

Panel 25. At the borders of biomedicine: How health and care are reconfigured as do-able problems beyond biomedical expertise

Convenors:

Stefano Crabu, Università di Padova

Caragh Brosnan, The University of Newcastle

Federico Neresini, Università di Padova

Pia Vuolanto, Tampereen Ammattikorkeakoulu

Keywords: health responsibility; Alternative healthcare practices; Biomedical boundaries; Individualization of health

In contemporary societies, neoliberal economic arrangements and the rise of consumerism have significantly reshaped cultural expectations and representations of the body, framing health as a highly individualized and morally charged responsibility. Individuals are expected to seek knowledge, exercise moral judgment, participate in healthcare decisions, and minimize health risks through personal choices. This emphasis on personal responsibility is reflected not only in public health discourses but also in knowledge domains that sit at the epistemic boundaries of biomedicine. Consequently, it is important to explore how these new public health discourses have created space for alternative practices—such as meditation, nutritional therapies, dance therapy, and healing methods drawn from naturopathy and homeopathy—to enter the healthcare arena. These practices are supported by an increased emphasis on individual choice, therapeutic pluralism, and associated funding packages.

Approaches that encompass health and wellness practices that lie outside and are not accepted within biomedicine, otherwise labeled as "refused knowledge", do not simply reflect an alleged opposition to biomedical advice stemming from health illiteracy or distrust of medical practitioners. Instead, they signify a demand from citizens, consumers, and patient advocacy groups to become more informed and accountable in their relationship with biomedicine. This trend involves "opening the black box" of biomedicine, critically assessing its inner workings. Further research is needed to explore how alternative knowledge systems challenge biomedical boundaries and contribute to shaping contemporary understandings of health and care.

This panel aims to bring together multidisciplinary STS research to deepen our understanding of the social and epistemic conditions under which health and care are discursively and materially enacted as "do-able problems" at the margins of biomedical science. It seeks to analyze the extent to which such enactment may reduce individuals' reliance on prevailing medical practitioners by promoting activities such as self-care, health enhancement, chronic disease management, and the acquisition of diagnostic and therapeutic skills, thereby increasingly shifting medical expertise and responsibility to the individual.

We invite scholars and practitioners to submit theoretical, empirical, and/or methodological contributions that explore how forms of health and care emerging at the boundaries of science reshape biomedical authority while becoming entangled in contemporary politics of life.

We especially encourage a focus on the intersection of knowledge-making practices and individualization processes, and how these processes are enacted in relation to bodily experiences, health, and care management, particularly with regard to the emphasis on personal and moral responsibility for health.

Contributors may focus on the following dimensions:

- Analyze how health and care are practiced at the boundaries of biomedical sciences.
- Examine classification systems, technical objects, therapeutic practices, care relationships, self-experimental techniques, evidence production, and public communication strategies that either reinforce or challenge the narratives and normative stances framing health as an individualized moral responsibility and personal duty.



- Explore knowledge legitimization strategies employed to frame health and care as do-able problems beyond biomedical expertise.
- Provide methodological reflections on the importance of maintaining a non-normative, symmetrical perspective when studying health and care practices beyond the biomedical, while also considering the researcher's positionality in the field.

12 JUNE 2025 14.00 - 17.00

ID 259 - Navigating the Boundaries of Biomedicine: Pro-Vaccine Choice Communities and the Ideal of Pure Science

