is situated at the intersections of narrative theory, feminist/queer/crip theory, embodied cognitive science, and the medical humanities. Her recent publications include the special issue “Applied Narratology” in *Narrative Inquiry* (coedited with SjoerdJeroen Moenandar and Laura Karttunen), the article “Toward Engaged Narratology: Critical and Embodied Close Reading and Social Justice in a Narrative Medicine Classroom” (2024), and the monograph *Shattering Minds: Experiences of Mental Illness in Modernist Finnish Literature* (2023).

2. “The Afterlife of Injury: Compulsory Positivity and the Moral Framing of Disability”

Sofiia Sarkisian and Anna Nikoleishvili

Abstract: Disability studies has long critiqued the figure of the “supercrip,” the disabled subject rendered socially valuable through narratives of resilience and inspiration. In wartime contexts, such frameworks often intensify around injured soldiers, whose bodies are elevated as symbols of sacrifice and national endurance. These figures do not disappear once the moment of injury has passed. As war-related injury becomes an ongoing condition rather than a singular event, expectations of resilience increasingly harden into forms of compulsory positivity that shape how suffering can be expressed, recognized, and morally evaluated. This paper examines how compulsory positivity operates within the narrative afterlife of war-related injury through a comparative analysis of Georgian and Ukrainian public discourse. While both contexts are shaped by post-Soviet histories of militarized sacrifice, they occupy different temporal positions of war: Ukraine within an ongoing conflict, and Georgia within a longer aftermath. This contrast enables an exploration of how narratives of injury function over time, supporting collective meaning in moments of urgency while constraining how lingering bodily disruption may be articulated once immediacy fades. Methodologically, the paper adopts a comparative critical narrative-discourse approach informed by sociological work on stigma, moral regulation, and affective norms. The analysis focuses on publicly circulating digital narratives surrounding war-related injury, including social media posts, visual materials, and audience responses. Digital platforms are treated as sites where emotional norms are negotiated, reinforced, and contested. By shifting attention from moments of symbolic elevation to the extended narrative life of injury, the paper argues that compulsory positivity reshapes rather than resolves stigma. In both contexts, ongoing disability becomes publicly intelligible primarily through demonstrations of endurance and emotional restraint, revealing how suffering is governed not through silence or exclusion, but through expectations about how one should feel and speak in digitally mediated public space.

Bio: Sofiia Sarkisian is a sociology student at Sorbonne University. Born and raised in Ukraine, her research is driven by observing how the ongoing war is reshaping social narratives and public initiatives in her home country. She has previously conducted research on the saturation of journalistic wartime imagery and the role of art in communicating the problems of war. Informed by her volunteer experience with the Red Cross and the lived realities of marginalized groups and people with physical and psychiatric impairments, Sofiia is currently developing a comparative study of Ukraine and Georgia through public narratives of war, injury, and vulnerability.

Bio: Anna Nikoleishvili is a Georgian sociology student at Sorbonne University. Her research focuses on cultural and political sociology, specifically how symbolism and narrative shape identity and belonging in public life. She has explored protest culture and political communication within the Georgian context, and her current work examines the moral regulation of disability and war-related injury. Alongside her studies, she works with a Paris-based NGO supporting asylum seekers and individuals with disabilities, bridging theoretical interests in stigma and affective norms with practical institutional engagement.

3. “Women’s Chronic Illness Stories: Creating a New Understanding of Illness”

Catherine Medici

Abstract: Women’s experiences of illness are being shared everywhere. From the social media trend #MedicalGaslighting bringing light to common experiences, to award winning memoirs focused on individual and collective experiences of the ways chronic illness clashes with personal and societal expectations, and women with chronic illness as main characters in bestselling romance novels. The explosion in women’s chronic illness narratives has not only brought to light a clear element of women’s experiences of illness and healthcare, but has also challenged traditional understandings and norms about the structure and purpose of illness narratives. This new perspective also illuminates the way that rather than universal, the expectations of illness narratives are gendered. This presentation will examine the explosion of non-fiction books of women’s chronic illness narratives that began in the late

2010s including Meghan O'Rourke's *Invisible Kingdom* and Maya Dusenberry's *Doing Harm*, the recent rise of romance novels featuring female main characters with chronic illness from the fantastical *Fourth Wing* to contemporary romantic comedies like *Get a Life Chole Brown*, and narratives submitted and shared by women as part of a living library event on women's health in 2023. Using an intersectional feminist disability studies framework, I will highlight the ways that these stories challenge longstanding beliefs about the narrative arc of illness in literature, culture, and medicine itself and propose a new understanding of what it means to be ill.

Bio: I am a historian and medical humanities scholar and my current research focuses on women, gender, medicine, and chronic illness. I am the coordinator of Outreach Access and Resources and faculty co-director of LGBTQ+ Health Advocacy at the University of Nebraska Medical Center and affiliated with Women's and Gender Studies at the University of Nebraska Lincoln. My work has appeared in *Early Modern Women Journal*, the *Oxford Dictionary of National Biography*, multiple edited collections, and Nursing Clio. I have presented at multiple international conferences including the National Women's Studies Association, Renaissance Society of America, American Historical Association and many public humanities events.

Panel 5: Narratives in and on Health Institutions

Room: 1420-234-M2.2
Chair: Jane Ege Møller

1. "Towards a Typology of Literary Doctor-Patient Encounters"

Pernille Meyer

Abstract: Doctors and patients meet every day. Narrative medicine seeks, among other things, to enhance these encounters by introducing doctors to literature, thereby making them "more attentive to patients, more attuned to patients' experiences, [and] more reflective in their own practice" (Charon 2006, 154). In this paper, I shift the focus from real-life clinical encounters between doctors and patients to their literary representations and ask: How are doctor-patient encounters represented in contemporary Scandinavian literature? The paper opens with a brief overview of contemporary Scandinavian literature that thematizes doctor-patient encounters. As previous research has pointed out, illness narratives often critique medical authority and asymmetrical power relations (see, e.g., Andersen 2016). However, I argue, there seems to be a move towards more complex and nuanced representations of doctor-patient encounters in contemporary Scandinavian literature. On this basis, I propose a typology consisting of three different types of literary doctor-patient encounters, of which the first remains the most prevalent: 1) The critical encounter, 2) The dialogic encounter, and 3) The fascinated encounter. These types are illustrated through close readings of selected passages from Karen Fastrup's *Hungerhjerte* (2018), Anna Rieder's and Birgit Bundesen's *Smerte-hjerte* (2023), and Sara Roepstorff's *Min far er en tiger* (2015).

The paper is anchored in the research project *Narrativ medicin i den kliniske hverdag – et samarbejdsprojekt mellem AU, AUH og Dokk1*, led by Carsten Stage and Jane Ege Møller. The research project aims to strengthen doctors' well-being, to the benefit of both doctors and patients, by integrating literature and narratives into everyday clinical practice at the hospital. A key objective is to build an archive of illness narratives that doctors can use independently in brief (10-15-minute) narrative medicine sessions, e.g. during morning conferences.

Bio: Pernille Meyer, PhD, is a postdoctoral researcher at Department of Scandinavian Studies and Experience Economy, Aarhus University, working on the project *Narrativ medicin i den kliniske hverdag – et samarbejdsprojekt mellem AU, AUH og Dokk1*, led by Carsten Stage and Jane Ege Møller. Her PhD dissertation concerns second-person narratives in Danish literature, and she has published on second-person narratives, autobiographical writing, and illness narratives in journals such as *Edda*, *The Problems of Literary Genres*, *Passage*, and *Frontiers of Narrative Studies*. She is co-editor of the anthology *Dangers of Narrative and Fictionality: A Rhetorical Approach to Storytelling in Contemporary Western Culture* (2024).

2. “Between Care and Bureaucracy: Swedish Illness and Healthcare Narratives Across Time”

Katarina Bernhardsson, Katarina Båth and Torbjörn Forslid

Abstract: The Scandinavian welfare states are widely recognised for their collectively financed and universally accessible healthcare systems. These systems are founded on ideals of equality, solidarity, and respect for every citizen’s need for care, yet also entail an increasing emphasis on efficiency, standardisation, and bureaucracy that risk dehumanising patients. This presentation takes as its point of departure the 1978 publication of two Swedish novels: *Babel’s House* by physician-author P.C. Jersild and *Death of a Beekeeper* by philosopherauthor Lars Gustafsson. While Jersild portrays healthcare as an industrial conveyor belt, where patients are processed and distributed between departments like products, Gustafsson depicts a man who actively rejects medical intervention, burning the hospital’s letter to avoid diagnosis and prognosis. Beginning with this earlier literary critique of the healthcare system at a transitional phase of the welfare project, we ask how encounters with the healthcare system have changed over time in Swedish literature: Has the experience of meeting healthcare become more diversified, fragmented, and individualized, or increasingly technocratic, standardised, and mediated by institutional language and digital procedures? Focusing on fictional and autobiographically based works from the 2000s onwards, we examine how illness and care are retold through depictions of hospital environments, vulnerable individuals’ encounters with medical institutions, and the friction between everyday language and technocratic, medical vernaculars. Our analysis includes dystopian visions of biopolitical care in Ninni Holmqvist’s *The Unit* (2006), retrospective and ambivalent representations of psychiatric institutions in Sara Stridsberg’s *The Gravity of Love* (2014), and narratives of informal caregivers overwhelmed by responsibility in Tom Malmqvist’s *In Every Moment We Are Still Alive* (2015). Through these selected examples, we delineate how criticisms of the Swedish healthcare system are retold over time in illness narratives, foregrounding shifting temporalities, narrative positions, and the effects of an increasingly bureaucratised and digitalised welfare-state healthcare system. Key words: Illness narratives; temporality; welfare-state healthcare, bureaucracy

Bio: Katarina Bernhardsson is Associate Professor of Literary Studies, Senior Lecturer in Medical Humanities, and Assistant Director of Birgit Rausing Centre of Medical Humanities at Lund University. Her research explores illness narratives and literature’s role in healthcare and medical education. Since 2025, she leads a five-year project on narrative medicine in Scandinavia, where Båth and Forslid are project members.

Bio: Katarina Båth is Senior Lecturer in Literary Studies at Lund University, with research interests in literary trauma studies, bibliotherapy, and creative writing focused on literature’s capacity for healing.

Bio: Torbjörn Forslid is Professor of Literary Studies at Lund University, specialising in literary value, literary public spheres, and shared reading as a health-promoting and pedagogical practice.

