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## In the Journals, December 2019

2020-01-01 18:05:33

By Raha Peyravi

Here is the December In the Journals. Among the highlights is a special issue of BioSocieties on [Cancer in the Global South](#). Enjoy!

[American Anthropologist](#)

[Shouldering Moral Responsibility: The Division of Moral Labor among Pregnant Women, Rabbis, and Doctors](#)

*Tsipy Ivry, Elly Teman*

This article contributes to the anthropology of morality through an ethnographic focus on the consultations of religiously observant Jews with rabbis and medical specialists regarding dilemmas surrounding prenatal diagnosis of fetal anomalies. Our ethnography looks at religious couples who consult rabbinic authorities on their reproductive dilemmas rather than making autonomous decisions and the procedures of decision-making that rabbis enact. We examine the rabbis' emic practice of dividing moral labor and outsourcing it in a chain reaction to various medical and rabbinic experts. The purpose of outsourcing moral decisions and aggregating expert opinions is to lighten the heavy weight of moral responsibility for consultees as well as for the rabbinic consultants. In seeking expert consultations, people might actually be opting for liberation from freedom of choice—at least as defined in the model of autonomous decision-making—rather than merely submitting to an authoritative doctrinarian power, whether of religion or biomedicine.

[BioSocieties](#)

[Cancer and Secrecy in Contemporary India](#)

*Dwaipayan Banerjee*

In examining the secrecy around cancer in India, I develop recent anthropological work on how practices of medical non-disclosure

grow out of contextually rooted notions of care. I extend the insights of this work in rejecting the framing of non-disclosure as a sign of cultural lack. But while much of this recent literature on biomedical non-disclosure is framed as a critique of bioethics, I am concerned here with describing the complexity of the lived experience in between disclosure and non-disclosure. Paying attention to this processual nature of non-disclosure reveals how it does not operate as a binary choice between concealing and revealing, and consequently, knowing or not knowing. Instead, I argue that weaving between disclosure and non-disclosure allowed my interlocutors to inhabit the space of the 'as-if'—of living in a subjunctive tense. Living in the subjunctive made possible brief respites from the real, even as such respite often turned out to be temporary, and the as-if never really escaped the grasp of the actual. Finally, I suggest finally that what one tells, to whom, and when reveal how the burden of cancer is distributed across social networks, vitally shaping possibilities and trajectories for cancer treatment and care.

### [Cancer in the Tropics: Geographical Pathology and the Formation of Cancer Epidemiology](#)

*Lucas M. Mueller*

Researchers have long been concerned with cancer in what has been called the tropics, developing world, and low- and middle-income countries. Global health advocates' recent calls to attend to an emergent cancer epidemic in these regions were only the latest effort in this long history. Researchers, known as geographical pathologists, sought to determine the etiologies of cancer and other non-infectious diseases between the 1920s and the 1960s by comparing their occurrence across different environments. The geographical pathologists used the concept of the environment to analyze the influences that natural and artificial surroundings had on health. While the international network of geographical pathology fostered medical thinking about environmental health in the early and mid-twentieth century, the very meaning of environment, alongside the scientific methods for studying the environment, changed in this period. In the 1960s, epidemiology, previously used for the study of infectious diseases, displaced geographical pathology as the cohesive framework of cancer research. This signaled a shift in research focus, from one dedicated to diagnostics and the environment to one centered on population and statistical studies. This article shows that it was not the lack of knowledge about cancer in the developing world but

rather specific configurations of knowledge that shaped which cancer interventions in the developing world researchers and public health officials conceived.

[An Irritable State: The Contingent Politics of Science and Suffering in Anti-Cancer Campaigns in South India \(1940–1960\)](#)

*Kavita Sivaramakrishnan*

This article traces the making of anti-cancer campaigns in South India. Set at the cusp of decolonization, it explores how provincial physicians and women activists framed cancer care in the 1940s and 1950s. It offers insights into the argumentative, contingent ways in which public health concerns were framed and mobilized in Indian cities between a middle class public, medical experts and state agency. These cancer campaigns and local health debates have been neglected because historians have tended to focus on national level, political visions of health, on debates regarding international aid, transfer of medical technology, and targeted disease control programs. This has also shaped and limited how we have understood the complex, changing meanings and expectations of health and development in newly decolonized societies such as India. Analyzing the activist campaigns and writings of Dr. Muthulakshmi Reddi an influential physician, renowned Women's Indian Association leader, and legislator, and tracing the making of urban, anti-cancer networks, I argue that cancer care campaigns both invoked and challenged nationalist and developmental priorities, and questioned assumptions about what were termed as 'normative' diseases and health risks in India. Even though they spoke of the curative, technoscientific and specialized aspects of cancer treatment and urged its provision in local hospitals, they also encouraged the state and philanthropists to assume moral responsibilities for care and chronic suffering. They built on contemporary social and political metaphors, especially Tamil cultural representations of women. These ideas created emerging spaces for debates through multiple discursive ambits that emerged while trying to articulate and balance 'needs' that were seen as dichotomous and competing between managing population wide, curable diseases and the needs of a vocal, minority of advocates supporting cancer care. These debate were no doubt also limited by the visions of middle-class women, urban philanthropy, and engagements with male political leaders, and health officials.

## [Pluripotent Trajectories: Public Oncology in Rwanda](#)

*Darja Djordjevic*

This article examines how Rwandan patients understand and represent cancer, as well as how state actors articulate the agenda of public oncology and related expectations of citizens. Patients view cancer and infection as co-existent and processually intertwined. This elides with the reality of epidemiology on the ground, as the local burden of disease encompasses both infectious and noncommunicable diseases. Further, patients still consider the efficacy of occult acts in causing tumors, particularly in the face of a disease marked by etiological uncertainty in the biomedical realm, and frequent resistance to treatment. At the same time, both policy makers and clinicians servicing public oncology expect citizens to quickly relinquish any beliefs in the occult and fully embrace a biomedical value system. Beyond the fact that this project cannot be fulfilled, its articulation only limits the ability to envision a more capacious framing of oncology which acknowledges both the limits of treatment, and the diverse ways in which patients suffering from cancer make meaning in the face of grave illness.