Barbara Morsello, Università degli Studi di Padova

Federico Neresini, Università degli Studi di Padova

Keywords: refused knowledge, vaccine hesitancy, public understanding of science

In contemporary societies, the rise of consumerism and neoliberal health discourses has emphasized health as an individualized moral responsibility, reshaping how knowledge and care practices are legitimized and enacted. Within this context, alternative knowledge systems have gained prominence, particularly in domains sitting at the epistemic boundaries of biomedicine. Our research focuses on Italian pro-vaccine-choice Refused Knowledge Communities (RKC), which challenge mainstream biomedical authority while adhering to an idealized vision of "pure science". These communities do not outright reject science but instead critique what they perceive as its political and economic entanglements, advocating for a more trustworthy and unbiased form of scientific knowledge. From January 2020 to July 2021, we conducted qualitative case studies using digital ethnography across online platforms (e.g., Facebook, YouTube, webinars, and instant messaging) and engaged with prominent pro-vaccine-choice associations, such as Comilva and Corvelva, along with European partners like the European Forum for Vaccine Vigilance. This was complemented by 21 qualitative interviews with vaccine-hesitant individuals in Italy. Our findings reveal that these RKC employ three key strategies to construct and validate knowledge aligned with their "pure science" ideals: (1) recruiting scientists and referencing scientific papers; (2) constructing evidence by mimicking scientific formats and narratives; and (3) intertwining experience-based knowledge with "pure" science. These strategies exemplify how RKC challenge the boundaries of biomedicine by asserting alternative epistemologies and reframing health as a do-able problem through personalized, community-driven knowledge practices. Far from being anti-scientific, these communities reflect broader societal shifts toward individual choice, therapeutic pluralism, and critical engagement with institutional authority. By emphasizing self-directed inquiry and localized forms of care, RKC enact health and wellbeing in ways that reposition responsibility onto individuals while simultaneously demanding greater accountability and transparency from institutional science. We argue that such dynamics not only challenge conventional biomedical boundaries but also illuminate how lay critiques of science intersect with broader trends of individualization in health care. By exploring how pro-vaccine-choice RKC navigate the interplay between institutional rejection and personal responsibility, our research contributes to a deeper understanding of how health and care practices at the margins of biomedicine reshape epistemic authority and contemporary politics of life.



12 JUNE 2025 14.00 - 17.00

ID 413 - Just a little more different than the others: neurodivergence and the re-articulation of knowledge production in autism research

Alessandro Cazzola, Università degli Studi di Trento

Lorenzo Beltrame, Università degli Studi di Trento

Keywords: Neurodivergence, biomedical and clinical research, styles of thought and styles of reasoning, diagnostic categories

Since its first conceptualization in the early 20th century as infantile schizophrenia, autism has represented a category in constant evolution, not exclusively within what is commonly referred to as "scientific practice" but in continuous interaction across various domains of knowledge. It is impossible to examine the history of autism without considering the role of situated knowledge - first from parents of autistic children and later from autistic individuals themselves - in constructing understanding on the subject. Not coincidentally, an initial conceptualization of autism as rooted in biological factors was developed in opposition to the psychoanalytic theory of "refrigerator mothers," shifting parents from being viewed as the cause of the condition to becoming its most knowledgeable advocates. The paradigm of neurodivergence, that is not only shaping public discourse and perception about autism, but is also gaining traction among researchers and medical experts, has emerged from autistic individuals themselves, who claim autonomy in defining their condition and needs, often opposing the idea of a cure advocated by many parents groups.

Building on these observations, this paper analyses how the paradigm of neurodivergence, originated outside inner scientific circles, is currently shaping categorizations and practices in autism diagnosis, behavioral and cognitive treatments, neurocognitive rehabilitation and also neurobiological and genomic research. Building on notions of 'style of thought' (Fleck, 1979) and 'styles of reasoning' (Hacking, 1992), and on historical analysis and semi-structured interviews with researchers active in the field of biomedical and clinical research on autism, this paper shows how the acknowledgement of cerebral individuality and diversity is involved in a process of re-articulation of diagnostic categories and practices. Moreover, the paper shows how neurodivergence as a style of thought is also informing the post genomic approach on genetic bases of autism: having abandoned the idea of the "autism gene", researchers have started to search for polymorphisms associated with different autism sub-types in connection with a diagnostic and clinical redefinition of neurodivergent categories. Our work demonstrates how research and clinical circles engage with the evolving concept of neurodivergence in different ways: some integrate it into the production of autism knowledge, diagnosis, and clinical practice, reshaping these fields accordingly; others adopt neurodiversity rhetoric strategically; while in some cases, the paradigm is openly contested. We will show that the production of knowledge on autism and categorization of autistic subjectivities remains deeply political, situated, and contested. While the growing recognition of cerebral diversity reflects a broader shift toward valuing individuality, it simultaneously reinforces biomedical paradigms that prioritize modulation and control or management over holistic inclusion. As classifications continue to be redefined and negotiated, the study highlights the necessity of critically examining how these shifts both challenge and perpetuate entrenched logics, paving the way for more nuanced and inclusive understandings of autism within and beyond clinical and biomedical frameworks.