3. “Retelling Illness Otherwise: Redefining Chronicity, Mediation, and Narrative Diffusion in Contemporary South Asian Narratives”

Sakshi Srivastava

Abstract: The study of illness narratives as sites for voicing the ‘biographical disruption’ conforms to the dominant approach of treating illness as consisting primarily of crisis, diagnosis, and recovery. However, illness experience in most societies, goes beyond this tripartite model. In treating illness narrative as a narrative practice rather than a genre of autobiography, this paper examines contemporary South Asian narratives as spaces where illness narratives are mediated, chronicled, and relationally cared for, resisting the dominant models of illness narratives that are linearly recoverable or authentic. Focusing on Avni Doshi’s *Burnt Sugar* (2020) and Sanya Rushdi’s *Hospital* (2023), it argues that these narratives theorize illness as chronic, relationally appropriated and experienced, and most

	importantly, embodying unresolved narrative conventions which are shaped by mediation of the family, authority of the institution, and long-term bodily precarity. *Burnt Sugar* represents dementia not simply as a medical diagnosis, but a circulating condition re-organizing notions about memory, practices of care, and inter-generation obligations and resentments. Resisting closure, the text disperses the illness in the relational realm of the family, focusing on care fatigue and emotional endurance rather than recovery. Whereas Rushdi's *Hospital* positions psychiatric illness between the patient's life-world and the biomedical world. This reveals the overwriting institutional impulses which use diagnostic categories and language against subjective experiences. Both the texts show the frequent presence of diagnostic uncertainty, conflicted narrative ownership, and unresolved temporalities. In order to show how these narratives challenge the Western illness narrative templates, this paper draws on Narrative Medicine and recent work in medical humanities on chronicity, invisible illness, and narrative plurality. Rather than a linear experience and expression of illness, South Asian narratives offer alternative epistemologies of illness founded on the necessary reframing of cultural situatedness and expansion of the ethical and formal possibilities of illness storytelling. Bio: Dr. Sakshi Srivastava is currently an Assistant Professor of English in the Faculty of Liberal Arts and Humanities, Chandigarh University-Uttar Pradesh, India. She has received her PhD in English from Banaras Hindu University, Varanasi, India. Her area of research is Critical Medical Humanities with a special interest in illness narratives. She has published her research in *Literature and Medicine* and *Sanglap Journal*. She has also presented papers at conferences organized by Banaras Hindu University, Durham University, University of Oslo, and University of Debrecen among others.
Panel 6: Creative Explorations of Illness Experiences	
Room: 1420-226-M2.4 Chair: Karen Schriver	**1. "Critical Explorations of Poetic Language and Illness"** **Hilde Bondevik and Oddgeir Synnes** Abstract: The increasing interest and research into practices of creative writing in illness contexts have shown that access to an expressive language can be helpful. At the same time, critical voices have raised concerns of an instrumentalization of language where poetic language might risk being submerged under the goal of medicine (writing as treatment and therapy) or where uncritical practices of sharing end up producing confessors. In his recent criticism of narrative medicine Alan Bleakley (2024) questions the dominance of narrative as a genre, and how the dominant metaphor of "life as narrative" might be a hindrance to other linguistic means of being in the world. Based on our long-standing research and practice with creative writing in healthcare contexts (cancer, dementia and young adults in treatment for psychosis) we will critically discuss how narrative and lyric poetry might offer complementing linguistic affordances when living with a serious disease. In particular, we would like to highlight the less explored language of lyric poetry. While narrative to a large degree concerns *horizontal time*, lyric poetry is more connected to *vertical time* and the time of the lyric present (Bachelard). Or as Paul Ricoeur argues, lyric poetry "gives a voice, which is also a song" to the experience of time outside of narrative. In her work with creative writing in the treatment of mental illness, Julia Kristeva has been particularly concerned with how poetry in the treatment of mental illness can involve a balancing act between the semiotic and the symbolic, between the bodily and the linguistic. By applying perspectives from Ricoeur, Kristeva and Bleakley's argument for a lyric medicine, we will explore how both narrative and lyric poetry together can contribute to nuanced ways of living with illness. Bio: Hilde Bondevik, PhD, Professor of Medical Humanities at the University of Oslo, Norway. She has her background in intellectual history and gender studies and holds a doctoral degree in medical history from the University of Oslo (2007). Among her main fields of interest are the history of medicine, gender perspectives on health and illness, philosophy of science, creative writing in health care settings (including cancer care and mental health) and literary representations of illness. Bio: Oddgeir Synnes, PhD, Professor of Health Humanities at VID Specialized University,

Oslo, Norway. Synnes has a master’s degree in literature. His PhD was a narrative analysis of texts from creative writing practices in palliative care. Among his key areas of interests are cultural and narrative gerontology, creative writing in health care settings (including cancer care, palliative care, dementia care, mental health) and literary representations of illness.

2. “Validation gap: Interactive Illness Narratives and the Politics of Representation in VR”

Yi (Luna) Wang

Abstract: Illness narratives in Virtual Reality (VR) are frequently shaped by a crisis model and justified as an “empathy machine” because they seek to place users inside another’s illness experience, usually from the first-person perspective. This research uses a term from design research to analyse the deficiencies of illness-related VR films: a “validation gap”. Building on this concept, However, this essay argues that even when VR films claim to present first-hand experiences of illness, people with relevant experiences (for example, in relation to sensory or psychosocial disability) may face structural barriers to accessing the medium and experience, posing a representational problem of authenticity. Engaging critical disabilities studies and critical neurodivergence scholarship, I treat disability as a condition of the social and structured barriers that shape access in the public. This research undertakes a phenomenological analysis of *Goliath: Playing with Reality*, an interactive VR film focus on the inner world of a person living with schizophrenia. Guided by Echo’s narration, users are invited to a Deleuzian nomadic movement between real and unreal worlds. Such managed ambiguity is affectively persuasive, yet it also generates what I call the “validation gap,” to examine how sensory intensity and scripted interactivity can be misrecognised as experiential evidence. The validation gap is therefore not only epistemic but political and ethical. In this case, immersive experiences and carefully designed participation become a moral guarantee, that influences how audiences accept authenticity claims. VR, in this sense, as a so-called “empathy machine”, may become merely a design achievement, thus enabling the consumption of spectacularised illness.

Bio: Yi (Luna) Wang is a PhD student in the Medical Ethics and Humanities Unit, LKS Faculty of Medicine, University of Hong Kong. She has an academic background of literature, film studies and critical theory. In her PhD study, she is interested in what happens when illness narratives move from words and images into immersive environments, where feeling and attention are shaped by interaction design. She is particularly interested in design ethics, and the political representation of illness related VR, including how empathy and participation are institutionalised through platforms, festivals, and public discourse.

3. “Onwards Through Words: Creative Writing Workshops for Patients Suffering from Chronic Neurological Diseases”

Marianne Raakilde Jespersen

Abstract: Being diagnosed with and suffering from serious, chronic diseases turns life upside down and challenges the narratives through which you have previously understood your life. Instantly, for some, for others gradually, life changes fundamentally. The impact of illness on your ‘being-in-the-world’ is by S.K. Toombs described as a series of losses: of wholeness, certainty, control, freedom, and of the familiar world (Toombs, in Havi Carel 2016).

In the project “Ord på!” (OnWords!) we address these losses through writing: We invite patients suffering from chronic neurological diseases to join creative writing workshops. The project is a collaboration between Region Midtjylland, Regionshospitalet Gødstrup and VIA University College (December 2024-June 2026), with the intention of offering the patients a non-pharmacological approach to handling and coping with the fundamentally life altering challenges of being ill and increase their thriving. The goal is not for the participants to produce a new coherent life narrative, but rather to gain tools to handle shifting life conditions and narratives on your own. It has, furthermore, been central to the project to engage health professionals in the initiative and to address its potential of competence development for nurses.

Though we are still running workshops and have not yet finished collecting data, three findings stand out: The participants recount how 1. Writing has a calming effect; 2. Writing makes them aware of things they haven’t thought about and changes their perspective on their current life situation; 3. Joining a community and meeting with others nudges them to write and is socially beneficial. In this paper I want to present the very first research results and reflections on the potential of writing as a ‘tool’ to increase thriving and strengthen narrative agency. Furthermore, I will add some reflections on the feasibility – and challenges – of offering creative writing workshops in hospitals.

Bio: Marianne Raakilde Jespersen, PhD in comparative literature; researcher at Research Center for citizens and society, VIA University College. PI of the projects “Ord på!” (2024-2026; for patients) and “OmsorgsOrd” (2025-2027; for relatives). Both projects are collaborations between VIA, Region Midtjylland and Regionshospitalet Gødstrup. Part of an Eramus+ project on creative writing and AI (“WrAIte”). Since 2016, teaching medical students in literature and medicine. Extensive teaching experience in the field of medical humanities. Developer and facilitator of writing courses for citizens suffering from chronic diseases, as part of public health programs in Aarhus Kommune. Co-editor of and contributor to *Skrivning og sundhed*, Aarhus University Press, 2021.

Panel 7: Queering Time

Room: 1421-118-M1.1
Chair: Marianne Raakilde Jespersen

1. “Narratives of (Un)Recovery”

Avril Tynan

Abstract: What recovery means, at different times, in different places, and to different people is never neutral but always entangled in socioeconomic and cultural structures of power and privilege. Like health and illness, recovery is an ambiguous and slippery concept, but it is defined by an intrinsic consequentiality: to recover, one must first be ill. Yet illness is not as democratic and neutral as we might like to think; it is arbitrarily policed by factors such as gender, race, age, class, income, and sexuality. Crossing the threshold into a medical framework that can name and explain symptoms, prescribe treatments or therapies, and ultimately alleviate suffering is foundational to any experience of recovery, but access may be a privilege and even a luxury.

If recovery necessitates the antecedence of illness, then illness must first be visible and identifiable. But for many, and particularly those who live in vulnerable or precarious situations often shaped by ongoing injustices and inequalities, it can be difficult to separate illness from everyday life. What is recovery from trauma, for example, when trauma is not a single, extraordinary, and catastrophic event but is woven into the everyday? Drawing on Billy-Ray Belcourt’s memoir *A History of My Brief Body* (2020), I argue that Indigenous, feminist, and queer perspectives have much to contribute to existing debates around illness and recovery. Recovery is never distinct from illness but emerges from its ashes, and Belcourt’s works challenge dominant Euro-American narratives of recovery to demonstrate that recovery must not break from the past but enable its ongoing influences and affects—both joyful and sad—to take shape and evolve. With the concept of utopia, borrowed from José Esteban Muñoz, Belcourt articulates a narrative of *unrecovery*, shaping recovery as elusive but always potential, and opening up possibilities for change, contestation, and transformation.

Bio: Dr Avril Tynan is a Research Council of Finland Fellow (2023–2027) at the University of Turku, partner in the Erasmus+ project #ENDOs (2023–2026), and co-editor of *Storyworlds: A Journal of Narrative Studies*. Her research takes a critical perspective on the role and representation of illness, recovery, ageing, and death in contemporary literature. Her current project, ‘Reading Recovery: Narratives of Recovery in Culture, Medicine, and Society’ seeks to dismantle the monolithic conception of triumphant story arcs in recovery narratives. Her monograph, *Critical Narratives of Recovery: Rejecting Repair, Restoration and Resolution*, is forthcoming with Edinburgh University Press.

