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## In the Journals – December 2017

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By Anna Zogas

Happy new year! This post rounds off Somatosphere's 2017 "In the Journals," with articles published in December. Enjoy!

### [Medical Anthropology Quarterly](#)

[\(In\)Visibility Online: The Benefits of Online Patient Forums for People with a Hidden Illness: The Case of Multiple Chemical Sensitivity \(MCS\)](#)

*Tarryn Phillips, Tyson Rees*

Sufferers of medically unexplained conditions that are not observable in the clinic can experience multiple layers of invisibility: a lack of biomedical diagnosis; legal skepticism; political disinterest; and a loss of their prior social identity. For those with environmental sensitivities, this is compounded by literal hiddenness due to often being housebound. Drawing on an online survey of people with multiple chemical sensitivity, this article examines how the everyday experience of invisibility is mitigated by engaging with other patients online. Respondents used online forums to undertake various forms of "visibility work," including attempts to crystallize their suffering into something recognizable medically, legally, and politically, and to reconstruct an identity considered valid and deserving—although the therapeutic potential of online support was contingent on intra-group politics. This study demonstrates that online forums allow biomedicine's "invisible others" to struggle for alternative forms of recognition beyond the clinical gaze.

[Corporate Mortality Files and Late Industrial Necropolitics](#)

*Peter C. Little*

This article critically examines the corporate production, archival politics, and socio-legal dimensions of corporate mortality files (CMFs), the largest corporate archive developed by IBM to systematically document industrial exposures and occupational health outcomes for electronics workers. I first provide a history of IBM's CMF project, which amounts to a comprehensive mortality record for IBM employees over the past 40 years. Next, I explore a recent case in Endicott, New York, birthplace of IBM, where the U.S. National Institute for Occupational Safety and Health studied IBM's CMFs for workers at IBM's former Endicott plant. Tracking

the production of the IBM CMF, the strategic avoidance of this source of big data as evidence for determining a recent legal settlement, alongside local critiques of the IBM CMF project, the article develops what I call “late industrial necropolitics.”

[Efficacious Holidays: The Therapeutic Dimensions of Pleasure and Discipline in Czech Respiratory Spas](#)

*Susanna Trnka*

As evidence-based medicine has increasingly become the standard for assessing the efficacy of health care, the Czech Republic finds itself in a dilemma, with centuries of sanatorium-style spa treatments resisting easy categorization. Despite some critics’ contentions that spas are “pointless holidays” and reductions in government funding of health spas, in 2014 Czech courts affirmed every Czech citizen’s right to spa treatments if their health status merits it. Drawing on research in two children’s respiratory spas, this article considers the experiences of patients aged 2–15 and their accompanying parents or guardians (mainly mothers) to suggest that in addition to the range of therapeutic procedures highlighted within spa cures, more amorphous aspects—such as pleasure and discipline—may be just as central to spas’ successes. Indeed, as some spa physicians contend, spas may be considered a “package deal,” to which EBM criteria is not easily applied.

[To Keep this Disease from Killing You: Cultural Competence, Consonance, and Health among HIV-positive Women in Kenya](#)

*Toni Copeland*

The HIV/AIDS crisis continues in sub-Saharan Africa, where nearly 70% of infections are found. Despite recent efforts to supply antiretroviral therapy to those infected, most are not receiving medication and are forced to rely on self-management to remain healthy. In Kenya, many of those infected are women living in extreme poverty. This article presents the findings of research among poor women in Nairobi that examined the relationship between knowledge of a cultural model of self-managing HIV/AIDS, cultural consonance, and health. This biocultural study expands on earlier findings showing that knowledge of the model (competence) is a significant predictor of health by examining here how behavior consistent with that knowledge (consonance) affects health outcomes, as measured by CD4 counts, perceived stress, depressive symptoms, and recent illnesses.