References:

- Fleck, L. (1979). *Genesis and development of a scientific fact* (1935). University of Chicago Press
- Hacking, I. (1992). 'Style' for historians and philosophers. *Studies in History and Philosophy of Science*, 23(1), 1–20. [https://doi.org/10.1016/0039-3681\(92\)90024-Z](https://doi.org/10.1016/0039-3681(92)90024-Z)



12 JUNE 2025 14.00 - 17.00

ID 493 - Researching at the borders of biomedicine: positioning ourselves, and being positioned, as social scientists studying complementary and alternative medicine

Caragh Brosnan, University of Newcastle

Jenny-Ann Brodin Danell, Umeå Universitet

Pia Vuolanto, Tampereen yliopisto

Keywords: contested knowledge, complementary and alternative medicine, reflexive methodology, the challenge of symmetry

Studying contested knowledge fields presents theoretical, methodological and ethical challenges for social scientists. The principle of symmetry is advocated in STS, whereby researchers treat knowledge claims equally, investigating the processes that allow some to stabilise as facts and others to remain contested, rather than establishing which are 'true'. How to maintain this stance in practice, especially when engaging directly with epistemic communities through fieldwork, is not straightforward. The implications of remaining neutral are also increasingly complicated as scientific expertise is publicly contested in the so-called 'post-truth' era. These quandaries have recently been grappled with by social scientists studying conspiracy culture (Harambam 2020), refused knowledge communities (Morsello 2024; Neresini and Crabu 2024) and contested illness (Dumes 2020).

In this paper, we extend the discussion by analysing our experiences as sociologists/STS scholars studying complementary and alternative medicine (CAM). CAM comprises a broad range of practices and professions concerned with enhancing health beyond the borders of biomedicine. Its popularity and alternative, individualised philosophy of health are seen to threaten biomedical authority, making CAM highly contested in medical spheres, and well-studied in sociology. At the same time, some CAM types are gaining gradual acceptance within medicine and academia.

Each author has studied various aspects of CAM over the past decade, including its status and trajectory within the academy. We have navigated similar challenges around managing our own positioning and position-taking, captured in our ethnographic fieldnotes, interviews with CAM actors, and discussions and written reflections we have shared with each other. Drawing on this material, we analyse three aspects of our experiences:

How we have negotiated access to participants, and the need to establish credibility, noting that this credibility is 'vulnerable', especially when engaging with those in biomedicine;

Once in the field, finding that sociology is already deeply entwined with CAM professions' self-image and strategies – as per the 'looping effect' (Hacking 1995) and the 'double hermeneutic' (Giddens 1984). This entanglement affects our positioning as researchers and CAM actors' expectations of us as potential allies;

How researching CAM positions us in the wider academic field. For example, fearing that collaboration with CAM actors risks our own 'contamination', and considering how to manage these relationships beyond fieldwork.

The call to take a symmetrical, agnostic stance to studying knowledge implies a detached approach that does not account for the complexity of relationships in fieldwork. These relationships can invoke emotions such as guilt and sympathy that throw researcher neutrality into question. In CAM, there is an existing relationship between the CAM professions and social science, meaning researchers may already, inadvertently, be positioned in the field they hope to study. Another challenge is that the knowledge legitimization strategies used by CAM actors include attempts to enrol social scientists and/or our publications into networks where CAM's legitimacy is being established – a tension unlikely to be replicated on the side of established biomedicine. Our analysis suggests that although these positions and relationships pose a challenge to symmetry, they are also what makes research with CAM communities possible.



12 JUNE 2025 14.00 - 17.00

ID 500 - The Academisation of Complementary and Alternative Medicine

Pia Vuolanto, Tampereen yliopisto

Caragh Brosnan, University of Newcastle

Jenny-Ann Brodin Danell, Umeå Universitet

Keywords: academisation, scientific/intellectual movements, complementary and alternative medicine, epistemic authority

Complementary and alternative medicine (CAM) is a controversial topic that triggers heated debate in the media, and among health care practitioners, particularly among medical doctors. The issue has become more contentious as CAM aims to enter academic institutions. Currently, CAM is establishing itself as a research field through conferences and networking, but also through a growing number of publications and the establishment of specific CAM research institutions at universities. According to the World Health Organisation there are over 70 CAM research centers around the world. About 4-5000 publications on CAM are being produced annually. Despite these developments, the academisation of CAM has thus far been analysed very little, which leaves underexplored both CAM's significance in transforming knowledge production institutions and the ways in which CAM is shaped by knowledge production structures.