## [Contemporary Drug Problems](#)

### [New for Who?: Novelty and Continuity in Drug-Related Practices of People Who Use New Psychoactive Substances](#) (*Open Access*)

*Lucy Pickering, Sharon Greenwood*

New (or Novel) Psychoactive Substances (NPS) are so named because they are characterized by a shared property of “newness.” In this article, we critically unpack NPS as a category and as a single object, bounded by a shared “newness”. In doing so, we examine whose ways of knowing are afforded epistemological authority and the harms that can emerge from an overemphasis on pharmacological properties at the expense of everyday practice. Through accounts of buying and selling NPS discussed in interviews with five “at risk” populations in Scotland, we examine the ways NPS use can be more usefully characterized by *continuity* with existing practices, relationships, and identities than by novelty. This raises the question that if everyday practices are not characterized by newness, what makes new psychoactive substances *new*? Comparing the discourses of pharmacologists and people who use them exposes contrasting claims about the

“reality” of NPS: While pharmacologists describe their own ways of knowing as real, they often downgrade others as mere belief; those who use them do not do this. A common epistemological hierarchy is shared between these parties, where everyday practices (often characterized by continuity) are devalued relative to pharmacological ways of knowing that foreground novelty. When services have finite resources, this epistemological authority has significant consequences: When attention is paid to “newness” (in an attempt to gain mastery of an ever-shifting drug landscape), it is not being paid to the ways NPS are consumed within wider contexts characterized more by continuity with “traditional” drug use than divergence.

[Beyond Treatment Versus Enhancement: A Qualitative Study of Pharmacological Neuro-Enhancement Among Dutch and Lithuanian University Students](#) (*Open Access*)

*Aleksi Hupli, Gabija Didžiokaitė, Marte Ydema*

This article examines the ambiguous relationship between treating illness and enhancing normalcy through the use of “cognitive enhancement” drugs. Although the literature on pharmacological neuro-enhancement generally differentiates between the “licit/therapeutic” and “illicit/enhancement” use of substances, in-depth interviews with 35 university students in the Netherlands and Lithuania—both with and without formal medical diagnoses of (mainly) Attention Deficit Disorder and Attention Deficit Hyperactivity Disorder—reveal the fluidity of these categories. Our study of the perceptions and experiences of people who use such drugs further suggests a much broader range of substances, motives, and sought-after effects than are commonly acknowledged in the “cognitive enhancement” literature. We need a more inclusive and context-sensitive approach to study pharmacological neuro-enhancement, for instance, by approaching both licit and illicit drugs as tools or instruments.

[Critical Public Health](#)

[Critical Social Science with Public Health: Agonism, Critique and Engagement](#) (*Open Access*)

*Eric Mykhalovskly, Katherine L. Frohlich, Blake Poland, Erica Di Rugierro, Melanie J. Rock, Leigha Corner*

This article is about a mode of scholarly practice we call critical social science *with* public health. The article responds to our dissatisfaction with established approaches to social science engagement with public health that have developed out of Straus' early distinction between sociology *in* and *of* medicine. By critical social science *with* public health we mean a set of research practices that orients to epistemological and political differences between social science and public health as productive opportunities. We draw on Mouffe's notion of agonism to ground our argument conceptually and on our collaborative research *with* tobacco control to substantively illustrate our case. As we imagine it, critical social science *with* public health unsettles knowledge relations that position social science either as a conceptual resource for public health or as a source of negative critique of public health activities. Critical social science *with* public health engages directly with public health actors, while remaining committed to the specificity of social science theory and methodology. It aims to transform public health, often by seeking to lessen the harmful effects of public health practice, while, at the same time, contributing to critical social science scholarship.

### [Culture, Medicine, and Psychiatry](#)

### [Genealogies and Anthropologies of Global Mental Health](#) (Open Access)

*Anne M. Lovell, Ursula M. Read, Claudia Lang*

Within the proliferation of studies identified with global mental health, anthropologists rarely take global mental health itself as their object of inquiry. The papers in this special issue were selected specifically to problematize global mental health. To contextualize them, this introduction critically weighs three possible genealogies through which the emergence of global health can be explored: (1) as a divergent thread in the qualitative turn of global health away from earlier international health and development; (2) as the product of networks and social movements; and (3) as a diagnostically- and metrics-driven psychiatric imperialism, reinforced by pharmaceutical markets. Each paper tackles a different component of the assemblage of global mental health: knowledge production and circulation, global mental health principles enacted in situ, and subaltern modalities of healing through which global mental health can be questioned. Pluralizing anthropology, the articles include research sites in meeting rooms, universities, research laboratories, clinics, healers and health screening camps, households, and the public spaces of everyday

life, in India, Ghana, Brazil, Senegal, South Africa, Kosovo and Palestine, as well as in US and European institutions that constitute nodes in the global network through which scientific knowledge and certain models of mental health circulate.