[Pregnant Metaphors and Surrogate Meanings: Bringing the Ethnography of Pregnancy and Surrogacy into Conversation in Israel and Beyond](#)

*Tsipy Ivry, Elly Teman*

This article explores the way that surrogacy and normal pregnancy share cultural assumptions about pregnancy. Through a juxtaposition of our ethnographic studies of two groups of Jewish–Israeli women—women who have undergone “normal,” low-risk pregnancies and women who have given birth as gestational surrogates—we argue that surrogacy and pregnancy emerge as potent metaphors for one another. Both pregnant women and surrogates divided their bodies into two separate realms: fetus and maternal pregnant body. Both trivialized the effect of gestational influence on fetal health, making the fetus seem detached from gestational capacities of the mother. We argue for closer scrutiny of the way local cultural priorities and experiences of pregnancy shape surrogacy and for bringing the scholarship on pregnancy and on surrogacy into deeper conversation.

[Living the Social Determinants of Health: Assemblages in a Remote Aboriginal Community](#)

*Richard D. Chenhall, Kate Senior*

This article provides a critical discussion of the social determinants of health framework and compares it with theoretical perspectives, such as that offered by assemblage theory, offering an alternative view of the complex interplay between human relationships and the structures around us. We offer an ethnographic perspective, discussing the lived experiences of the social determinants in an Indigenous community in a remote part of northern Australia.

[Only Near Is Dear? Doing Elderly Care with Everyday ICTs in Indian Transnational Families](#)

*Tanja Ahlin*

In Kerala, South India, young people, especially women, are encouraged to become nurses in order to migrate abroad for work and thereby improve the financial status of their family. Meanwhile, many of their parents remain in India by themselves. This is occurring in the context of a strong popular discourse of elder abandonment, related to the local norms of intergenerational co-habitation. Based on fieldwork in Kerala and one of the nurses' destination countries, Oman, I present evidence that complicates this discourse by showing how: (1) migration is a form of elder care practice in itself; and (2) care for the elderly continues across countries and continents with the help of information and communication technologies (ICTs). Using the theoretical approaches of science and technology studies, I analyze ICTs as key members of care collectives and argue that ICTs have a significant role in reshaping care relations at a distance.

[Care in the Context of a Chronic Epidemic: Caring for Diabetes in](#)

## [Chicago's Native Community](#)

*Margaret Pollak*

American Indians have some of the highest rates of diabetes worldwide, and they are disproportionately affected by the secondary complications of the disease. While most research on Native populations focuses on reservations, this study investigates diabetes care in Chicago's Native community. People living with diabetes manage blood sugar levels to prevent the development of secondary complications. As with many diabetics, the majority of their health care work is completed outside of the biomedical setting. In this article, I explore how, in a community facing epidemic rates of disease, care is enmeshed in the everyday lives of not just those living with the disease but also significant others. As care in this context is accomplished across multiple spheres, from inside individual households to community-wide considerations, Chicago's intertribal community ties are strengthened. Care, in this sense, becomes a (perhaps tragic) means of Native American community building tied to cultural identity.

## [Anthropology & Medicine](#)

### [A critique of medicalisation: three instances](#)

*Sonia Ryang*

By briefly exploring three different examples where the existence of mental illness and developmental delay has been presumed, this paper sheds light on the way what Foucault calls the emergence of a regime of truth, i.e. where something that does not exist is made to exist through the construction of a system of truth around it. The first example concerns the direct marketing of pharmaceutical products to consumers in the US, the second the use of psychology in semi-post-Cold War Korea, and the third the persisting authority of psychology in the treatment of the developmentally delayed. While these instances are not innately connected, looking at these as part of the process by which the authoritative knowledge is established will help us understand, albeit partially, the mechanism by which mental illness penetrates our lives as truth, and how this regime of truth is supported by the authority of psychology, psychiatry and psychoanalysis, what Foucault calls the 'psy-function,' reinforcing the medicalisation of our lives.