In this presentation, we will critically analyse the development of CAM as an academic field by looking at its nascent developments in the frame of science and technology studies (STS). In particular, we will explore the potential of Frickel and Gross's (2005) general theory of scientific/intellectual movements (SIM). We are interested in the extent to which CAM could be understood as a SIM, that is, a movement that aims at transforming the academic landscape. Also, we are keen to provide understanding on why and how CAM has been able to, despite its controversial starting points, succeed with its aims or has it, in fact, rather not succeeded but failed, or else developed some low-status areas within established disciplines at some university systems rather than in others.

By this analysis, we hope to contribute to the theoretical discussion about SIM and also to the analysis of the contestations of epistemic authority, struggles for the ownership of legitimate knowledge, and the boundaries of the academic 'battlefield' (Bourdieu 1975, Gieryn 1999). A growing body of research is examining how marginalized and emerging academic groups in the health research domain are struggling to gain legitimacy by challenging the hegemony of the medical randomized controlled research method and put forward the epistemic value of their own forms of research (Albert et al. 2017; Eakin 2016). We complement this work by focusing on the legitimising strategies used by CAM health professionals to enter the academic health research domain. It has become topical to understand the reasons why and how certain societal groups arise to alter the academic landscape as it deepens our understanding of the underlying processes shaping academic transformation (Frickel & Gross 2005).

12 JUNE 2025 14.00 - 17.00

ID 512 - Back and Forth, Inside and Out: Plural Healthcare-Seeking Practices and Entangled Actor Networks of Tibetan Medicine in Qinghai

Jin Chen, 大阪大学 (Osaka University)

Keywords: Tibetan Medicine, Medical Anthropology, Medical Pluralism, Actor-Network Theory

Tibetan Medicine (བོད་རྒྱ་གསལ་བརྩེག་པ།, TM), with over 2,300 years of history, is one of China's most significant Indigenous medical traditions. Rooted in Buddhist philosophy and a holistic understanding of the body, mind, and spirit, facilitated by Qinghai Province's strategic modernization efforts, it has emerged as not only a way of ethnic revitalization, but also an increasingly popular medical practice. Qinghai Province, a region marked by centuries of multiethnic coexistence, provides a unique setting for examining medical practices in a complex network.



Drawing on ethnographic fieldwork in Qinghai Province, this study explores how Tibetan and Han Chinese patients navigate their healthcare choices, practices, and beliefs. Padma, diagnosed with a "mental disorder" due to her ability to see supernatural beings, constantly seeks ways to "restore peace" by consulting advanced psychiatric hospitals, receiving rituals from lamas, and taking medicines prescribed by traditional medical monks. Yang, who has suffered from rheumatoid conditions since 2011, chooses to receive treatment at a modernized Tibetan hospital while remaining deeply skeptical of the latest biomedical immunosuppressants. Meanwhile, when seven-year-old Blo-Gros and nine-year-old Sam-phel both contracted an adenovirus, their parents started a search for treatment from everywhere - informal medical monks, small private clinics, regional hospitals, recognized medical monks, and public Tibetan hospitals.

These individuals move fluidly between seemingly contradictory options—at times embracing "rational" biomedical treatments while at others turning to Buddhist rituals; adhering to state-sanctioned, science-based medical guidelines while simultaneously challenging dominant norms; remaining within the comfort zone of their lived traditions or venturing into unfamiliar healthcare alternatives. While exercising agency in the pursuit of health and well-being, they are also subject to structural constraints.

By unique stories from multiple patients, this study demonstrates the interactions between individual medical choices and the design of public healthcare systems, addressing three key dimensions:

1. The tensions between the contemporary advocate on personal health responsibility, shaped by China's "science-first" discourse, and the top-down control exercised by an authoritarian state.
2. The coexistence of official TM institutions and marginal, non-official healing spaces within Tibetan medical practice, as well as the dynamics of inclusion and exclusion between the two.
3. The interactions and often ambiguous boundaries between "scientific" biomedicine and "non-scientific" religious healing, particularly in the context of the Chinese government's secularization policies.