[Schizophrenia Infrastructures: Local and Global Dynamics of Transformation in Psychiatric Diagnosis-Making in the Twentieth and Twenty-First Centuries](#)

*Nicolas Henckes*

This article uses the concept of “diagnosis infrastructures” to propose a framework for narrating the history of schizophrenia as a global category in the twentieth century. Diagnosis infrastructures include the material and architectural arrangements, legal requirements, and professional models that enable both the ways in which patients come to clinics and navigate the world of schizophrenia as well as the means through which clinicians organize their diagnostic work. These infrastructures constitute a framework for how schizophrenia has been identified as a disorder. This article explores three moments in the history of schizophrenia infrastructures in the twentieth century. The first is the German psychiatrist Kurt Schneider’s discussion of first- and second-rank symptoms in the interwar period. The second is the research on criteria for defining schizophrenia within the framework of the WHO International Pilot Study of Schizophrenia at the turn of the 1970s. The third corresponds to the changing infrastructures of mental health care in the context of both global mental health and the changing landscape of schizophrenia research over the last decades.

[Finding “What Works”: Theory of Change, Contingent Universals, and Virtuous Failure in Global Mental Health](#)

*Dorte Bemme*

Global Mental Health has developed interventions that strive to work across great difference—variously conceptualized as cultural, socio-economic, geographic, or pertaining to the characteristics of health systems. This article discusses how the evaluation framework Theory of Change (ToC) facilitates the production of ‘global’ knowledge across such differences. Drawing on 14 months of multi-sited fieldwork among Global Mental Health actors in Europe, North America and South Africa, it traces the

differential use of ToC in GMH interventions. While much critical scholarship of Global Health metrics holds that techniques of quantification rely on universals that necessarily betray the “real world”, ToC unsettles these critiques. It comes into view as an epistemic and relational device that produces ‘contingent universals’—concepts that are true and measurable until they stop working in the field, or until the parameters of ‘what works’ shift to a new iteration. As such, Theory of Change produces actionable—rather than true—knowledge attuned to open-ended change, both desirable (impact) and unforeseen (adaptation). Its effects, however, are ambiguous. ToC presents us with a horizoning technique that enables what I call “virtuous failure” within the evidence-based paradigm. It may equally harbor the potential to disrupt distinctions such as bricolage (tinkering) and design (planning) and their respective politics, as it may tie neatly into audit cultures, depending on its use. The article analyzes the novel stakes of reflexive evaluation techniques and calls on anthropology and critical Global Health for renewed empirical engagement.

[Inspecting Mental Health: Depression, Surveillance and Care in Kerala, South India](#)

*Claudia Lang*

Depression has become a major public health concern in Kerala, South India. Media and mental health professionals often attribute the rise of depression and suicide to a discontent around modern transformations and the flipside of the “Kerala model of development”. Kerala’s primary health care system of health governance, surveillance and care with its backbone of community and multi-purpose health workers is currently being expanded to target inner feelings, emotional suffering and existential despair, as a result of complex global, national and local processes of making visible and stabilizing depression as a public health category. Rather than relying on NGOs and foreign funding, mental health policy planners in Kerala engage the state of Kerala. Using the case of a junior health inspector’s counseling, I argue that the reconfiguration of suffering from an existential part of life and symptom of adversity into a medical condition can also lead to mobilization of (gendered) care in a context of familial marginalization and neglect. In this context, individual bodies are healed by restoring social bodies. Medicalization does not necessarily silence social inequalities and marginalization but can become productive in providing an idiom to critique a family’s

moral economy.

[Adolescent Sex and Psyche in Brazil: Surveillance, Critique and Global Mental Health](#) (*Open Access*)

*Dominique P. Behague*

Drawing on a historical ethnography conducted in Southern Brazil, this article explores how public health programs for adolescent reproductive and mental health have emerged in Brazil and begun to intersect with the growing field of “global mental health” (GMH). The story I recount begins not in the 2010s with the rapid rise of expert interest in adolescent health within GMH, but in the 1990s, the decade when young teens in Brazil were first coming into contact with practices and approaches in research, schools and clinics that have both underpinned *and* critiqued the production of an adolescent mental and reproductive health sub-field. In parsing what young women’s encounters with the then newly-emerging questionnaires, measurement tools, school-based programs and clinical practices came to mean to them, I use a genealogical approach to consider how histories of education reform, population control, psychoanalysis, social medicine, the transition to democracy, feminism and grass-roots politics all entered the fold, shaping the way adolescent sex-and-psyche materialized as a contested object of expertise. I end by exploring what this case can teach global mental health advocates and social theorists about practices of critique.

[East Asian Science, Technology, and Society](#)

[Racializing Ch?senjin: Science and Biological Speculations in Colonial Korea](#) (*Open Access*)

*Jaehwan Hyun*

Recent literature on the history of medicine in colonial Korea has revealed that Japanese medical scientists studied Korean bodies to expose racial differences between the Japanese and Koreans and justify Japanese colonial rule. Previous scholars, however, have focused mainly on finding a connection between colonial medical research and eugenics. This article attempts to consider things as yet underinvestigated, in particular, the way in which medical research on Koreans emerged and was intertwined with Japanese colonialism in other ways, separate from contemporary

eugenics projects. The article examines the emergence and development of what we now considered as “racial sciences”—physical anthropology, serological anthropology, and human genetics—with regard to the biological characteristics of Koreans. In doing so, it argues that biological speculations on Koreans originated as a subdiscipline of Japanese origin studies and resonated with a newly emerging type of colonial racism in colonial Korea—inclusionary racism. The article also presents the colonial scientific enterprise’s conclusion that Koreans were biologically heterogeneous, contradicting colonial Korean intellectuals’ assertion about Korean ethnic homogeneity. The use of Korean ethnic homogeneity as an ideological basis for nation building by two Korean governments meant that postcolonial Korean scientists had to seek a way to reconcile the colonial era’s “scientific conclusion” (biological heterogeneity) with the postcolonial era’s “politically approved” conceptualization (biological homogeneity). Therefore, regardless of whether it was trying to refute, appropriate, or revitalize the colonial legacy, biological research on Koreans in the postcolonial period was carried out under the framework that had been constructed by colonial racial sciences.