2. ““I Have Seven Limbs, So That Was Very Relatable”: Interviewing Autistics about Time, Kinship, and Science Fiction”

Sean Yeager

Abstract: This paper builds on my recent publication, “*Kakokairos*: A not-altogether-unserious theory of time, language, and autism” (Poetics Today, March 2025, link). That publication draws from my background as a physicist to outline my theory of neurodivergent temporalities, using Kurt Vonnegut’s *Slaughterhouse 5* and Ted Chiang’s *Story of Your Life* as case studies. Both of these narratives establish a tension between serial temporalities, which proceed from one moment to the next, and simultaneous temporalities, which experience all of time at once. Yet each narrative’s protagonist occupies a temporality which is a hybrid of the two. I borrow the term kakokairos from Remi Yergeau and use it to describe autistics’ unusual experiences of time. I understand these experiences as akin to the hybrid temporalities featured in the aforementioned narratives. That theoretical work served as the foundation for a series of 15 interviews that I conducted in summer 2023. These interviews occurred over Zoom, with participants tuning in from four continents. Interviewees were self-identified autistics who were familiar with at least one of four science fiction narratives: the prior two, along with Ursula Le Guin’s *The Dispossessed* and Denis Villeneuve’s *Arrival*. The premise is that sharing these narratives allowed us to discuss temporal phenomenology (i.e. how people experience time) without resorting to the field’s notoriously complicated jargon. The present paper outlines my interview methodology, which was a form of distributed storytelling that was rooted in neurodivergent communication practices. And while autism is not an illness in-and-of-itself, many participants discussed their experiences with chronic pain and their struggles with PTSD – and I have shared some of my preliminary findings on this subject as part of a panel on “Trauma” at 2025 International Conference on Narrative.

Bio: Sean Yeager is a Visiting Assistant Professor of Science and Nature Writing at Kenyon College. Their data-driven visualizations of narratological temporal structures received the Paul Fourtier Prize for best paper by an emerging scholar at the 2019 Digital Humanities Conference. Their research on neurodivergent reading practices received honorable mention for the Nadal Prize at the 2022 International Conference on Narrative, and their theorization of autistic temporalities received honorable mention for the Bruns Prize at the 2024 meeting of the Society for Literature, Arts, and the Sciences. Sean studies contemporary literature through the lenses of narratology, digital humanities, and neuroqueer theory.

3. “Queer Aging, Intersectional Illness, and Narrative Witnessing”

Christian Schulz-Quach

Abstract: This presentation examines illness narrative through the dual lens of healthcare professional and lived experience patient, situated within intersectional queer and trans identities. Anchored in the award-winning short documentary "On Queer Aging and Endings” (Director: Christian Schulz-Quach, 2025, 19min), the paper explores the biography of Esben Esther Pirelli Benestad—a pioneering Norwegian trans physician and queer rights advocate diagnosed with advanced colon cancer—as both subject and narrator. The work foregrounds the multiplicity of contemporary illness narratives, challenging the crisis model by centering ongoing, relational, and collective dimensions of patienthood, identity, and care.

Through filmed dialogues and creative witnessing, the documentary and this analysis highlight the entanglement of medical expertise and existential vulnerability when the professional is also the patient. The narrative disrupts conventional boundaries of clinician and storyteller, revealing how queer temporality, aging, and mortality are experienced and articulated at the intersection of cancer care, trans embodiment, and evolving social contexts. The presentation also addresses issues of voice, agency, and story ownership, drawing from both the subject's testimony and the filmmaker's own professional engagement with sexual and gender diversity in oncology.

This contribution situates illness narrative as inherently intersectional and dynamic, reflecting contemporary shifts toward chronicity, distributed storytelling, and digital mediation within queer and trans health experiences. By foregrounding plural identities and the creative encounter between filmmaker, subject, and community, this work calls for expanded narrative models that recognize the ethical, political, and affective complexities of narrating illness in an entangled, digitalized, and diverse world.

Bio: Christian Schulz-Quach is an Associate Professor in the Department of Psychiatry at the University of Toronto and Medical Director of the Sexual and Gender Diversity in Cancer Care Program at Princess Margaret Cancer Centre, UHN in Toronto, Canada. A psychiatrist, psychoanalyst, and filmmaker, Schulz-Quach integrates lived experience and clinical expertise across intersectional healthcare, workplace violence prevention, and gender-affirming oncology. Their documentary work, including the award-winning short "On Queer Aging and Endings", explores queer aging, trans health, and mortality through intimate narrative forms. Schulz-Quach's scholarship examines existential psychoanalysis, healthcare systems, and the intersections of professional knowledge and patient experience. They hold doctorates in neurobiochemistry, psychoanalysis and a global executive MBA in health leadership.

Panel 8: Health and Illness in News and Journalism

Room: 1420-234-M2.2
Chair: Peter Simonsen

1. “When Health Journalism Becomes Economic Policy”

Anna Krogh

Abstract: “One in eight people worldwide has a mental disorder. It costs the global economy billions”. This is the headline of an article published in the Danish newspaper *Kristeligt Dagblad* on September 23, 2025. This article is just one among many health-journalistic news articles in which economic arguments are used to explain why it is relevant to talk about a given disease at a given time. By examining a range of Danish health-journalistic news articles through a rhetorical lens, drawing on the theory of topics, this paper explores how health-economic news angles shape which illness narratives are represented in health journalism, and perhaps more importantly, which are marginalized or excluded. As Phelan emphasizes, rhetorical readings offer “valuable knowledge about narrative” (2023), which can complement other modes of reading. My rhetorical perspective on illness narratives thus functions as a supplement to other approaches. The theory of topics is both broad and pluralistic, ranging from Aristotle (1983) and Cicero (1993) to Burke (1950) and Toulmin (1958, 1984). Across positions, one of its key strengths lies in foregrounding framing, making topoi (meaning “places”) particularly useful for identifying news angles and the often implicit warrants they carry. Among the many existing topoi, some frames become institutionalized over time. One of them is the economic topos (meaning “place”), which several scholars have described as an exceptionally powerful and pervasive frame that seeps across multiple domains. But what happens when the economic topos operates within health journalism? I argue that the deployment of an economic topos not only shapes the illness narratives we encounter in health-journalistic news articles, but also determines which diseases are granted news value and column space. In this way, health journalism risks functioning as a form of economic policy, prioritizing diseases that can be framed as costly over those that resist economic quantification.

Bio: Krogh is a PhD student at the Department of Comparative Literature and Rhetoric at Aarhus University. Her research examines how the use of rhetorical strategies (such as narratives and framing) in Danish news media coverage especially of depression, COPD, and dementia simultaneously enable and constrain the public conversation about health and diseases, and the significance of this rhetorical tension for the establishment of openness and plurality in health journalism. In addition, she is affiliated with the Center for Health Communication and Center for Rhetoric, both based at the School of Communication and Culture at Aarhus University.

2. “Public/Private Illness: AIDS Narratives in Danish Print Media”

Camilla Bruun Eriksen

Abstract: In this paper, I present findings from my archive of approximately 2,500 newspaper articles on the Danish AIDS crisis, drawing in particular on my article *The Moral Tapestry of AIDS: Negotiations of Innocence and Blame in Danish Media Narratives* (2025). The article analyzes media portrayals of groups affected by AIDS, including gay men, haemophiliacs, heterosexual women, children, sex workers, immigrants, and drug users. Building on this material, I examine how Danish print media narrated the AIDS epidemic from 1981 to 1996, transforming private experiences of illness into public moral stories, and how journalistic narratives organized these diverse experiences through a framework of innocence and blame.

Certain figures—most notably children and haemophiliacs—were constructed as “particularly innocent” victims and became emblematic of the tragedy of AIDS, attracting empathy and public recognition. Others—especially gay men, drug users, sex workers, and immigrants—were framed as “morally blameworthy” and were met with stigma, fear, and social exclusion.

The paper further highlights how the racialisation of AIDS in Denmark enabled the control and disciplining of racialised bodies and worked in tandem with the production of a national health crisis narrative. Together, these media constructions shaped public debate and legitimised political interventions, culminating in the passing of the HIV Act in 1994. By tracing how print media circulated and stabilised these narratives, the paper shows how ownership of illness stories shifted from affected individuals to public discourse, reinforcing hierarchies of morality, sexuality, race, and national belonging.

Bio: Camilla Bruun Eriksen is associate professor in Gender Studies at the Center for Gender, Sexuality and Difference at the University of Copenhagen, Denmark. Her research is rooted in cultural studies and grounded in critical theory, particularly poststructuralist feminist theory and affect theory. Drawing inspiration from feminist and gender studies traditions such as queer, crip, and fat theory, her work explores how questions of health, power, gender, and sexuality operate across both aesthetic culture and everyday popular culture. Through a broad analytical approach, she investigates contemporary and historical cultural phenomena, media, institutions, and technologies, examining how bodies, emotions, and identities are produced and negotiated within these contexts.

3. “Did You Sleep Alright? Small Stories about Sleep between Health and Illness”

Maja Klausen and Yukun You

Abstract: Did you sleep alright? A question we frequently ask to someone we care about. The question does not simply inquire about last night; it carries an implicit awareness that sleep is never guaranteed*,* never stable and acknowledges sleep as a volatile, day-to-day achievement, a potential minor battle to be won again each night. In this paper, we explore sleep as fluctuating between health and illness by engaging with mediated sleep and people’s everyday experiences of sleep and sleep trouble, specifically, the ambivalent entanglements of (digital) media with sleep (Coveney et al., 2023; Williams, 2011).

Stories of sleep rarely are about episodic crisis and biographical disruptions, rather, sleep trouble show up as what Bamberg & Georgakopoulou (2008) refer to as ”small stories”: Brief, situated tellings of or hesitations about on-going, future or hypothetical events. Narratives about sleep cast sleepers as at-risk subjects and they rarely cohere into a single event, rather they unfold as diffuse, re-occurring and entangled with anticipatory health technologies (Stage & Nielsen, 2025) like apps, SoME and wearables, co-authoring how sleep, sleepiness, (un)rest and hygiene surrounding sleep is experienced and retold.

Our analysis draws on two empirical strands from the *ToSleep*-project funded by The Carlsberg Foundation (2025-2028). First, a cultural-historical analysis of Danish news papers (around 1920-1940) traces early public discourses on sleep, articulated across different genres and voices including medical experts and commercial advertisers, illustrating how mediated stories of sleep's entanglement with blame, productivity and risk have long circulated. Second, interviews, workshops and media diaries with ”healthy” Danes (not chronically ill, +18 years of age) explore(digital) sleep technologies and everyday night life, and show how people narrate their nightly routines and sleep as fluctuating, uncertain states haunted by algorithmic feedback, wearable data, and cultural norms.

Bio: Maja Klausen is associate professor in Media Studies at Department of Design, Media, and Educational Sciences, University of Southern Denmark. She is PI of the Carlsberg Foundation-funded project *ToSleep: Decelerative media and technologies of sleep in the everyday* (2025-2028). Her research is situated in the field of digital health communication exploring empirical perspectives on transformations of health and illness in digital and datafied everyday life.