Using Actor-Network Theory and intersectionality as analytical frameworks, this study reveals the complex dynamics under the concept of "individualized health responsibility", as well as the underlying political visions behind medical practices, rectifying the proneness towards essentialization or oversimplification within this topic. By introducing a multiethnic perspective and ethnographic case studies, this research not only contributes to the understanding of TM's modernization but also enriches discussions on health and care by incorporating knowledge systems and personalized practices beyond biomedical expertise. The goal is to expand the conceptual boundaries of "medicine" itself by demonstrating how TM challenges and reshapes contemporary discourses on health and care.

12 JUNE 2025 14.00 - 17.00

ID 567 - Advancing Patient Engagement in Pain Research: Insights from Science and Technology Studies

Anja K. Ruess, Technische Universität München

Elisabeth S. May, Technische Universität München

Laura Tiemann, Technische Universität München

Paul T. Zebhauser, Technische Universität München

Alena Buyx, Technische Universität München

Ruth Müller, Technische Universität München

Markus Ploner, Technische Universität München

Keywords: patient engagement, public engagement, pain research, embedded ethics and social sciences

Patient engagement has received growing attention in pain research in recent years. While a growing number of researchers and clinicians recognize the importance of incorporating patients' perspectives into pain research, there are still significant challenges in how to engage with their perspectives in meaningful ways. These challenges are increasingly discussed among pain researchers, who have begun to develop guidelines to reconfigure emerging challenges as do-able problems. For instance, IMMPACT recommended



considerations on patient engagement in clinical research (Haroutounian et al., PAIN, 2024), proposing a set of practical guidelines to plan, implement, and evaluate patient engagement at all stages of clinical pain research. In this paper, we both critically discuss and further the implementation of patient engagement in pain research by adding an STS perspective to the IMMPACT considerations as well as the broader field of pain research. While the IMMPACT considerations provide a comprehensive roadmap for patient engagement, STS expertise points to a range of caveats that our contribution addresses. In particular, we leverage STS expertise and insights from our ongoing empirical work as embedded social scientists to elaborate on three aspects: Firstly, the challenges of integrating different forms of knowledge, such as patient experience and expert knowledge. Secondly, it is necessary to manage expectations carefully for all stakeholders involved. Thirdly, patient engagement is not always inherently beneficial, but requires continuous and context-specific reflection to avoid inequalities in pain research and healthcare contexts. By specifying and discussing these challenges, we provide a research agenda for patient engagement and trace the practical implications for pain researchers who want to integrate patients into their research practices. Our contribution builds upon the experience with an interdisciplinary research initiative dedicated to using neurotechnology to diagnose and treat mental health conditions, including chronic pain, at the Technical University of Munich. In doing so, we hope to add a valuable viewpoint to the ongoing discussion on implementing patient engagement in pain research and highlight potential synergies between STS expertise and recent discussions in pain research.

12 JUNE 2025 14.00 - 17.00

ID 570 - Awareness as diagnosis, responsibility as therapy. Mindfulness as a rehabilitative practice from drug addiction

Lorenzo Urbano, Università di Roma La Sapienza

Keywords: addiction, rehabilitation, responsibility, mindfulness, illness experience

Calls to "be responsible" permeate the common discourse on drug addiction – a condition that is usually framed as the product of a deliberate (and "irresponsible") choice of the addict. "Responsibility" is represented as both the recognition of one's role in becoming an addict, and of the necessity of taking charge of one's own healing process. However, "responsibility" is also often seen as the inversion of the key aspects of the addict's character – being that of a person who is by definition "irresponsible" in their choices, towards others and towards themselves, unable or unwilling to face the problems of everyday life. To overcome addiction, even more than undertake pharmacological therapy, the addict must "become responsible" for themselves, for their choices, for their life. This representation is far from confined in common discourse on addiction; it's also present in the narratives of institutions and organizations that work with addicts, and underlies many of their therapeutic practices. Both inside public health and outside (such as in therapeutic communities and self-help groups), the representation of responsibility as a pillar of rehabilitation produces different kinds of intervention that reject the primacy of pharmacological therapy – and, in this way, argue for a particular conception of addiction and rehabilitation.