## [Ethos](#)

### [“Soothing My Child’s Soul and My Own”: Dealing with Pregnancy Loss in Postcommunist Romania](#) (*Open Access*)

*Erica van der Sijpt*

In Romania—where induced abortions were legally prohibited during communism and are now morally condemned by many—those who lose a pregnancy against their will have long been regarded with suspicion, confronted with a sense of culpability, and surrounded by silence. This ambiguity is reflected in the local terminology and the perceived etiology of loss. In this article, which is based on 15 months of fieldwork between 2012 and 2015, I illustrate the various meanings and manifestations of a silenced sense of culpability around involuntary pregnancy loss in the lives of women from Bucharest and a small town in Central Romania. I also show how many of these women attempt to break the silence around their lost fetuses and carve out a personal space of commemoration and consolation. Their informal use of forbidden religious rituals paradoxically allows them to confirm the existence of their lost little ones and to position themselves as caring, rather than culpable, mothers

[Medicine Anthropology Theory](#) (Open Access)[Epistemic Prejudice and Geographies of Innovation](#)

*Kate M. Centellas, Emma Willoughby, John J. Green*

This article seeks to understand how and why certain locations are excluded from or seen as foreclosed as places of innovation and knowledge production in health research and practice. Rooted in several years of collaborative ethnographic research in Mississippi, we develop this conceptual framework to understand the persistence of – and often ineffective response to – racialized and classed health disparities. We define our concept of epistemic prejudice as a structural inability or resistance to seeing certain places, bodies, and locations as capable of knowledge production and innovation. The history of the community health center movement, paired with the portrayal of Mississippi in contemporary media representations, helps us develop our concept. We use an interface ethnography method as Mississippi scholars to demonstrate the importance of this model of research in understanding persistent inequality in places of ‘lack’, noting that the challenges of addressing health problems in Mississippi stem in part from epistemic prejudice of scholars, health care practitioners, and policy-makers. Epistemic prejudice has broader implications for how global health initiatives are implemented, how postcolonial frameworks still shape knowledge production, and how knowledge is generated and taken as authoritative.

[Medical Pluralism, Boundary Making, and Tuberculosis in Lambaréné, Gabon](#)

*Anne Lia Cremers*

Scholars of medical pluralism are interested in how healers position themselves and their healing practices within a therapeutic landscape, and how patients navigate an array of therapeutic traditions. Based on fieldwork in Lambaréné, Gabon, this article examines the discursive practices of tuberculosis patients and healers, finding that therapeutic traditions were kept separate. Examining a national programme that fosters traditional medicine, I show how the Gabonese government engages in practices of boundary making by reinforcing traditional healers’ position within the Gabonese therapeutic landscape. This research confirms popular paradigms of boundary making within the medical

pluralism debate, wherein boundaries are produced and crossed to contrast, strengthen, purify, and divide the therapeutic landscape. Additionally, formal state-sponsored discursive practices refer to a merging of traditional medicine and biomedical medicine. This stands in contrast with patients' and healers' discursive practices, and their wariness of fluid or adaptive boundary-making processes. To explain this, I introduce the concept of 'conventional boundary making' and then analyse it in the context of tuberculosis and in relation to theories of state power, Gabonese therapeutic identity politics, and structural violence.

### [Opening Up 'Fever', Closing Down Medicines](#)

*Justin Dixon, Clare Chandler*

Rising concerns about antimicrobial resistance have sparked a renewed push to rationalise and ration the use of medicines. This article explores the case of the Integrated Management of Childhood Illness (IMCI) guideline, a periodically updated 'global' algorithm that shapes and normalises the centrality of medicines to care in low- and middle-income countries and, increasingly, the imperative to ration them. Using 'classification work' as analytic frame, we firstly consider the IMCI algorithm as a blueprint for global health that classifies illnesses, patients, and care in particular ways relative to available medicines. Zooming in on this blueprint, we then offer a classificatory reading of 'fever' over time, tracing 'nonmalarial fever' from being malaria's residual 'other' category to becoming increasingly legible through attention to diagnostics and antibiotic (over)use. Our reading suggests that an apparent refinement of the 'fever' category may concurrently entail the closing down of medicine options. This raises the possibility that an increasingly high-tech but 'empty' form of pharmaceuticalised care is being incidentally worked into the infrastructure of weak health systems.

### [On the Coloniality of Global Public Health](#)

*Eugene T. Richardson*

The continued inordinate demise from communicable pathogens in the global South is not the result of an intractable problem thwarting our best efforts to prevent and cure disease; we have the means. Rather, as an accomplice to contemporary imperialism, public health manages (as a profession) and maintains (as an

academic discipline) global health inequity. It does this through 'bourgeois empiricist' models of disease causation, which serve protected affluence by uncritically reifying inequitable social relations in the modern/colonial matrix of power and making them appear commonsensical.

### [Disaggregating Diabetes: New Subtypes, Causes, and Care](#)

*Lauren Carruth, Sarah Chard, Heather A. Howard, Lenore Manderson, Emily Mendenhall, Emily Vasquez, Emily Yates-Doerr*

Interest in disaggregating diabetes into numerous subtypes is growing as patients and providers recognize the limitations of standard diabetes typologies. As anthropologists, we draw attention to how 'subtyping' may reduce stigma derived from the connection between obesity and 'type 2 diabetes'. We highlight the complexities that drive diabetes and argue that an exclusive or dominant focus on diet and obesity obfuscates other underlying risks. Yet, we warn that subtyping may promote unnecessary pharmaceuticalization, especially for other subtypes of diabetes that may be associated with stress and inflammation. We call upon providers to continue to closely attend to patients' lived experiences. While we recognize the shortcomings of the existing classificatory scheme, patients' outcomes and prognoses are often more closely connected to the social and medical support they receive than to the underlying metabolic classification.