Bio: Yukun You is a postdoc researcher in Media Studies at Department of Design, Media, and Educational Sciences, University of Southern Denmark. She researches sleep-tracking technologies and user experiences at the *ToSleep*-project. Her research interests are self-tracking and digital wellbeing, mobile apps and advanced technologies, and digitalisation and everyday life.

Bio: Sofie Exner Koch is a PhD student in Media Studies at the Department of Design, Media and Educational Science, University of Southern Denmark. Her PhD is part of the *ToSleep*-project and focuses on the cultural history of sleep in Denmark, examining how sleep has been mediated across different historical periods. Through analyses of media her work explores how sleep functions as a site where morality, norms, political agendas, and technological developments intersect.

Panel 9: Writing Uncertainty

Room: 1427-246-M2
Chair: Anna Krogh

1. “Inhabiting the Unmasterable Now: The Narrative-Epistemological Paradox in Samantha Harvey's *The Wilderness*”

Fahime Serhatti

Abstract: This presentation examines the temporal architecture of Alzheimer's disease in Samantha Harvey's *The Wilderness*. Focusing on Jake, the protagonist whose sense of time and self dissolves throughout the illness, I contend that Harvey's novel functions as a complex narrative apparatus that negotiates the “narrative-epistemological paradox” (i.e., the challenge of conveying a condition that resists both knowing and narrating) inherent to the representation of cognitive decline. Through close reading, I suggest that the novel inhabits an unmasterable now, depicting Alzheimer's as an ongoing present that unsettles linear time and narrative conventions. Drawing on Susanne Katharina Christ's framework in *Fictions of Dementia* (2022), distinguishing between “simulating *what is*” (the lived experience) and “reflecting upon *what it is like*” (the interpretive, often metaphorical representation), my analysis proceeds in two phases. First, I demonstrate how Jake's perspective simulates the fragmented temporality of Alzheimer's, capturing his attempts to impose order and tame the symptoms of the disease. Second, I analyze how the narrator's reflective voice, particularly through metaphors such as the overgrown garden and the wilderness, helps readers navigate and make sense of this disorientation without offering false resolution. Ultimately, I propose that Harvey's narrative resists the crisis model of illness narratives that privilege order and hopeful resolution. Instead, the novel records the lingering erasure of self within a continuous, overgrown present. By foregrounding the impossibility of restoring health or an optimistic ending in Alzheimer's narratives, Harvey invites readers to traverse a spatialized wilderness rather than pursue resolution.

Bio: Fahime Serhati, Assist. Prof. Dr. School of Foreign Languages, Yuksek Ihtisas University, Ankara, Turkey Department of Foreign Language Education, Middle East Technical University, Ankara, Turkey Email: fahimeserhatti@gmail.com & fahime@metu.edu.tr

2. “Altered Paths: Narrating Age-Related Memory Loss”

Alex Pickett

Abstract: Amnestic Mild Cognitive Impairment (aMCI), generally, is diagnosed when a person’s memory range is below that of what is expected of people their own age. Yet, though aMCI affects millions of people, the condition has rarely, if ever, been specifically addressed in literary works or examined in literary studies. This paper explores how qualitative research and critical analysis can be utilised to create a fictional voice for age-related memory loss as well as map a potential future for a character who lacks the ability to create memories. My goal is to animate and offer new directions for the illness narrative as literary fiction through the process of writing my novel-in-progress, which is told from the perspective of a septuagenarian living with aMCI. I will discuss my current research study—undertaken with Professor of Neuropsychology Catherine Loveday and in conjunction with the eldercare charity Age UK—combining these findings with 1) critical analyses of linguistic study via “mind style,” 2) literary studies involving character development without the use of memory, and 3) neuropsychological investigations into how the mind functions with age-related memory loss. Ultimately, through a discussion of my methods and a reading of my novel-in-progress, I will demonstrate how the creation of a fictional voice for aMCI will offer new narrative possibilities that provide both a literal and metaphorical altered path; one that allows the character to change his relationship with time and prioritises the immediate environs of his experience, shifting from a defunct view of selfhood—i.e. the creation and accumulation of achievements and memories—to a transformed self via an unconventional narrative. By reflexively narrating my methods of creating a fictional voice for the subjective terrain of cognitive impairment, this talk demonstrates how such a voice can challenge representational modes and literary conventions of age-related memory loss.

Bio Alex Pickett is a second-year doctoral researcher in Creative Writing at the University of Westminster with funding through the Quintin Hogg Trust. He is the author of two books of fiction: a novel, *The Restaurant Inspector*; and a short story collection, *Camera Lake*, both published by University of Wisconsin Press. His short stories have been published in numerous literary journals.

3. ““Not be able to think doesn’t mean to not know”. Ethics and the essay in Anne Boyers *The Undying* (2019)”

Luna Dieleman

Abstract: Anne Boyer structures the opening of *The Undying: A Meditation on Modern Illness* (2019) around a metanarrative inquiry into the (un)easy proximities between the autobiographical “I” and the act of writing about breast cancer through that “I” (Boyer 2019). Through intertextual reflections, Boyer introduces an “I” that is neither neutral nor self-evident but acutely aware of its own formation within the cultural expectations and conventions that shape the forms, affects, and truths of breast cancer narratives (Wasson 2018; Green 2025). Beyond the preface, Boyer’s quotations and other referential practices anchor her illness experience within a broader critique of contemporary healthcare under neoliberalism (Boyer 2019). Through an “essayistic mode”, the author opens a space where the public and the private, the intimate and critical distance converge (Aquilina 2022; De Obaldia 1995)

In my contribution, I approach metanarrative passages as key sites where the essayistic mode of reflecting on (illness) experience and its narration becomes explicit and further developed (Meretoja 2022). Drawing on the notion of “metaization” - both as a self-reflexive engagement with cultural practices of narrative meaning-making and as a “cognitive process that requires active readerly reflection” (Wolf 2007) - I examine how such moments not only prompt readers to question the conventional narrative frameworks of illness writing, but also invite them to reflect on the ethical assumptions embedded within those conventions (Struth 2019). Through an ethical-narratological reading (Berning 2013; 2017), I analyze how Boyer employs metanarrative strategies to explore tensions between certainty and uncertainty and to introduce an “ethics of unknowing” (Russell 2021), a mode deeply involved in representing, constructing, and circulating values and norms surrounding questions of knowledge about illness and individual and collective perceptions of self and other within that knowledge.

Bio: Luna Dieleman (° 1996) is a PhD candidate at the Department of Literary Studies at Ghent University. She is a member of the CHARM network (Consortium for Health Humanities, Arts, Reading, and Medicine) and, within this context, works on a research project on the meanings and functions of the concept of ‘discomfort’ within contemporary illness writing. The supervisors of the project are Prof. Jürgen Pieters and Prof. Zoë Ghyselinck. Dieleman also participated in the Erasmus+ project *Essays Beyond Borders,* focused on exploring and promoting the use of essayistic writing to encourage civic engagement and develop critical and creative thinking abilities.

Panel 10: Narrating and Governing the Female Body

Room: 1421-118-M1.1
Chair: Lisbeth Frølunde

1. “Representation of Illness Narrative in Contemporary Slovak Fiction: Mental Illness Experience and Strategies of its Mediation to Public Through Literature”

Eva Dudáková

Abstract: The study of autobiographical accounts of mental illness has, for centuries, been a valuable source of insight into the subjective experience of such conditions for individuals who have not personally encountered them. Despite the advances in neuroimaging and other medical technologies, it is asserted that only individuals who have experienced mental illness firsthand are capable of authentically conveying its subjective dimensions. It is conceivable that, to circumvent the social stigmatisation associated with being perceived as a mental patient, some individuals have opted to present their narratives as fictional accounts. Irrespective of their personal choices in this regard, the desire to comprehend their experiences and the aspiration to assist other patients and their families have been potent motivators for the numerous patients who have documented their encounters with mental illness. In the context of Slovak contemporary literature, Ivana Dobrakovová has assumed the role of narrator, addressing these themes. The quality of her work has been demonstrated by a plethora of positive reviews and awards. Literary critics have designated her literary repertoire of six books as “one big text”, a designation that underscores her approach to depicting illness across various phases of the human life cycle. In her literary works, she employs a narrative strategy known as a “chaos narrative”, in which the experience of depression, OCD, bulimia and other mental illnesses are conveyed to the reader authentically. The present study will examine specific aspects of I. Dobrakovová's depiction of the mental illness that lingers and transforms in the context of the life's different stages. The objective of this paper is to analyse the utilisation of language in chaos narrative (with particular reference to fragmentation, stream of consciousness, elliptical sentences, defective syntax and parataxis) and explore the author's gradual transition from the genre of fiction (or autofiction) to that of autobiography which can be perceived as indicative of a broader societal shift towards greater openness regarding mental health issues, but it is also likely to reflect the author's personal journey of acceptance.

Bio: My name is Eva Dudáková, and I am currently in my third year of a doctoral programme at the Faculty of Arts at Matej Bel University in Slovakia. I completed a Master's degree with honours in 2023, and I am now in the final stage of my PhD (with a defence scheduled for June). Throughout my academic studies, I have presented my research at eight international and national conferences and had articles published in several anthologies and indexed journals (ERIH+). In my dissertation, I analyse contemporary Slovak literature, particularly Slovak prose written by women. One of my research objectives is to examine how mental illness narratives are formulated in the literary works of Slovak writer Ivana Dobrakovová, and to identify the distinguishing features of her depiction of mental illness and hereditary psychological disorders in Slovak literature. I would be delighted to discuss the topic in more detail at the conference.

2. “Between Confinement and Self-Making: Autobiographical Narratives of Institutionalized “Mad” Women in Europe and Latin America”

Natacha Ferreira Moreira

Abstract: This paper examines autobiographical narratives produced by women who experienced institutionalization in the 19th and 20th centuries, focusing on a comparative corpus from Europe and Latin America. In a period marked by the consolidation of medical and legal regimes of confinement, women’s life writing emerged as a powerful site of self-inscription, where subjects negotiate authority within structures designed to silence them. While personal testimony has long been recognized as a key mode through which marginalized subjects negotiate visibility and agency, the life writing of institutionalized women remains understudied within narrative theory, particularly regarding its socio-historical specificities. Drawing on memoirs, letters, and other forms of self-narrative authored within or after confinement in asylums, the paper explores how these women articulate experiences of discipline, moral scrutiny, and bodily regulation. The analysis contrasts European cases, shaped by Enlightenment rationalities and emergent psychiatric paradigms, with Latin American contexts marked by colonial legacies, Catholic moral frameworks, and hybrid forms of institutional governance. This comparative approach highlights how social and moral diagnoses of madness operated beyond strictly medical frameworks. Many of these narratives make sense of how accusations of deviance, immorality, or insubordination functioned as sociopolitical tools to regulate women’s behavior, particularly those who transgressed gendered expectations. The paper situates women’s autobiographical production within broader histories of coloniality and patriarchy, demonstrating how their narratives expose the power relations embedded in the very act of defining, confining, and narrating “madness.” Methodologically, the study uses feminist theory to trace how narrative authority is constructed amid coercion and institutional mediation. Ultimately, the paper argues that these autobiographical texts form an alternative historical archive of gendered confinement and resistance, illuminating how women in different colonial and metropolitan settings mobilized narrative as a tool for survival, legitimation, and self-making.