### [From distress to disease: a critique of the medicalisation of possession in DSM-5](#)

*Divya Padmanabhan*

This paper critiques the category of possession-form dissociative identity disorder as defined in the Diagnostic and Statistical Manual of Mental

Disorders 5 (DSM-5) published in 2013 by the American Psychiatric Association (APA). The DSM as an index of psychiatry pathologises possession by categorising it as a form of dissociative identity disorder. Drawing upon ethnographic fieldwork, this paper argues that such a pathologisation medicalises possession, which is understood as a non-pathological condition in other contexts such as by those individuals who manifest possession at a temple in Kerala, South India. Through medicalising and further by creating distinctions between acceptable and pathological possession, the DSM converts a form of distress into a disease. This has both conceptual and pragmatic implications. The temple therefore becomes reduced to a culturally acceptable site for the manifestation of a mental illness in a form that is culturally available and possession is explained solely through a biomedical framework, denying alternative conceptualisations and theories which inform possession. By focussing on the DSM-5 classification of possession and the limitations of such a classification, this paper seeks to posit an alternative conceptualisation of possession by engaging with three primary areas which are significant in the DSM categorisation of possession: the DSM's conceptualisation of self in the singular, the distinction between pathological and non-pathological forms of possession, and the limitations of the DSM's equation of the condition of possession with the manifestation of possession. Finally, the paper briefly highlights alternative conceptualisations of possession, which emerged from the perspective of those seeking to heal possession at the Chottanikkara temple.

[Of sacraments, sacramentals and anthropology: is anthropological explanation sacramental?](#)

*Harish Naraindas*

This paper suggests that what is usually called a cultural misunderstanding of biomedical disease categories may be construed as a biomedical and anthropological misunderstanding of cultural categories. This is premised on the fact that anthropology often functions as an intimate double and handmaiden of biomedicine, in so far as it refuses to countenance the possibility of theurgic aetiologies in the realm of what is called 'mental illness'. Such a refusal displaces native explanations of divine or demonic agency to human agency. This is best elucidated by examining the unexamined religious beliefs of Anglo-European anthropology, which appears to be the terra firma of its emic explanatory categories. The paper attempts to demonstrate this by proposing that while native explanations are akin to the sacraments, anthropological explanations are akin to sacramentals (holy water, the cross, the scapular, verbal blessings). While the sacraments, like divine agency, operate *ex opere operato*, the sacramentals are dependent on the disposition of the recipient and on the good offices of the church, as they operate *ex opere operantis ecclesiae* (from the work of the working church), as well as *ex*

opere operantis (from the work of the working one). If the sacraments are efficacious as it is work done by Christ alone, and akin to work done by the possessing agent, sacramentals are efficacious as they are also dependent on human agency. In other words, anthropological explanations are, at best, 'sacramental' as they replace emic theurgic explanations by etic ones, where human agency in the form of the priest, the institution of the church, and the lay person who is the recipient of divine dispensation, also have a role to play; or, as is often the case, the only role to play.

### [Humanitarian quarantine in practice: medicine, religion and leprosy in New Caledonia](#)

*Ingrid J. Sykes*

Medicine and religion worked in close synchronisation during the leprosy outbreak of New Caledonia (1890–1950). Once isolation of leprosy-affected people became mandatory doctors and missionaries came together to promote a particular form of medical practice that tied charitable zeal with cutting-edge medical research, developing a sophisticated set of medical practices that catered for the soul as well as the body. Such practices went hand-in-hand with ideas developed by doctors in the earlier stages of the epidemic about the way in which the disease had entered the Kanak (local Melanesian) population. Doctors and missionaries admitted that immoral colonial channels had upset the delicate balance of local social and biological rhythms. Yet they also believed that the highly contagious nature of the outbreak was linked to the inferior state of Kanak. This paper aims to highlight the way in which the leprosaria system in New Caledonia represented a double-edged moral high-ground within the French medical colonial narrative. It tracks the complex way in which emotionally charged arguments about contagion, science and spirituality constructed an ideology of humanitarian quarantine which was used to justify a highly aggressive form of medical biocontrol.

### [Hospitals as factories of medical garbage](#)

*Sarah Hodges*

Over the course of the twentieth century, as hospitals cleaned up, they came to produce more and more rubbish. Beginning in the 1970s and gaining pace in the 1980s and 1990s, single-use plastic items (syringes, blood bags, tubing) saturated everyday medical practice across the globe. This essay brings the question of plastic to bear upon the longer history of twentieth century sanitary science. The widespread adoption of single-use disposable medical plastics consolidated a century's worth of changes in medical hygiene. As strange as it may seem today, the initial uptake of medical plastics was not driven primarily by concerns about hygiene.