### [Medical Anthropology Quarterly](#)

### [The Anthropology of Plastics: An Agenda for Local Studies of a Global Matter of Concern](#)

*Gauri Pathak, Mark Nichter*

Anthropology has largely ignored plastics, even as they have emerged as the paradigmatic material—and problem—of our times. In this article, we make the case for an anthropology of plastics as a priority for environmental and medical anthropological research. Drawing from exploratory fieldwork in India, we briefly highlight the benefits and risks of different types of plastics, identify areas for anthropological investigations of human–plastic entanglements, and unpack major debates about plastic control. We recommend analyses that take into account the social life of plastics and the life cycle of plastic production, consumption, circulation, disposal,

retrieval, and decomposition. We propose a facilitator role for anthropologists in bringing environmental NGOs and the plastic industry to the table to reduce the human and environmental health risks related to widespread reliance on plastics. Overall, we argue that anthropological analyses are urgently needed to address environmental and global health concerns related to plastics.

### [Global Ambitions: Evidence, Scale, and Child Well-being in El Salvador](#)

*Tomas Matza*

Experimental design and metrics have become increasingly common in international assistance, as donor agencies have demanded rigorous forms of evaluation and monitoring. This article contributes to debates about the effects of an “evidence-based turn” on interventions and recipients by exploring two questions: What constitutes evidence when it comes to everyday practices of aid at global scales? How are the goals of assistance affected? The article draws on collaborative research with an NGO and a group of social scientists who seek to improve child well-being in El Salvador. It shows how evidence-making was polysemic and costly, ultimately impacting the NGO’s planned intervention. This outcome, I argue, was not a matter of poor planning, but reflects structural, evidence-making demands placed on global assistance at this historical juncture. Discussions among stakeholders about the trade-offs between evidence-making and assistance is a possible future route through the challenges described in this article.

### [“There Is a Big Question Mark”: Managing Ambiguity in a Moroccan Maternity Ward](#)

*Jess Marie Newman*

In Morocco, where extramarital sex and abortion are illegal, single mothers’ ambiguous status before the law inflects medical decision-making. Leaky boundaries between the court and the hospital required doctors and administrators to work with multiple forms of documentation while anticipating external surveillance. Gaps between everyday experience and legalized forms of identity created confusion across multiple institutions. When discussing single mothers, hospital staff often spoke of “question marks” that flagged tensions between legibility and liability, disappearance and documentation. Managing question marks ramified surveillance

and categorization. Ultimately, however, attempts to administratively resolve single mothers' ambiguity created gaps and inconsistencies that allowed vulnerable patients to disappear from view.

### [Medical Humanities](#)

#### [Disrupted Breath, Songlines of Breathlessness: An Interdisciplinary Response](#) (Open Access)

*Alice Malpass, James Dodd, Gene Feder, Jane Macnaughton, Arthur Rose, Oriana Walker, Tina Williams, Havi Carel*

Health research is often bounded by disciplinary expertise. While cross-disciplinary collaborations are often forged, the analysis of data which draws on more than one discipline at the same time is underexplored. Life of Breath, a 5-year project funded by the Wellcome Trust to understand the clinical, historical and cultural phenomenology of the breath and breathlessness, brings together an interdisciplinary team, including medical humanities scholars, respiratory clinicians, medical anthropologists, medical historians, cultural theorists, artists and philosophers. While individual members of the Life of Breath team come together to share ongoing work, collaborate and learn from each other's approach, we also had the ambition to explore the feasibility of integrating our approaches in a shared response to the same piece of textual data. In this article, we present our pluralistic, interdisciplinary analysis of an excerpt from a single cognitive interview transcript with a patient with chronic obstructive pulmonary disease. We discuss the variation in the responses and interpretations of the data, why research into breathlessness may particularly benefit from an interdisciplinary approach, and the wider implications of the findings for interdisciplinary research within health and medicine.

#### [Vulnerability as Practice in Diagnosing Multiple Conditions](#) (Open Access)

*Lindsay-Ann Coyle, Sarah Atkinson*

The paper contributes to contemporary understandings of vulnerability by expanding their scope with an understanding of vulnerability as generated through institutionalised practices. The argument draws on experiential accounts of navigating the practices of diagnosis by people living with multiple conditions of

ill-health and disability. Vulnerability as a concept is used widely across different domains and conveys a multitude of meanings. Contemporary biomedicine, and its associated health systems and services, understands vulnerability mostly as inherent to particular physical and mental bodily conditions that put people at risk of ill-health or emotional fragility. This may combine with a more epidemiological understanding of vulnerability as the experience of certain population groups subject to entrenched structural inequalities. Philosophers and feminists have argued that vulnerability is a universal experience of being human while political commentators have explored its potential as a resource for resistance and action. Diagnosis within medicine and psychiatry has been the subject of extensive social analysis, critique and activism. The paper draws on first-hand experiential accounts collected through face-to-face interviews with people living with multiple conditions about their experiences of diagnosis, mostly at the primary care level. We identify five aspects to diagnostic practice that are harmful and exacerbate the experience of vulnerability: temporal sequencing; diagnostic authority; medical specialisation; strategic symptom selection; medical isolation. However, these diagnostic practices are not best understood only in terms of the power asymmetries inherent to the medical consultation, but are embedded into the very institution of diagnosis. The paper thus proposes a combined approach to vulnerability that recognises it as a universal condition of humanity but one that becomes animated or amplified for some bodies, through their own inherent incapacities or the external structures of inequality, and through the practices of medicine as situated in particular times and places.