Bio: I hold a Bachelor’s degree in Media Studies and I am currently a Master’s student in Communication at Universidade Federal Fluminense (UFF), Brazil. My research interests encompass gender, media and society, digital technologies, and Global South perspectives, with particular attention to the social and symbolic construction of the “mad woman”. Methodologically, my work is informed by discourse analysis and critical theory, drawing on interdisciplinary dialogues between communication studies, sociology, and feminist scholarship. In 2026, I am scheduled to undertake a MA research stay at the University of Tübingen, where I will be affiliated with the Center for Global South Studies.

3. “Incomplete Stories of Illness and Suffering”

Kristen Loutensock

Abstract: In the late 1990s, as a cluster of diagnoses became more common in the U.S. context, an idea of the “chronically ill” woman began to emerge. The diagnoses of Chronic Fatigue Syndrome and Environmental Sensitivity were primarily attached to wealthy and white women in the popular media, drawing explicitly comparisons to hysteria and neurasthenia. Two films, *Safe* (1995) and *Mumford* (1999), were released into this larger cultural context, presenting views of chronic illness as a reversion to 1900s feminine responses to the pressures of modernity. Just as in the early 1900s context, the press around both films stressed that the illnesses suffered by these women were not measurable on recognized medical tests and posited a psychological link between stress, gender, class, and illness. Yet both films also present a version of the ill female body that lies outside biomedicine, visually opening up space for doubt in the biomedical mapping of the female body. In this paper, I argue that the illnesses in these films act as a precursor to the representation of long COVID in the 2020s: simultaneously visual and invisible, gendered and amorphous, medicalized and psychologized. The women in these films tell an incomplete story of illness and suffering, with the camera mediating and reminding the spectator of the limitations of medicine as an empathetic science. Instead, sympathy is foregrounded as a narrative and visual mode, re-opening a space for a ‘feeling alongside’ that offers a way forward in the modern moment in opposition to the ‘feeling into’ of empathy.

Bio: Kristen Loutensock received her PhD in Film and Media from the University of California, Berkeley, where she wrote a dissertation titled “Narrative Disorder: Autism and Genre in American Popular Culture.” She works between and across the fields of history of medicine, disability studies, health humanities, film studies, and gender and sexuality studies, and her current book project focuses on the representation of medicine in American film and television. Presently a lecturer in the Honors College at the University at Albany, she has previously held appointments in gender studies, disability studies, American studies, and film studies, and was the Mellon Postdoctoral Scholar in Health Humanities at St. Lawrence University.

Panel 11: In and Beyond the Pandemic

Room: 1420-234-M2.2
Chair: Sondre Kvamme

1. “More than a Virus: A Syndemic Approach to COVID-19 through Epistolary Literature in the U.S.”

Marta Fernández-Morales

Abstract: A few months in, it became clear that the COVID-19 pandemic was not merely a health problem. As Ien Ang suggested, it could be seen “as part of a long-term planetary crisis” (2021, 600).[1] The global conversation therefore expanded onto issues like inequality, geopolitics, healthcare models, and environmental awareness. The U.S., in particular, was experiencing extreme tension rooted not only in the management of the disease, but also in social injustice and the domestic chasm that resulted from Donald Trump’s decision-making. Invited by *Orion* magazine for the *Together Apart* series created during the lockdown phase, American authors Pam Houston and Amy Irvine maintained an intense correspondence that was later published as *Air Mail. Letters of Politics, Pandemics, and Place* (2020). In it, they addressed the virus, but also gender roles, systemic racism, trauma, healthcare and environmental policies, the future of feminism, and the role of writers during the COVID scare. The focalization on a complex present where several serious crises were interacting dominated the narrative.

Using a close reading method and within the epistemological paradigm of the Medical Humanities, this paper argues that Houston and Irvine’s portrayal of the COVID-19 scenario in *Air Mail* is best captured by the term *syndemic* as described by Richard Horton, that is, a phenomenon characterized by biological and social interactions between conditions and states, which cannot be fought solely with biomedical means (2020, 874).[2] As my analysis of its authors’ thematic and narratological choices will prove, in *Air Mail* COVID-19 features as a multi-dimensional syndemic in which a biomedical problem has to be faced simultaneously with profound challenges on the socioeconomic and environmental fronts. As ecofeminist activists, Houston and Irvine understand nature and our cultural and political conception thereof, as well as the body and its material conditions, as inseparable.

Bio: Marta Fernández-Morales is Professor of English Studies at the University of Oviedo, Spain. Her research explores American literature, film, and television. Her work has been published in journals like *Auto/Biography Studies*, *Tulsa Studies in Women’s Literature*, and *American Drama*. She has edited eight scholarly volumes and written five; the most recent one just published: *Rape Narratives that Paved the Way for #MeToo. The Crack in the Wall*. She is a member of the Research Group ‘HEAL’ at her home university (https://www.unioviedo.es/heal/), and this paper is part of a Medical Humanities project funded by the Spanish Ministry of Science (ref. PID2024-157649OB-I00).

2. “Recovering Hope or Hoping for Recovery? Narratives of Rehabilitation Potential and Imagined Futures among Long COVID Patients in Denmark”

Charlotte Nørholm and Anna Louise Skovgaard

Abstract: Long COVID has profoundly altered the lives of those affected, leaving patients in a state of chronic uncertainty regarding their health, social roles, and future prospects. While symptoms vary, many patients experience persistent exhaustion, not only as a bodily limitation but also as an existential condition. In the absence of established clinical knowledge about its trajectory and prognosis, Long COVID places patients in a state of chronic crisis, in which illness is neither an acute episode nor a stabilized chronic condition, but an open-ended temporal predicament that requires continual narrative adjustment. Based on ethnographic interviews with Long COVID patients in Denmark, this study explores how patients narrate their aspirations for the future in a prolonged state of disruption, suspended between expectations of recovery and forms of temporary chronic living. Drawing on the concept of horizon work, we investigate how patients continuously reconfigure and reorient their hopes and expectations by narrating the complex entanglements of bodily symptoms with medical assessments, rehabilitation programs, welfare benefits, and social relations. Through examples from our interview material, we demonstrate how patients fluctuate between hopes of bettering and fears of worsening when symptoms evolve, persist, or reappear, and how they manage everyday dilemmas between resting and participating in work or social life, as even minor exertions may trigger prolonged exhaustion, symptom flare-ups, and social withdrawal. Rather than a linear progression towards healing, we argue that rehabilitation is narrated as an ongoing process of reconfiguring expectations and aspirations for what constitutes a livable present and a desirable future. The study contributes to contemporary debates on pandemic illness narratives, suspended temporalities, and chronic living by showing how Long COVID patients actively reimagine their sense of self, health, and everyday life under conditions of prolonged uncertainty, where illness futures and hope must be continually renegotiated.

Bio: Charlotte Nørholm holds a degree in anthropology and a PhD in clinical medicine from Aarhus University. Guided by her interest in health technologies and how they transform everyday life and clinical practice, she has conducted ethnographic research on digital health, diabetes management, chronic illness, healthcare infrastructures, and pandemic testing. She is employed as a researcher at Hammel Neurorehabilitation Centre and University Research Clinic, Hammel Regional Hospital, where she is investigating patient non-attendance in ambulatory care settings.

Bio: Anna Louise Skovgaard holds degrees in anthropology, nursing, and a PhD in clinical medicine from Aarhus University. Her research is situated within medical anthropology/medical humanities, with a particular interest in chronic illness, pain, illness work, and decision-making. She is employed as a postdoctoral researcher at the University Clinic for Interdisciplinary Orthopaedic Pathways, Elective Surgery Center, Silkeborg Regional Hospital; the Interacting Minds Centre, Department of Clinical Medicine, Aarhus University; and the Research Unit of General Practice, Department of Public Health, University of Southern Denmark.

3. “Pandemic Pages: Building a COVID-19 Archive Through Academic Podcasting”

Lucyl Harrison

Abstract: Valeria Luiselli observes that “the first novels about COVID-19 written during the pandemic are a kind of primary-source archive that later might be built on” (2022). This paper examines how Pandemic Pages podcast developed the “primary-source archive” into the collaborative spaces of podcasting. Drawing from three seasons of published conversations with contemporary writers, medical practitioners and academics on Pandemic Pages (including Dr Roopa Farooki, Polly Crosby, James McDermott, Dr Mark Honigsbaum, Charlotte Wood, Professor Lucy Easthope, Dr Ane Thon Knutsen, and Roddy Doyle), the paper explores how COVID-19 literature highlights discourses of illness cultures and pandemic lived experience. Professor Lucy Easthope, the UK’s leading expert on disaster recovery and advisor to the British Prime Minister’s office on COVID-19 pandemic said Pandemic Pages “is fundamentally capturing the fragile that is so valuable in disaster studies… disaster research with a different ethical framework, a different urgency… an incredibly rare and excellent project”. The paper reflects on podcasting as a method of research methodology, public engagement and knowledge exchange. In the absence of an established body of secondary literature on COVID19 fiction, *Pandemic Pages* uses oral history interview formats to record and publish illness narratives across broadcast media, social platforms and streaming platforms, highlighting how viral pandemic illness narratives allow insight into disaster recovery and the evolving landscape of illness storytelling around COVID-19 and Long COVID. It also reflects on my experience of embedding the podcast as a supplementary pedagogical tool in my teaching at the University of Hull and how the podcast balances depth and accessibility.

Bio: Lucyl Harrison is a doctoral researcher in the Medical Humanities at the University of Hull. She was awarded a scholarship on the Living with Death: Learning from COVID project, and her thesis, ‘‘On Being Ill’: Writings from the 1918 Influenza Pandemic and COVID19’, is due for submission in March 2026. She is the founder and cohost of Pandemic Pages, a podcast featuring conversations with authors, academics, medical professionals, and creatives. Launched in 2023, the podcast ranked in Spotify’s top 30% of podcasts in 2025. Lucyl is a Story Maker for the National Centre for Writing in Norwich and a member of the Larkin Centre for Writing in the Humanities at the University of Hull. Her writing has appeared in The Journal of Gender Studies, The Polyphony (University of Durham), and The Conversation, and she has contributed to programmes on BBC Radio.