This contribution focuses on one such kind of intervention, based on the practice of mindfulness, and more specifically on mindfulness-based stress reduction (MBSR) and mindfulness-based relapse prevention (MBRP). Grounded in ethnographic research on rehabilitation practices in and around Italian public health Services for Addiction, the aim of this paper is twofold. On the one hand, mindfulness as a practice of presence and awareness suggests a non-biomedical (or non entirely biomedical) way of "diagnosing" the roots of the problem of addiction. If this is a "pathology of avoidance", a refuge from the difficulties of the everyday, mindfulness as a technique for returning to the present moment and for becoming "aware of oneself" can allow the addict to better identify the bodily and emotional states associated with addiction. On the other hand, mindfulness as a way of "managing the emotions" can be used as a practice of self-discipline in the rehabilitation process. In particular, the practice of MBRP aims to be a (again, non strictly biomedical) instrument to manage emotional states associated with abstinence, and to reduce the risk of relapse. Through an exploration of a few specific instances of the use of mindfulness in rehabilitation, I argue that these two dimensions together not only redefine addiction on the basis of personal,



bodily experience, but can also serve as a bridge that connects the "moral" representation of addiction, centered on responsibility, and the biomedical representation that underpins public health interventions on this pathology.

12 JUNE 2025 14.00 - 17.00

ID 643 - Early-Life Adversity, Epigenetics, and Parenthood: New Familial Responsibilities?

Mary Jones, Technische Universität München

Georgia Samaras, Technische Universität München

Prof. Ruth Müller, Technische Universität München

Keywords: Environmental epigenetics, early life adversity, responsibility for health, discourse analysis

Environmental epigenetics suggest that socio-material experiences, such as nutrition, toxicants, stress and trauma, influence our phenotypes through chemical modifications to our DNA, potentially leading to adverse health outcomes over the life course. In contrast to genetic mutations, scientists assume that epigenetic changes are reversible, which opens up a promising space for biomedical and lifestyle-related interventions to counteract adverse health trajectories or treat physical and mental diseases. Furthermore, environmental epigenetics leaves pressing questions for how responsibility for maintaining health and managing illness is conceptualized. Whether or not epigenetic modifications are permanent or plastic further obfuscates the question of how certain one's epigenetic fate may be. In this transition between laboratory and lived experience lies a multitude of confounding factors, sociopolitical influences, and potential for STS intervention.

Over the past two decades, environmental epigenetics has been increasingly used to explain how stressful experiences early in life alter DNA expression, leading to developmental changes and ultimately disease and providing a molecular mechanism for how adverse childhood experiences (ACEs) "get under the skin". Our project "Early Life Adversity, Epigenetics, and Parenthood", funded by the Bavarian State Ministry of Science and Art, explores how ACEs are reconfigured as do-able problems through conceptualizing them as being mediated by epigenetic modifications. ACEs, as an epidemiological concept, emerged in the 1990s as public health researchers in the United States established a dose-response correlation between forms of child maltreatment and household dysfunction and physical, mental, and behavioral health risk. The ACE framework has been extrapolated to other fields such as criminology, education, and economics; social science criticism has been introduced into this discursive landscape, including questioning its lack of consideration for structural forms of adversity.

Building on these debates, our project aims to unpack the scientific and social discourse on the long-term health effects of ACEs in Germany. In this talk, we will first present our findings from an analysis of the print media landscape and discuss how the relationship between ACEs and long-term health effects is discursively constructed, including commonly used narratives and allusions to responsibility for health. We will additionally share initial insights into our ongoing work on the academic discourse, informed through interviews with ACE researchers and analysis of relevant publications. These findings will depict how social conditions and events are reflected in the scientific discourse, including explicit and implicit influences on ACE knowledge-production in Germany. These various data points allow us to investigate how responsibility for long-term health in light of ACEs are constructed at either the individual, familial, or structural level as well as the interventions, both within and beyond the biomedical realm, discussed as possible solutions. With do-able solutions for the prevention and treatment of adversity's health effects plausible, whether those be through emotional resilience or pharmacological mechanisms, critical perspectives differentiating between responsibility and accountability on this emerging body of knowledge are needed. In analyzing the biomedicalization of adversity, we explore how the boundaries of epidemiological and clinical medicine are blurred and brought into the home.