Plastic began as a mid-century technology of convenience and durability. It was not until the end of the twentieth century that it morphed into a powerful symbol and instrument of medical hygiene. Today, both patients and practitioners have embraced plastic as an indispensable technology of clean medicine. The procession of single-use medical plastics through everyday medicine now comprises a constant, if disposable, infrastructure of medical hygiene. This new processional infrastructure of disposable hygiene has produced another, albeit unintended, consequence. This new regime has exponentially increased hospitals' material outputs. In so doing, plastic has refigured the ecologies of everyday medicine. Plastic hygiene has rendered hospitals factories of medical garbage.

[Performing piety in sexual health research: gender, health and evangelical Christianities in a Mexican human papillomavirus \(HPV\) study](#)

*Emily Wentzell*

Recent research suggests that health surveillance experiences like clinical trial participation might have unanticipated social consequences. I investigate how evangelical Christians participating in longitudinal, observational sexual health research incorporate that long-term medical surveillance into their religious practice. This exploratory research focuses on Mexican Cristianos' participation in the Cuernavaca arm of the multinational 'Human Papillomavirus in Men' ('HIM') study, which tested men for the common and usually asymptomatic sexually transmitted infection human papillomavirus (HPV) over time. I draw on interviews with heterosexual male research participants and their female partners throughout their medical research involvement, and data from church-based participant observation, to understand how couples framed the HIM study as an arena for performing piety. I argue that evangelical understandings of piety as moral practice encouraged participants to view long-term sexual health surveillance as assistance for living out the health, gender, and marital behaviors promoted by their congregations. This finding suggests that health research designers and ethics committees should consider the health and social outcomes of research participants' agentive incorporation of religious observance into study protocols.

[Living into death: a case for an iterative, fortified and cross-sector approach to advance care planning](#)

*Rebecca Llewellyn, Chrystal Jaye, Richard Egan, Wayne Cunningham, Jessica Young & Peter Radue*

Advance care planning (ACP) has been framed as best practice for quality palliative care, yet a growing body of literature affirms the need for an early iterative ACP process to begin when people are young and healthy. A significant gap appears to exist in the literature regarding the utility of death conversations outside the end-of-life context. Could 'death

conversations' early in life be an effective tool by which doctor and patient can co-construct a more healthful way of life, and realistic relationship with death? And what variables must be taken into account for these conversations to proceed successfully? This paper provides a narrative exploration of the value of death conversations in the clinical context in New Zealand. Five exemplars are discussed, drawn from a sample of 21 semi-structured interviews with young older adults (54–65 years old) not receiving palliative care or diagnosed with a terminal illness. Together, these narratives indicate that further community consultation is required to determine culturally appropriate ways to initiate productive conversations around aging, death and dying and how to build patient/practitioner/family relationships which allow these conversations to happen safely. There is a need to acknowledge the important factor of culture related to age, generation, sex, faith and ethnicity when engaging in conversations about aging, death and dying. By doing so, health professionals will be best equipped to assist their patients to live well into death.

### [Medical Humanities](#)

[Shame, stigma and medicine](#) (open access)

*Barry Lyons, Luna Dolezal*

[excerpt] The Shame and Medicine Project evolved from a conversation between the two editors of this Special Issue of Medical Humanities about the politics of shame and humiliation within healthcare. One is a philosopher with an academic focus in the phenomenology of the body, the other a clinician with an interest in medical training and regulation. Over the 2 years the project has run thus far, we have had the pleasure of hearing from scholars and practitioners from over 20 distinct and diverse disciplines—from theology and history to plastic surgery and contemporary visual culture. It has been a truly interdisciplinary engagement and one that has reflected shame's role as a commonplace social emotion, frequently 'underground' or hidden, but which has affected, and continues to impact on, many health-related interactions between individuals and society, patients and doctors, clinicians and regulators. Shame is the primary 'emotion of politics and conformity' particularly, as Myra Mendible points out in *American Shame*, 'for those who have the 'wrong' bodies or the 'wrong' desires'. Those who deviate from entrenched social norms are frequently subjected to stigma—'a social process, experienced or anticipated, characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group'. Stigma, as many of the articles in this Special Issue demonstrate, is intimately bound up with shame. In moments of stigma, Goffman famously noted, 'shame becomes a central possibility'. Stigma is a social, emotional, political and clinical issue of enormous significance—the



impact of social exclusion contributes substantially to the burden of illness, perhaps to the extent that in highly stigmatised disorders the suffering brought on by the disease process may be outweighed by the impact of stigma-induced social rejection.