Panel 12: The Narratives and Dangers of Care

Room: 1421-118-M1.1
Chair: Nora Simonhjell

1. “Illness and Its Many Voices”

Linda Hamrin Nesby

Abstract: This paper examines the significance of the enunciative instance particularly within caregiver narratives, with particular attention to how positions and perspectives narratively slide into one another. On this basis, the paper explores the caregiver narrative—curography—as a narrative form that always carries within it a patient narrative. The analysis takes as its point of departure Kjersti Annesdatter Skomsvold’s novel *Syke søster* (2023*)*, in which the narrator has died of anorexia and retrospectively recounts both her own illness and her twin sister’s life as the surviving caregiver. The posthumous narrative position destabilizes established assumptions about the relationship between patient and caregiver. The novel demonstrates how patient and caregiver positions are deeply entangled, as the experience of illness emerges as distributed across the sisters’ relationship. This reading is placed in dialogue with Vigdis Hjorth and Line Hjorth’s autobiographical novel *Kul i brystet* (2025), which recounts the year in which both authors were diagnosed with breast cancer and the complex flux of being both patients and each other caregiver. Despite clear generic differences, the two works share a narrative interest in distributed authorship and caregiving – something not exclusively belonging to the caregiver role. As a historical contrast, the paper also briefly draws on *Cancer in Two Voices* (1978) by Sandra Butler and Barbara Rosenblum, an early dual patient–caregiver breast cancer memoir in which the two narrative voices are clearly separated, and narrative authority remains more firmly anchored in the perspective of the ill subject. Through these analyses, the paper contributes to the field of illness narrative research by showing how illness does not appear as an individual and acute biographical disruption, but rather as a prolonged, relational, and narratively entangled condition, in which patient and caregiver voices continuously constitute one another.

Bio: Linda Hamrin Nesby is Professor of Nordic Literature at UiT The Arctic University of Norway. Her research focuses on illness narratives, patient and caregiver writing, and the relationship between literature, health, and society. She is the author of *Sinne, samhold og kjendiser* (2021) and one of the editors of *I skyggen av sykdom* (2024), and has published widely on pathographies and caregiving narratives in contemporary Scandinavian literature. Nesby leads the research group *Health, Art and Society* at UiT and is co-editor of *Edda. Nordisk tidsskrift for litteraturforskning*.

2. “Being Your Own Caregiver: The Use of Second-person Narration in Eivind Grip Fjær’s Novel *Det stemmer ikke*”

Sondre Johan Chesney Kvamme

Abstract: In this paper, I argue that second-person narration can act as an act of self-care for patients. As a case point, I will focus on the novel *Det stemmer ikke* [That is not right] (2021) by Eivind Grip Fjær, which depicts a man who is diagnosed with cancer. The novel is narrated as a traditional second-person narrative, meaning that there is no marked instance of enunciation, and the protagonist is referred to as «you». Firstly, the paper draws on second-person narrative theory, as well as Pernille Meyer's new second-person narrative typology (2024). Secondly, this is related to Grace Hibsham's theory of conceiving one's own life as a second-person narrative. Hibsham states that «conceiving of one's life narratively facilitates taking on the second-person experience that an audience would have in hearing one's life narrative» (2022, 616). Then, I relate this second-person experience to being a caregiver, and finally argue that *Det stemmer ikke* can be read as a caregiver narrative, or curography as Linda Nesby has termed it (2023).

The analysis of the novel demonstrates how traditional caregiving practices on the part of relatives and loved ones can solidify the ill person's role and self-perception as a patient. The narratological reading offers new perspectives to thematical readings in Medical Humanities, and offers insights into what it means to be both ill and a caregiver. By focusing on the second-person form, the novel expands the understanding of curographies to also include the ill person, and underscores the importance of self-care for the ill.

Bio: Sondre Johan Chesney Kvamme is a ph.d. student in Nordic literature at the University College of Volda. His ph.d. project is titled "Second-Person Narratives and the Caregiver Role". It focuses on second-person narration in a selection of Norwegian texts depicting caregivers. Pernille Meyer (Aarhus University), Linda Nesby (University of Tromsø) and Wenke Mork Rogne (University College of Volda) are supervising his project.

3. "The Paradox of Care: 'Controlling' Care in Narratives of Madness"

Tarun Athmika

Abstract: This paper examines the structures of care that mediate the relationship between patients, physicians and other professional and non-professional caregivers. Care is inherently normative: practices of care function as techniques of control and governmentality, and are shaped by the logics of neoliberal capitalism. If neoliberalism is celebrated for idealising freedom over equality and choice over control, practices of care expose the paradox at the heart of access to modern care. Focusing on three autobiographical narratives of mental illness (or "madness"), this paper interrogates and queers our dominant notions of care. These readings demonstrate how caregiving and care-receiving are organised around prescriptive ideals of the individual, one embedded within normative strictures of family and kinship. The three narratives are Kate Millett's *The Loony-Bin Trip* (1990), Swadesh Deepak's *I Have Not Seen Mandu* (2021), and Emma Grove's *The Third Person* (2022). The analysis draws on theoretical frameworks from Annemarie Mol's *The Logic of Care* (2008), Alison Kafer's *Feminist, Crip, Queer* (2013), Kathleen Lynch's *Care and Capitalism* (2022), among others.

Bio: Tarun Athmika is a doctoral candidate at the Indian Institute of Technology Delhi, working in medical humanities. His research examines representations of madness in autobiographical prose and comics, with a particular focus on personality and identity disorders. His broader interests include narrative medicine, the cultural history of psychiatry, and the intersections between literature, visual studies, and mental health. He is currently developing a series of articles on how narrative prose and comics shape understanding of psychiatric diagnoses, and has presented his work at several international conferences. He was recently a Visiting Scholar at Project Narrative at The Ohio State University.

Panel 13: (Post)reproductive Storytelling

Room: 1420-234-M2.2 Chair: Maja Klausen	**1. “What is at Stake in Social Influencers’ Stories about Pregnancy and Childbirth? The Case of Norway”** **Kari Nyheim Solbrække** Abstract: Fertility in a broad sense is of considerable importance to a nation in terms of identity construction and self-reproduction (Foucault, 1984). Today, it clearly aligns with our current era of polycrises, where political statements and changes around fertility are becoming increasingly prevalent, especially in the context of new leadership and administration in the United States. In Norway, on the other hand, there seems to be a more subdued concern about declining birth rates, which since 2009 have been negative, but surprisingly positive over the past two years. Taking a closer look at this field of social life, a remarkable narrative tendency is unfolding, namely the stories of pregnancy and childbirth told via social platforms, often by so-called influencers. Some of their narratives are not necessary in contrast to established and state ways of articulating how this process should be best managed, while other stories show explicit complaints about the traditional expert knowledge that the government and health professionals tell and advise citizens about prenatal birth, childbirth and postnatal care. In this paper, I want to explore some prominent Norwegian health influencers and their stories about pregnancy and childbirth on social media to shed light on the following: When the storytellers are not ill in any conventional sense and neither are in any form of health crises, to what extent can their stories be considered illness narratives at all? If not, is it perhaps more fruitful and relevant to define these narratives as part of late modern health activism (Rabeharisoa et.al 2014)? Bio: Kari Nyheim Solbrække is professor at the Institute of Health and Society, Faculty of Medicine, University of Oslo. Solbrække specializes in medical sociology, gender studies and qualitative methods, which includes a longstanding interest in narrative oriented theory and methods. During 2020-2025 she directed the Norwegian research project *Rethinking Cancer survivorship,* leading to several publications in international peer review journals as well an open access anthology in Norwegian. Currently she is part of a project aiming to enhance social support in the community for cancer patient living alone. Solbrække is also involved in research on patient activism in a Norwegian context.
	2. “#HotFlash: Menopause Influencers, Misinformation, and Me” **Sarah Brophy** Abstract: This presentation will trace the contours of the early 2020s health and wellness digital mediasphere, and explore the potential for an automedia lens to help us parse this domain critically and to understand its political and personal implications. Taking the subgenre of menopause wellness influencers as an analytical focus, I will combine theoretical work with discourse and media analysis and critical reflection on my own encounters with such content. I will begin by discussing how a members of an online cohort that Brené Brown has dubbed “the menoposse” are positioning themselves as stigma-breaking champions of middle-aged cis women’s health as they seek market share for supplements, moisturizers, and private clinics. I will then consider how, why, and to what effects evidence-informed clinician-advocates, as they jostle for visibility, credibility, and authenticity on social media platforms, adopt practices of digital self-representation and audience engagement that are fundamentally quite similar to those of the commercially motivated content creators they seek to counter. Drawing out the contradictions that arise as medically credentialled content creators compete for resonance, credibility, and reach in a digital public sphere conditioned by popular feminism, white supremacy, misogyny, transphobia, and conspirituality, I deliberately reach beyond my own algorithmic filter bubble to consider the urgency and possibility of new digital wellness solidarities. Bio: Sarah Brophy is Professor of English at McMaster University. She is the author of the book *Witnessing AIDS*; co-editor of the collection *Embodied Politics in Visual Autobiography*; and co-editor of “Postcolonial Intimacies,” a special issue of *Interventions*. Her SSHRC-funded research examining the nexus of visual self-portraiture, exhibition spaces, intimacy, digital labor, race, gender, disability, and health can be found in *Cultural Critique*, *Feminist*

Media Studies, *Somatechnics*, and *ASAP/Journal*. In 2024, her article "Mask Aesthetics: Prophylaxis, Post-Digital Arts, and Reimagining Vulnerable Selves" won the Hogan Prize for the best essay in *a/b: Auto/Biography Studies*.

3. “Metaphors and Narratives and Their Role in Politicized Health Care Discourses: The Case of Abortion”

Anita Wohlmann

Abstract: As a matter of reproductive health, abortion is closely intertwined with medicalization, reproductive justice and political agendas. Personal stories about abortion experiences share similarities with illness narratives, even though a pregnancy is not an illness. As Anne Hunsaker Hawkins argues in *Reconstructing Illness* (1999), in illness narratives, writers try to understand the meanings of a health issue and its consequences; they seek to come to terms with a (often problematic) health care encounter; and they call for political activism to increase awareness or change the health care system. Abortion narratives foreground these concerns, too.

My presentation will first identify some of the prevalent metaphors used in abortion narratives, such as “abortion is murder/genocide.” Secondly, I will analyze how these metaphors are employed in autobiographical and autofictional abortion narratives published by US American and Scandinavian writers. The literary analysis will demonstrate that, in addition, to powerful metaphors, it is the work of recognizable literary tropes (e.g. the mad scientist), literary genres (e.g. science fiction, detective fiction) and cultural narratives (e.g. conversion, redemption, confession) that may both amplify the vigor of rigid, polarized views on abortion and help explore the ambiguities and complexities that an abortion experience can entail. Thirdly, reader responses to highly political abortion narratives – collected from *Goodreads* and *Amazon* – will be surveyed to suggest that such digital platforms offer insight into how readers react to the metaphors and narratives used in abortion narratives.

A focus on the literary and cultural work of metaphors and narratives in politicized health care discourses is relevant because political and affective polarization erodes trust and negatively impacts health care, whether this relates to reproductive health, vaccinations or responses to pandemics.

Bio: Anita Wohlmann is Associate Professor in Contemporary Anglophone Literature at the University of Southern Denmark, Odense, where she is a member of the Center for Uses of Literature. She also teaches in the faculty of health sciences, where she co-coordinates the Narrative Medicine module. She is the coordinator of the German Network for Narrative Medicine. Anita’s research focuses among others on metaphors and illness narratives. Her latest monograph *Metaphor in Illness Writing: Battle and Fight Reused* was published open access in 2022; her current research focuses on politicized health care issues and the role of triggering metaphors and personal storytelling.