12 JUNE 2025 14.00 - 17.00

ID 653 - Care strategies and sleep problems in Uruguay: within and beyond the limits of biomedicine

Andrea Bielli, Universidad de la República

Lauren Predebon, Universidad de la República

Virginia Rodríguez Otero, Universidad de la República

Keywords: Sleep disorders, Biomedical boundaries, Alternative healthcare practices

Since the early 1980s, sleep medicine has gained ground as a field of expertise in various sleep disorders. Its primary objective is not only to facilitate optimal therapeutic interventions for inducing and sustaining sleep but also to address pathologies characterised by excessive sleep. Additionally, sleep medicine has played a pivotal role in promoting the significance of sleep for maintaining optimal health and well-being. The celebration of the World Sleep Day since 2008, supported by the World Association of Sleep Medicine, is a clear example of the efforts made to promote the benefits of good sleep among the population and to fight what the association defines as a contemporary epidemic of insomnia and sleepiness that threatens people's health. Despite these efforts, sleep problems remain common as many therapeutic interventions are not always effective.

In this paper, we will address the limitations of the biomedical approach to sleep in Uruguay, where sleep medicine is underdeveloped, but where it has recently been claimed that the population has serious sleep problems. To do this, we will draw on the experiences of men and women over the age of 18, residents of Montevideo, who consider themselves to be affected by sleep problems. We conducted 50 qualitative interviews to explore the different coping strategies used to deal with sleep disturbances and their expectations of a cure.

We have found that the field of sleep problems emerges as a preferably individual experience of discomfort in which the subject tries to deploy a series of strategies in which biomedicine - through consultations with general practitioners, psychiatrists and the use of hypnotic drugs and a few clinics specialising in sleep problems - is articulated with alternative medicine, home cures, meditation or yoga.

We conclude that subjects deploy trajectories of care in which different kinds of care intertwine, transcending the boundaries of biomedicine, challenging the medical authority, and creating a network in which hypnotic drugs, non-medical strategies and human experience come together to sustain an expanded and paradoxical vision of hope in sleep medicine.

12 JUNE 2025 14.00 - 17.00

ID 858 - Of heatpads and femtech apps: Law, vulnerability and the making of women's health as a 'do-able' problem beyond medical expertise

Nayeli Urquiza-haas, Lancaster University

Emilie Cloatre, University of Kent

Keywords: contested knowledges, women's health, regulation, vulnerability

State and biomedical institutions have been accused of neglecting and abandoning women to their fate when it comes to sexual and reproductive health problems. Brushed off and unseen or given unsatisfactory answers that do not address their situated knowledge, women have turned to a wide range of self-healing techniques and self-help practices to deal with debilitating conditions, from endometriosis to dysmenorrhea and maternal mortality. Within this context, the use of unregulated unproven and contested therapies and techniques has proliferated, arguably reshaping subjectivities and the relationship between individuals and the State's obligations to uphold citizen's right to health. However, tensions arise when some of these practices and techniques become branded as 'misinformation' or 'fraudulent' schemes exploiting vulnerabilities in the absence of adequate healthcare delivery but also limited regulations. If



regulators feel pressured to intervene, the range of interventions vary greatly, sometimes encroaching heavily on personal freedoms, and at other times, reinforcing historical patterns of discrimination against disadvantaged groups.

In this paper, we explore the conceptual, methodological and regulatory tensions that emerge when women's health and care is reconfigured as a 'do-able' problem beyond medical expertise. What problems and challenges arise when State authorities labeling some practices and techniques as 'misinformation' and not others? But also, how do users respond to misleading, unproven and disproven health claims? For example, patient advocacy groups claim medical misogyny is to blame for the disinformation around sexual and reproductive health, leading to greater dependence to health tracking apps. At the same time, one of the effects of this displacement is that users are increasingly expected to be vigilant about misleading, unproven or disproven health claims¹. But decisions about when and how to intervene against contested health-related claims have considerable implications. Understanding these boundary-making processes also call a critical examination of the subordination of class, gender and race, in the context of modern biomedical institutions, and their relationship to the State.

Methodologically situated between Socio-Legal Studies and Science and Technology studies, our aim in this paper is to unpack and question the usefulness of the label of 'misinformation,' but also the effects this has on conceptualizing women's reproductive and sexual health as a do-able problem beyond biomedical expertise. Indeed, the labeling of some claims as risky and women's bodies as vulnerable subjects calling for further regulatory interventions. These effects are potentially more insidious where health illiteracy is assumed, as in the case of indigenous midwives, or where conditions have been assumed to be of a psychological origin.