[Shame and the vulnerable self in medical contexts: the compassionate solution](#)

*Paul Gilbert*

Shame is a powerful experience that plays a vital role in a whole range of aspects of the clinical encounter. Shame experiences can have an impact on our psychological and physiological state and on how we experience ourselves, others and our relationships. The medical encounter is an obvious arena for shame because we are presenting (aspects of) our bodies and minds that can be seen as unattractive and undesirable, diseased, decayed and injured with the various excretions that typically might invite disgust. In contrast, experiences of compassion of acceptance, validation and kindness and can increase approach, openness and preparedness to engage with painful difficult scenarios. While shame is an experience that separates, segregates, marginalises and disengages people, caring and compassion facilitate integration, (re)connection and support. Given the potential opposite impacts of these different types of social experience, this paper will outline their evolutionary origins and compare and contrast them with particular reference to the medical context.

[A dirty little secret: stigma, shame and hepatitis C in the health setting](#)

*Jane Megan Northrop*

While recent medical innovation shows great promise in treating hepatitis C (HCV), it remains a condition associated with profound stigma. HCV is a bloodborne virus (BBV) most commonly transmitted in high-income countries by injecting drug use, and it is the stigmatising association between the two which is deeply problematic for those with HCV. A qualitative study undertaken in 2002 found that disclosure in health settings places those with HCV in positions of pronounced vulnerability. Disclosure is a primal scene, an interface, where the stigma of HCV, replete with connotations of disease and deviance, potentially transforms those affected into shamed subjects. Standard precautions protect health workers and minimise the transmission of contagion, measures which, in theory, also mitigate the requirement of those with BBVs to unnecessarily disclose their blood status. However, questions on pre-employment health checks, concerns that health treatments might adversely affect the liver and an ethical need to pre-emptively inform healthcare professionals undertaking exposure prone procedures are occasions when those with HCV confront the decision to disclose their blood status. This paper

employs Goffman's model of actual and virtual social identities, along with Douglas' notion of dirt and pollution, to examine the dilemmas around disclosure those with HCV negotiate within the health setting. Discriminatory responses by healthcare professionals elucidate the stigmatising potential HCV carries. The subsequent reticence by those with HCV to disclose their blood status risks less than optimum healthcare. Recent studies indicate that stigma occurring in health settings remains a perennial concern for those with HCV.

[Shame, stigma, HIV: philosophical reflections](#) (open access)

*Phil Hutchinson, Rageshri Dhairyawan*

It is a distinctive feature of HIV that its pathology cannot be adequately grasped separate from a number of psychosocial factors, and stigma is widely seen as the most prominent. We argue that it is equally important to have an adequate understanding of shame, as the emotional response to stigma. We have identified five ways shame might negatively impact upon attempts to combat and treat HIV, which emerge from the stigma HIV carries and STI-stigma in general. In this paper, we draw out four insights from philosophical work on emotions and shame which we propose will improve understanding of shame and stigma. We conclude by briefly discussing how these insights might shed light on the negative role shame can play for a person living with HIV engaging with, or being retained in, care. We conclude by proposing further study.

[Pain, objectivity and history: understanding pain stigma](#) (open access)

*Daniel S Goldberg*

The primary claim of this paper is that understanding the stigma so commonly endured by chronic pain sufferers today in the USA and the UK is unlikely without proper appreciation of the history of pain. Ameliorating such stigma is an ethical imperative, and yet most approaches eschew even an attempt to trace connections between historical attitudes, practices and beliefs towards pain and the stigmatisation so many pain sufferers currently endure. The manuscript aims to help fill this gap by framing pain in the modern era in context of two crucial intellectual schemes that waxed in the 19th and 20th centuries: mechanical objectivity and somaticism. The analysis explains these frameworks and applies them to exploration of primary sources connected to contested pain conditions such as railway spine. By properly situating the historical roots of what it means to cite the 'subjectivity' of pain as a problem, the modern roots of stigmatising attitudes and practices towards chronic pain sufferers become much clearer. The manuscript concludes by suggesting that interventions expressly intended to target the root causes of such stigma are much more likely to be successful than approaches that proceed in ignorance of the historical forces shaping and driving pain

stigma in the present.