Panel 14: Handling Embodied Data and Narratives

Room: 1427-246-M2
Chair: Carsten Stage

1. “Bankrupt 23andMe: Ethical, Legal, and Narrative Implications”

Allison Coffelt

Abstract This paper begins by investigating of the legal and ethical issues concerning the sale of the direct-to-consumer genetic information in the U.S., focusing on the 2025 bankruptcy case of 23andMe. Though the sale represents issues unique to the US legal and regulatory system, including federalism and 45 CFR 46, or “The Common Rule,” which is the federal law that establishes protection for human subjects research, including IRBs, the conclusions I draw can be applied in contexts beyond the US. (After all, Nuremberg and The Helsinki Report are important predecessors to codified US protections of human subjects in research.) After describing existing US protections, I argue that not only should the loopholes through which 23andMe slipped be closed, but that genetic data should be considered extra sensitive based on the volume of information, the longstanding relevance of the information, and the number of people implicated by just one person’s information. However, the way we protect such extra sensitive data matters: I conclude by asking how different protections may implicate the ways individuals conceive of their genetic data and the narratives they construct. For instance, placing genetic data in a property framework suggests metaphors of ownership and “possessing” traits, whereas situating the “research” 23andMe conducted with its data in the realm of human subjects research suggests individuals are not just customers, but participants—or, to some, guinea pigs. At the same, people can view DTC testing as a way to circumvent medical establishments, and the legal architecture that buttresses them. In this paper, we see how difficult—nigh impossible—it is to extricate metaphor from policy and ethics from narrative.

Bio: Allison Coffelt’s academic and creative work have been featured in JAMA, The Hastings Center, *BMJ Medical Humanities*, the *Los Angeles Review of Books*, and elsewhere. She is the author of *Maps Are Lines We Draw: A Road Trip through Haiti*, a lyric nonfiction exploration of health equity, colonialism, and the ethics of care, which won a journalism award. Allison worked for eight years in documentary film. She holds an MS in Narrative Medicine from Columbia University and an MA in English – Creative Nonfiction from the University of Missouri. She is a PhD student in Bioethics at Saint Louis University.

2. “Narratives of Genetic Risk in the Context of DTC Genetic Testing”

Ann-Katrine Schmidt Nielsen and Carsten Stage

Abstract: The paper will synthesize findings from an IRFD-research project on illness narratives in the context of DTC genetic testing. Based on various types of empirical material (interviews, media texts, qualitative survey), the paper argues that user engagements with DTC GTs are characterised by three different types of narrative and affective modes: 1) A haunted mode of engagement where testing is associated with difficult recollections of family histories of illness and suffering. 2) A playful and self-communicating mode of engagement where DTC GT is primarily used to narrate the identity and characteristics of the user and often in ways that stress potentially fun, surprising, or entertaining aspects of results. 3) A pragmatic and agential mode of engagement where DTC GT is approached in a cool and rational way and as empowering the user by offering her valuable genetic knowledge. Here knowledge of risk is framed as power and as a far better alternative than risk ignorance. By outlining these narrative and affective modes of engagement with DTC GTs, the paper shows how the user-driven production of knowledge about genetic risk is lived, narrated and felt in quite different ways by various user groups. It also shows how the spread of consumer genetics might produce new forms of pre-symptomatic illness experiences and narratives – characterised by, e.g., playful or pragmatic approaches to risks – that challenge the prevalent crisis model in illness narrative research.

Bio: Ann-Katrine Schmidt Nielsen is Assistant Professor of Culture and Media at the School of Communication and Culture, Aarhus University. Her work addresses media discourses and illness narratives, e.g. genetic imaginaries and pre-patient illness narratives across media formats. She holds a special interest in hauntology, and a large part of her work relates to the affective and political complexities of disordered temporalities. She is currently part of several research projects, e.g., “Human-Machine Narration: How Generative Artificial Intelligence Transforms Recreational Storytelling (GAITS)” (2026-2030) and “Genetic Hauntings – Pre-patient illness narratives in the era of direct-to-consumer genetic testing” (2023-2026).

Bio: Carsten Stage is Professor of Culture and Media at the School of Communication and Culture, Aarhus University. His research has focused on the affective, narrative and participatory processes linked to using media and technologies in relation to human and existential crisis and illness. He is currently PI of several projects, e.g., the IRFD-project ”Genetic Hauntings – Pre-patient illness narratives in the era of direct-to-consumer genetic testing” (2023-2026).

3. “Digital Traumascapes: Victim-survivors’ Stories of the Aftermath of a Psychotherapy-related Data Breach”

Marjo Kolehmainen

Abstract: The Finnish private psychotherapy center Vastaamo was the target of massive data breach in 2018 and 2019. Both personal identification information and psychotherapists' private notes from sessions, stored in a digital data register, were leaked. This information was used to blackmail both psychotherapists and their clients, and was largely made available on the darknet in 2020. Many victims of the data breach experienced the breach and its aftermath as deeply painful and traumatic, finding themselves repeatedly reminded of it through a wide range of activities embedded in digitalised societies. To shed light on these experiences, this presentation maps how networked societies make the memory of trauma caused by data hacks inescapable and how they function as sites of re-traumatisation: a day-to-day sense of risk and danger continues to haunt victim-survivors' lives despite their various attempts to minimise the harms. The data encompasses anonymous digital stories written by the victims of the data hack (N=100). Autobiographical writing has been identified as a valuable way to elicit trauma-survivor knowledges. Although stories about deeply painful experiences often remain untold because they are difficult to tell and hear, anonymous storytelling enables victim-survivors to articulate their experiences without disclosing their identities. To increase understanding on the particularities of traumatic temporalities present in these stories, I bring together scholarship on 'traumascape' and 'suspended time' to argue that the concept of 'digital traumascapes' offers a powerful lens for understanding both the enduring psychological harm initially produced by data hacking and the affective pervasiveness of unavoidable remembering in a digital society. The notion of 'digital traumascape' sheds light to the ways in which the aftermath of psychotherapy data breach is lived and re-lived across time in digitalised societies. Digital traumascapes highlight the inescapable and omnipresent qualities of networked technologies, which compel victim-survivors to remain with experiences of failed care.

Bio: Dr Marjo Kolehmainen works as Academy Research Fellow at the University of Turku. She is the PI of 'Networked Care: Intimate Matters in Online Mental Health Support' (funded by the Research Council of Finland). Kolehmainen has published numerous articles in for example, *Social Science & Medicine, Sociology of Health & Illness*, *Health*, and *Body & Society*. Moreover, she is a coeditor of *Affective Intimacies* (MUP, 2022) and *Affective Inequalities in Intimate Relationships* (Routledge, 2018). Currently, Kolehmainen is co-editing a SI on digital mental health for *European Journal of Cultural Studies.* She is also general editor at *The Sociological Review*. More info at: https://www.marjokolehmainen.net/

Panel 15: Images and Sounds of Illness

Room: 1421-118-M1.1
Chair: Linda Nesby

1. "Selfie-Production as a Method of Self-exploration in Sickness and Ill-being"

Kaisu Hynnä-Granberg and Mari Lehto

Abstract: Contemporary research on illness narratives has criticized master narratives of sickness, often found in autobiographies, women's magazines and social media, for their use of fighting metaphors, linear storytelling, and happy narrative conclusions. Scholars have emphasized the need of people to tell their own counter narratives (e.g., Kosonen, Meretoja & Kinnunen 2025; Joutseno 2025; Spencer 2021), suggesting that self-writing can help navigate the experience of sickness. Yet, for many people (e.g. some neurodivergent individuals), writing is not necessarily the most accessible form of selfexpression, as it unfolds differently depending on abilities, resources, and prior experiences. Following the definition of affect by Spinoza (2001 [1677]), affections, including those related to sickness and ill-being, are further something which cannot be expressed, or are not yet in the realm of being expressible, through verbal language. Another method may therefore be in order. Inspired by the research on illness narratives and classical feminist theories of media culture and images (e.g., Betterton 1987; Mulvey 1975; Silverman 1996), this paper introduces a novel approach to studying counter narratives of sickness narrated through, not the written language of stories, but the visual language of selfie-production. The paper presents a workshop model, developed by the presenters. The model can be used as a tool of identity negotiation and self-exploration in sickness, mental illness, body-related concerns, and body image issues. The model further functions as a new kind of methodological apparatus in knowledge production. Our paper discusses selfie-production as a form of self-exploration, where the incomplete, imperfect, fragmented, and good-enough meet, often in a productive manner. We maintain that selfie-production is not inexplicably tied with the publication of images on social media platforms. Rather, selfie-production can be used as a private tool of self-exploration and insight.

Bio: Kaisu Hynnä-Granberg is a Postdoctoral Fellow of Media Studies at the Turku Institute for Advanced Studies (TIAS) in Turku, Finland. Her postdoctoral project develops new approaches to studying the relationship between visual culture and bodies through analyzing self-shooting, the digital practice of creating selfies and other still and moving images of oneself, as a digital pedagogy of feeling. Hynnä-Granberg defended her doctoral dissertation on body positive social media in media studies at the University of Turku in 2022. Her research has been published in journals, such as *Feminist Media Studies*, *Social Media + Society*, and *Fat Studies*.

Bio: Mari Lehto is a Postdoctoral Fellow at the Turku Institute for Advanced Studies (TIAS), University of Turku. Her project, running from 2025 to 2028, explores how adult ADHD is experienced in relation to digital media and platformed exchanges. Lehto's research has been published in journals such as *Feminist Media Studies*, *European Journal of Cultural Studies*, and *Convergence*. She has also co-edited special issues, including the *Social Media + Society* special issue on Affective Body Politics of Social Media.

2. "What Does Pain Sound Like? Video Art as an Experiment of Episodic Reading of Chronic Illness"

Anna Leppo, Salome Tuomaala-Özdemir, Elina Niinivaara and Iida Putkuri

Abstract: People living with somatic, chronic illness experience a material-discursive reality that is not shared by healthy people, even those who share everyday life with them. Margaret Price (2024) refers to this distinct reality as "crip spacetime". It is not fixed, a place or a stable experience, but always becoming. It is thus obscure, not perceptible to those not experiencing it. This gap of understanding is difficult to close - yet all the more important to cross. We ask how chronically ill people's embodied knowledge of their reality could be expressed in a way that is legible also to healthy people. Attempts to express crip spacetime tend to be interpreted in the vein of "chaos narrative" (Arthur Frank 2013), threatening in their unexplainability. We explore how academic approaches could benefit from the means of art and artistic research when trying to reach towards understanding the experience of chronic illness. In our research project, two researchers with non-fatal but incurable somatic illnesses collaborate with two artists. Based on autoethnographic diaries kept by the researchers for over two years, the artists created a video artwork titled "Part 1: Time". The artwork explores different temporalities of living with somatic chronic illness; repetitive cycles of managing symptoms, going through a variety of treatments, reaching out for care, and the bodily experiences of fatigue and pain - but also rare moments of pleasure. In our presentation, we will show excerpts of the artwork to illustrate how media art can be an illuminating method to portray the slow rhythms, tiresome repetitiveness and forever enduring yet constantly transforming reality of being chronically ill. The artwork can be understood as an experiment of what Sara Wasson (2018) calls "episodic reading", an attempt to make space for experiences often left unacknowledged due to their incoherence that resists conventional narrative form.