[Essential\(ist\) Medicine: Promoting Social Explanations for Racial Variation in Biomedical Research](#) (*Open Access*)

*Iliya Gutin*

Biomedical research has a long and complicated history as a tool of oppression, exemplary of the racial science used to legitimise and maintain racial hierarchies in the USA and abroad. While the explicit racism and racial inferiority supported by this research has dissipated and modern methods of inquiry have increased in sophistication and rigor, contemporary biomedical research continues to essentialise race by distilling racial differences and disparities in health to an underlying, biogenetic source. Focusing on the persistence of essentialism in an era of genomic medicine, this paper examines the deep social origins and social implications

of the essentialist viewpoint in biomedicine and how it relates to the broader construction of social and scientific knowledge. Invoking Hacking's 'looping effects' as a useful conceptual tool, I then demonstrate how sociohistorical forces influence scientific and medical research in producing evidence that favours and legitimises a biological construction of race. I extend the looping framework to consider a parallel 'louping' process whereby applying a socially rooted meaning to race in biomedical research results becomes magnified to influence social norms and ideas about race. As many biomedical researchers are motivated by a desire to eliminate racial disparities in outcomes, I argue that greater social acuity allows scientists to avoid individualising and racialising health, challenge preconceived assumptions about the meaning of racial variation in health and medicine and thus promote and strengthen a socioenvironmental focus on how to best improve individuals' and population health. Concluding with a call for structural competency in biomedical research, I suggest that empowering scientists to more freely discuss sociostructural factors in their work allows for the continued use of race in biological and medical research, while social scientists and medical humanities scholars stand to benefit from seeing their work imbued with the cultural authority currently granted to biomedicine.

[The Participatory Zeitgeist: An Explanatory Theoretical Model of Change in an Era of Coproduction and Codesign in Healthcare Improvement](#)  
(Open Access)

*Victoria Jane Palmer, Wayne Weavell, Rosemary Callander, Donella Piper, Lauralie Richard, Lynne Maher, Hilary Boyd, Helen Herrman, John Furler, Jane Gunn, Rick Iedema, Glenn Robert*

Healthcare systems redesign and service improvement approaches are adopting participatory tools, techniques and mindsets. Participatory methods increasingly used in healthcare improvement coalesce around the concept of coproduction, and related practices of cocreation, codesign and coinovation. These participatory methods have become the new Zeitgeist—the spirit of our times in quality improvement. The rationale for this new spirit of participation relates to voice and engagement (those with lived experience should be engaged in processes of development, redesign and improvements), empowerment (engagement in codesign and coproduction has positive individual and societal benefits) and advancement (quality of life and other health outcomes and experiences of services for everyone involved should improve as a result). This paper introduces Mental Health

Experience Co-design (MH ECO), a peer designed and led adapted form of Experience-based Co-design (EBCD) developed in Australia. MH ECO is said to facilitate empowerment, foster trust, develop autonomy, self-determination and choice for people living with mental illnesses and their carers, including staff at mental health services. Little information exists about the underlying mechanisms of change; the entities, processes and structures that underpin MH ECO and similar EBCD studies. To address this, we identified eight possible mechanisms from an assessment of the activities and outcomes of MH ECO and a review of existing published evaluations. The eight mechanisms, recognition, dialogue, cooperation, accountability, mobilisation, enactment, creativity and attainment, are discussed within an 'explanatory theoretical model of change' that details these and ideal relational transitions that might be observed or not with MH ECO or other EBCD studies. We critically appraise the sociocultural and political movement in coproduction and draw on interdisciplinary theories from the humanities—narrative theory, dialogical ethics, cooperative and empowerment theory. The model advances theoretical thinking in coproduction beyond motivations and towards identifying underlying processes and entities that might impact on process and outcome.

### [New Genetics and Society](#)

### [Imagining the Future of Cell Therapies: Clinical Trials, Innovation and the Intersection of Clinical-Academic and Commercial Visions](#) (*Open Access*)

*Ruchi Higham*

This paper examines the role of clinical trials in regenerative medicine innovation, exploring how trials have contributed to translational challenges in the field. Using data from an ethnographic study of UK cell therapy trials I interrogate the institutional framework for clinical trials and the identity-making of trialists. This analysis uncovers a disconnect between a commercially-aligned regulatory framework and a clinical-academic identity apparent in the majority of current trialling activity. These different pathways appear to represent two distinct sociotechnical imaginaries for cell therapies; one which reflects the assumptions of commercial innovation and prioritizes economic success, and another which embodies the cultural expectations of academia and emphasizes the importance of clinical care. These two imaginaries operate in synergy to some extent but there are significant tensions between them. How and to what extent these tensions

are reconciled is likely to determine both the long-term success and the future shape of the field.

### [Yeast: One Cell, One Reference Sequence, Many Genomes?](#)

*Erika Szymanski, Niki Vermeulen, Mark Wong*

The genome of *Saccharomyces cerevisiae* – brewer’s or baker’s yeast – was the first eukaryotic genome to be sequenced in 1996. The identity of that yeast genome has been not just a product of sequencing, but also of its use after sequencing and particularly of its mobilization in scientific literature. We ask “what is the yeast genome?” as an empirical question by investigating “the yeast genome” as a discursive entity. Analyzing publications that followed sequencing points to several “yeast genomes” existing side-by-side: genomes as physical molecules, digital texts, and a historic event. Resolving this unified-yet-multiple “genome” helps make sense of contemporary developments in yeast genomics such as the synthetic yeast project, in which apparently “the same” genome occupies multiple roles and locations, and points to the utility of examining specific non-human genomes independent of the Human Genome Project.