Bio: Anna Leppo is a sociologist and a Lecturer in Social and Public Policy at the University of Helsinki. Her research has focused on the experiences of people in a range of vulnerable situations, such as living with illness or addiction. Currently, she studies chronic somatic illness from the perspectives of embodied experience, materiality and temporality, social and health care services and the possibilities for agency and participation. Leppo is the PI of the research and art project *Realm of the Sick – Exploring the Agency and Participation of People Living with Chronic Illness* (Kone Foundation 2024-2027).

Bio: Salome Tuomaala-Özdemir is a researcher in the *Realm of the Sick* project at the University of Helsinki. Her doctoral research in Comparative Religion examined ethical agency in women's abortion narratives, and since then she has explored intersections of embodiment, narrative and society. Her work spans neighbourhood relations, political imagination and social reproduction of everyday utopias, drawing on experience as both a researcher and a community developer. She has written an autoethnographic diary on living with multiple chronic illnesses and, together with Niinivaara, has co-developed research on embodied knowledge of chronically ill people since 2022.

Bio: Elina Niinivaara is an anthropologist and ethnographer who works as a part-time researcher in the *Realm of the Sick* project at the University of Helsinki. Her PhD research concerned mundane political agency of refugee background young men. Her research interests include embodiment, power and everyday politics, and materiality. As partly disabled due to chronic pain and illness, these form a central field of interest for her as well. In collaboration with Tuomaala-Özdemir, she has been writing an autoethnographic diary since 2022 on encounters with medical professionals, navigating in normative ableist society, and affects and embodied experiences arising in these contexts.

3. ""Hopeful but Cautious": Self-editing and Affective Economies in Turkish Women's Breast Cancer Narratives on Instagram"

Ayşecan Terzioğlu

Abstract: Breast Cancer is the most common type of cancer among women in Turkey, and it is also most institutionalized and visible one. There are currently numerous formal organizations and informal support groups, mostly founded and benefited by women who go through or completed their breast cancer treatment, and their close relatives, such as sisters and mothers. Both types of groups are highly active on the social platforms, especially on Instagram, which is the most widely used one in Turkey, with more than 58 million users. They are women-dominated spaces, where men rarely contribute as patients or patient's relatives.

Within this framework, my talk explores the self-editing strategies of Turkish women with breast cancer treatment experience, in contributing to the Instagram pages of these groups, including their hesitations and negotiations with the page's rules. It focuses on how these women narrativize their bodily and gendered illness experiences, and adjust their emotional tone and writing style, as well as deciding on which information is worth to be a content to share. It is based on a digital ethnography on four groups' highly popular Instagram pages (2 formal and 2 informal groups) and semi-structured, in-depth interviews with 10 women (5 breast cancer patients, 3 survivors and 2 close relatives) who are active on these pages as both content creators and commentators. It points out how these women create affective economies in Sara Ahmed's terms, as a process where the raw affect is vocalized and shared as somewhat more coherent emotions along the ebbs and flows of the online-offline continuum, challenging the binaries of private and public, (self)victimization or passivity and agency, hopeful and hopeless, individuality and collectivity.

Bio: Ayşecan Terzioğlu is a faculty member at Sabancı University, Cultural Studies and Gender Studies Programs. She earned her Ph.D. degree in Cultural Anthropology, at the City University of New York, the Graduate Center, following her B.A. and M.A. degrees at Boğaziçi University, Department of Sociology. Her research interests include illness experiences and narratives, Middle Eastern studies, anthropology of the body, gender, social studies on temporality and spatiality. She has several articles and edited books on these topics. She is in the coordinating committee of the RHWG (Reproductive Health Working Group) and directory board of AMEA (Association of Middle East Anthropology).

Panel 16: Narrative Communities of Illness

Room: 1420-234-M2.2

1. "The Shared Story in Autoethnographic Illness Narrative Research"

Lena Englund

Chair: Charlotte Nørholm

Abstract: The rise of autoethnography in illness narrative research is producing scholarly work that draws on the researchers' own experiences of illness. This paper predicts that such research will further increase in the future, considering the prominent role of personal narration and the social and political conflict zones into which it emerges (Dawson and Mäkelä 2023). The topic thus requires further attention, and this paper examines the extent to which autoethnographic study relating to illness creates a shared narrative, and what the challenges, advantages and limits are. Subjectivity in illness narrative research has been studied before in terms of how it is constructed (cf. Kokanović 2017; Kenny 2017), and qualitative research is never neutral. Analysis of personal narratives inevitably involves researchers' world views, life trajectories, and social contexts, and the debated role of positionality statements in scholarship relates to this issue as well (cf. Savolainen et al. 2023). Scholars who utilize autoethnographic approaches acknowledge the criticism such work is faced with, relating to scientific legitimacy, and they often choose to emphasize the importance of a shared story (cf. Greenhalgh 2017; Fixsen 2023). Seeing illness autoethnography as a shared story invites critical potential in terms of insider/outsider dichotomies, and this paper is particularly interested in the power relationship between different illness experiences. Illness as a life-altering event is remembered by some scholars in their autoethnographic work while still looming large in others with the risk of returning, shaping different starting points for research. As a form of shared narrative, the interaction between the illness scholar, the ill scholar, and the personal stories of illness with which they engage promises new perspectives on illness narrative research, its limits, challenges, and possibilities.

Bio: Lena Englund works as an Academy Research Fellow at the School of Humanities at the University of Eastern Finland. Her research focuses on autobiographical writing in many different cultural and geographical contexts, including medical humanities, autothanatography, migration narratives, popular culture, and celebrity studies. She is currently working on a research project on Nordic narratives of migration, funded by the Research Council of Finland. To date, Englund has published three single-authored monographs.

2. "Renegotiating Epistemic Authority: Relational-Experiential Knowledge in Twenty-First-Century Family Memoirs of Schizophrenia"

David Lombard

Abstract: In the twenty-first century, the development of social movements and fields such as Mad Pride, neurodiversity, and the health humanities has revised our understanding of schizophrenia. While schizophrenia used to mainly take shape as highly experimental literature (Woods 2011, 147), recent narratives have been gradually committed to portraying this illness as a non-normative but meaningful mode of mental functioning. Memoirs from our century generally reflect this thematic shift through, for example, their focus on raising awareness of mental illness or offering self-help advice in ways that differ from the aesthetic inwardness of twentieth-century 'cult' memoirs. Through close reading and comparative analysis inspired by rhetorical narratology (Phelan 2022; 2017b; 1996), this presentation will scrutinize how narrative features in two memoirs written by mothers of people living with schizophrenia – Dominique Laporte's *Mon fils, schizophrène* (2008) and Josie Méndez-Negrete's *A Life on Hold* (2015) – are deployed to renegotiate diagnostic certainty and epistemic authority over this condition. More specifically, I will examine how polyvocality, simile and metaphor, as they relate to illness (Wohlmann 2023), and "fictionality" (Phelan 2017a; Nielsen et al. 2015) function as rhetorical strategies for conveying *relational-experiential knowledge* about schizophrenia, that is, shaped by the relationship between relatives and patients, which complements available medical expertise. Twenty-first-century memoirs written by people diagnosed with schizophrenia – e.g., Elyn Saks' *The Center Cannot Hold* (2007) and Esmé Wang's *The Collected Schizophrenias* (2019) – will then be used as a comparative framework to assess the epistemic value of family memoirs as *relational illness narratives* and their rhetorical potential for destigmatization, empowerment, and improving the quality of life lived with mental illness. In doing so, I will argue that family memoirs convincingly contribute to redistributing agency in building knowledge about schizophrenia, thus challenging psychiatric authority while exploring beyond the patient-focused recovery narrative (Woods et al. 2022).

Bio: David Lombard is a postdoctoral researcher funded by the Research Foundation Flanders (FWO), who works within the KU Leuven-based English Literature and Cultural Studies research groups, and the Leuven Centre for Health Humanities. He has also been a visiting scholar at VU Amsterdam (2025), OSU/Project Narrative (2023), and UT Austin (2022). He is the author of *Techno-Thoreau: Aesthetics, Ecology and the Capitalocene* (2019) and seven peer-reviewed essays. His current project, "The 21st-century Schizophrenia (Graphic) Memoir: A RhetoricalNarratological and Multi-Actor Materialist Approach" (2024–27) investigates the forms, functions, and relations of the schizophrenia (graphic) memoir in its multiple 21st-century contexts.

3. "Telling through Doing: Men's Illness Narratives Emerging in Acts of Paying it Forward"

Amanda Karlsson

Abstract: Living with chronic illness leads some citizens to join peer-driven online groups where sharing illness narratives, exchanging knowledge about symptoms, treatment, and care strategies, produces a community in which connection with others "like you" becomes possible. However, for some men living with long-term illness, these kinds of sharing practices feel unnecessary, unpleasant, or even difficult to take part in. Some of the reasons for this reluctance appear to be rooted in the intersection of illness and masculinities. In other words, illness is not to be shared; it is to be kept private. Yet we know from research that sharing one's illness experiences – and witnessing others' – can have a healing effect and help make life with long-term illness more bearable. Based on 17 individual interviews with men aged 27–63 living with chronic illness, this paper investigates how one way of sharing illness narratives occurs through mentoring and acts of paying it forward. This mode of sharing and showing vulnerability becomes necessary, meaningful, and not at all difficult, due to a deep-felt commitment to helping others and "leading the way." Thus, telling through doing becomes a legitimate way for men to share their illness narratives and show vulnerability, while simultaneously performing traditional masculine ideals of supporting, caring for others, and taking the lead. As one participant puts it: "My strength is my vulnerability. And I'm damn proud of that!" The paper draws on Connell's hegemonic masculinity to explain why men tend to avoid sharing illness stories, and from a hybrid understanding of masculinity to show how caring and mentoring can be incorporated without challenging masculine status. Arthur Frank's work further illuminates how mentoring becomes a form of witnessing others' suffering, making vulnerability possible through action rather than confession.

Bio: Amanda Karlsson is an Associate Professor of Gender and Digital Health at Aarhus University. Trained in Media Studies (PhD), her research explores how men with chronic illness navigate, resist, or withhold illness narratives in peer-driven social media communities. She examines how dominant masculinities tend to shape men's discomfort with vulnerability and their limited participation in sharing practices often dominated by women. Her work brings together gender studies, digital health, and illness narrative research to understand how embodied experiences and cultural norms structure who feels able to speak – and who remains silent.