### [Science as Culture](#)

#### [The Political Space between Words and Things: Health Claims as Referential Displacement](#)

*Kim Hendricks*

In the EU today, health claims on food labels are regulated as a form of information. Before the 2000s, statements referring to health on packaged food were subject to different national regulations across the EU, with different perspectives on where the boundary lies between food and drugs. The turn to more horizontal legislation in EU food law and increased emphasis on the role of information for the functioning of the Single Market does not in itself explain why, and especially *how*, health-related statements on food products have been turned into information and what consequences this has produced. Construction of such a European ‘technological zone’, where health claims circulate as a form of information, can be understood as ‘information’s constitutive outside’ (Barry, A. (2006) Technological zones, *European Journal of Social Theory*, 9(2), pp.

239–253; Barry, A. (2013) *Material Politics: Disputes along the Pipeline* (Oxford: Wiley-Blackwell)). This outside hinges on techno-political discussion, lobbying and decisions where the boundary between health and disease is at stake, along with food's materiality. The concept of *referential displacement* shows how decisions in the regulatory process have transformed controversial references to human health on food labels into 'health claims' as an informational category by shifting the relation between the health claim and its material referents: food itself, health and the body. Referential displacement produces a new kind of information that implies similar efficacy to pharmaceutical drugs, without interfering with the zone or market of pharmaceuticals.

### [Devices of Difference: On the Socio-Material Forms and Effects of Technologies in Complementary and Alternative Medicine](#)

Jaroslav Klepal, Tereza Stockelova

Despite the widespread view that complementary and alternative medicine (CAM) is a 'natural' and low-tech form of healthcare, by contrast with biomedicine, there are numerous devices used in the field of CAM that employ electricity as a diagnostic and therapeutic agent. These devices bring together different types and sources of knowledge, Western and Eastern theories, and expert and lay hands. They foreground complex psychosomatic, social, and environmental relations in which the patient's body and well-being are constituted. They are used to address biomedicine's iatrogenic effects and its indifference to specific bodily processes and entities (such as meridians or parasites). In effect they challenge, extend, and reinterpret biomedicine, thereby becoming one of the mediators between it and CAM. Although these devices are sought out by patients and used effectively by CAM practitioners, their ontological choreography and radius can become precarious in a healthcare system dominated by biomedicine. Different CAM devices then deal with the realities of biomedicine in different ways. While some modes of practising CAM devices are inclusive of biomedicine and carefully experiment with the realities it has inscribed in patients' bodies, others reject biomedicine altogether.

### [Science in Context](#)

### [The Uses of Trauma in Experiment: Traumatic Stress and the History of](#)

[Experimental Neurosis, c. 1925–1975](#)

*Ulrich Koch*

The article retraces the shifting conceptualizations of psychological trauma in experimental psychopathological research in the middle decades of the twentieth century in the United States. Among researchers studying so-called experimental neuroses in animal laboratories, trauma was an often-invoked category used to denote the clash of conflicting forces believed to lead to neurotic suffering. Experimental psychologists, however, soon grew skeptical of the traumatogenic model and ultimately came to reject neurosis as a disease entity. Both theoretical differences and practical circumstances, such as the technical challenge of stabilizing neurotic symptoms in rats, led to this demise. Yet, despite their reservations, experimental psychologists continued to employ traumatic stimuli to produce psychopathological syndromes. In the 1960s, a new understanding of trauma evolved, which emphasized the loss of control experienced by traumatized animal subjects. These shifting ideas about trauma, I argue, reflect both varying experimental cultures, epistemic norms as well as changing societal concerns.

[Social History of Medicine](#)

[‘Treatment Not Trident’: Medical Activism, Health Inequality and Anti-Militarism in 1980s Britain](#) (*Open Access*)

*Christoph Laucht*

In 1985, Britain’s chief group of medical anti-nuclear weapons activists, the Medical Campaign Against Nuclear Weapons (MCANW), launched its ‘Treatment, Not Trident’ (TNT) campaign. TNT called on the Thatcher Government to cancel the acquisition of the Trident nuclear weapon system and divert those funds to the National Health Service and foreign aid instead. Using TNT, this article makes some more general observations about key aspects of the history, nature and ideologies of medical activism in relation to anti-militarism and health inequality. Alongside a conceptualisation of ‘medical activism’, it offers an examination of chief ways in which the strategic mobilisation of health and welfare priorities, and a growing interest in developing nations enabled MCANW to reach a larger audience. Moreover, higher levels of professionalisation, politicisation and inclusivity contributed to TNT’s success, making it a crucial moment in the development of

both MCANW and medical activism in general.

[The Experimental Conception Hospital: Dating Pregnancy and the Gothic Imagination](#) (*Open Access*)

*Isabel Davis*

The Experimental Conception Hospital is a fictional laboratory described in a note by Robert Lyall on the medical evidence given in the Gardner Peerage dispute (1825–26). This fantasy institution would discover the natural length of human gestation and ascertain from when and what to date conception, calculations which eluded the House of Lords Peerage Committee which heard the case. This article introduces the Gardner case and Lyall's writing about it, focusing on the Gothicism which emerges particularly in relation to the perceived secrecy of the female reproductive body. By considering Lyall's Experimental Conception Hospital alongside three other technologies—the Panopticon, the hot air balloon and anatomical drawings of the gravid uterus—this article discovers the anachronistic persistence of supposedly out-dated modes of thoughts around female sexuality and reproductive biology in an apparently hyper-modern moment.

[Social Science and Medicine](#)

[Tracking Biomedicalization in the Media: Public Discourses on Health and Medicine in the UK and Italy, 1984–2017](#)

*Federico Neresini, Stefano Crabu, Emanuele Di Buccio*

This article examines historical trends in the reporting of health, illness and medicine in UK and Italian newspapers from 1984 to 2017. It focuses on the increasing “biomedicalization” of health reporting and the framing of health and medicine as a matter of technoscientific interventions. Methodologically, we relied on two large datasets consisting of all the health- and medicine-related articles published in the online archives of *The Guardian* (UK) and *la Repubblica* (Italy). These articles underwent a quantitative analysis, based on topic modelling techniques, to identify and analyse relevant topics in the datasets. Moreover, we developed some synthetic indices to support the analysis of how medical and health news are “biomedicalized” in media coverage. Theoretically, we emphasise that media represent a constitutive environment in shaping biomedicalization processes. Our analyses

show that across the period under scrutiny, biomedicalization is a relevant, even if sometimes ambivalent, frame in the media sphere, placing growing centrality on three dimensions: i) health and well-being as a matter of individual commitment to self-monitoring and self-surveillance; ii) biomedicine as a large technoscientific enterprise emerging from the entanglement between research fields and their technological embodiments; iii) the multiverse reforms of welfare systems in facing the trade-off between universal health coverage and the need to render the national healthcare system more sustainable and compatible with non-expansionary monetary policies and austerity approaches in managing state government budgets.

[The Embodied Relationality of Blood-Borne Viruses: How Families Matter in the Context of a Stigmatised Viral Infection](#) (*Open Access*)

Asha Persson, Christy E. Newman, kylie valentine, Myra Hamilton, Joanne Bryant, Jack Wallace

This paper argues that blood-borne viruses are *relationally embodied*, providing an alternative ontology to the individualising tendencies in medical science, and a more inclusive analysis of serodiscordance (mixed infection status) than the literature's focus on transmission risk in couples. We know little about the wider world of significant relationships in the lives of those with blood-borne viruses. People with HIV and hepatitis C are in a mixed-status relationship not just with intimate partners, but with other family members too. Drawing on qualitative interviews and phenomenological theory, we make the case that families (broadly defined) *matter* in the context of stigmatised, transmissible infections in ways that extend beyond individual bodies and beyond the usual preoccupation with risk. Despite recent advances in the treatment of blood-borne viruses, our study shows that these infections continue to be experienced and negotiated through embodied connections to significant others, made meaningful through culturally situated understandings and expectations regarding kinship, affinity, love, shared history and obligations. Our findings encourage broader recognition of these viral infections as intercorporeal phenomena, with families intimately entangled in co-creating the meanings and experiences of disease.

[Biographical Disruption or Cohesion?: How Parents Deal with their Child's Autism Diagnosis](#) (*Open Access*)

*Pernille Skovbo Rasmussen, Inge Kryger Pedersen, Anne Katrine Pagsberg*

Currently, we are witnessing a precipitous rise in autism diagnoses among children, and several bodies of sociological research are attempting to explain this development. However, the experiences within parental contexts have been inadequately examined; that is, how parents feel about and act upon the awareness of their child's autism diagnosis. Drawing upon a qualitative study among Danish parents of 20 children recently diagnosed with autism, this paper contributes with situated insights into parents' experiences. We identify a spectrum of feelings towards the autism diagnosis, including both relief and grief. In the absence of theoretical notions drawing attention to how a child's diagnosis influences parents' self-conceptions and understandings of their child, we develop the concept of 'parent-biographical disruption': the parents' rethinking of themselves and their child that might be caused by a chronic condition such as autism. Based on the variety of findings, we discuss what we call 'parent-biographical cohesion' as a counterpart to 'disruption'. By 'cohesion' we refer to the diagnostic awareness potentially creating clarification for parents about the past, present and future parenting of their child instead of disrupting their self-understandings as parents. In this way, through the notion of a parental-biographical spectrum of disruption and cohesion, we emphasize the diversity in how parents deal with a child's autism diagnosis and the variety of needs for rethinking parental biographies in the wake of a diagnosis.

### [Transcultural Psychiatry](#)

['Ayn Mika: Traumatic Experience, Social Invisibility, and Emotional Distress of Sub-Saharan Women with Precarious Status in Morocco](#) (*Open Access*)

*Abdelwahed Mekki-Berrada*

Morocco has become a *permanent transit* country for tens of thousands of sub-Saharan migrants heading to Europe. Many of these migrants are women who have a precarious legal status and can no longer reach Europe, whose borders have been considerably securitized since September 11, 2001. They also have no wish to risk their lives again returning south across the Sahara Desert. This paper discusses the results of an exploratory research project conducted in Morocco on the relationships

between the sub-Saharan migrant women's traumatic experiences, social invisibility, and emotional distress in the context of a massive securitization of Euro-Mediterranean borders.

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#### AMA citation

Peyravi R. In the Journals, December 2019. *Somatosphere*. 2020. Available at:  
<http://somatosphere.net/2020/in-the-journals-december-2019.html/>. Accessed January 2, 2020.

#### APA citation

Peyravi, Raha. (2020). *In the Journals, December 2019*. Retrieved January 2, 2020, from Somatosphere Web site:  
<http://somatosphere.net/2020/in-the-journals-december-2019.html/>

#### Chicago citation

Peyravi, Raha. 2020. In the Journals, December 2019. *Somatosphere*. <http://somatosphere.net/2020/in-the-journals-december-2019.html/> (accessed January 2, 2020).

#### Harvard citation

Peyravi, R 2020, *In the Journals, December 2019*, *Somatosphere*. Retrieved January 2, 2020, from  
<<http://somatosphere.net/2020/in-the-journals-december-2019.html/>>

**MLA citation**

Peyravi, Raha. "In the Journals, December 2019." 1 Jan. 2020.

Somatosphere. Accessed 2 Jan. 2020.<<http://somatosphere.net/2020/in-the-journals-december-2019.html/>>