[The medical reshaping of disabled bodies as a response to stigma and a route to normality](#) (open access)

*Janice McLaughlin*

Disabled people are said to experience stigma because their embodied presence in the world does not fit with how others interact and use their bodies to be social participants. In response they can turn to medical procedures, such as surgery or physiotherapy, in order to reshape their bodies to more closely approximate norms of social interaction and embodiment. This paper explores how medicine plays a role in attempts to be recognised by others as normal and acceptable by minimising disability. It will do so via a focus on disabled young people, in order to explore how their emerging identities and aspirations for the future influence how they think about their bodies, what normality means and their participation in multiple activities that work on their bodies. The paper draws from an Economic and Social Research Council (ESRC) project that used a range of qualitative research methods with a group of disabled young people. The project explored ways in which participants actively worked on their bodies to be more normal and examined the disciplinary and agency dynamics involved in this work.

[On shame and voice-hearing](#)

*Angela Woods*

Hearing voices in the absence of another speaker—what psychiatry terms an auditory verbal hallucination—is often associated with a wide range of negative emotions. Mainstream clinical research addressing the emotional dimensions of voice-hearing has tended to treat these as self-evident, undifferentiated and so effectively interchangeable. But what happens when a richer, more nuanced understanding of specific emotions is brought to bear on the analysis of distressing voices? This article draws findings from the ‘What is it like to hear voices’ study conducted as part of the interdisciplinary Hearing the Voice project into conversation with philosopher Dan Zahavi’s *Self and Other: Exploring Subjectivity, Empathy and Shame* to consider how a focus on shame can open up new questions about the experience of hearing voices. A higher-order emotion of social cognition, shame directs our attention to aspects of voice-hearing which are understudied and elusive, particularly as they concern the status of voices as other and the constitution and conceptualisation of the self.

[Current Anthropology](#)

[The Pharmaceutical Assemblage: Rethinking Sowa Rigpa and the Herbal Pharmaceutical Industry in Asia](#) (open access)

*Stephan Kloos*

Cutting-edge anthropological research on pharmaceuticals aims to trace the connections that link our health and subjectivity, via the drugs we ingest, to contemporary forms of science, governance, and market practice. Yet this research is mostly limited to biomedical pharmaceuticals, ignoring the vast and rapidly growing “traditional” pharmaceutical industry, which connects contemporary forms of culture, capitalism, and politics in arguably even more interesting ways. Addressing this gap, this programmatic essay proposes the concept of the “pharmaceutical assemblage” as a way to assess the traditional pharmaceutical industry as part of Asia’s growing knowledge industry sector and the global pharmaceutical nexus. Taking the emerging Sowa Rigpa (also known as Tibetan medicine) industry as a particularly illustrative example, the article outlines an interdisciplinary approach to study this industry as a larger, transnational entity with its own role and dynamics. Identifying and discussing four major domains of the Sowa Rigpa industry—raw materials, drug-manufacturing processes, the market, and intellectual property rights—this article argues that the concept of the pharmaceutical assemblage can generate a much-needed bigger picture of traditional medicine and a fresh perspective on the confluences of culture, health, economy, governance, and the environment in contemporary Asia.

### [BioSocieties](#)

#### [Parent perspectives on brain scans and genetic tests for OCD: Talking of difficult presents, desired pasts, and imagined futures](#)

*Louise Whiteley, Emily Borgelt, S. Evelyn Stewart, Judy Illies*

This paper investigates parent perspectives on potential future applications of neuroimaging and genetic research in the OCD clinical setting. Grounded in qualitative interviews with parents whose children had participated in an OCD neuroimaging and genetic research study in the United States, we situate parent discussions of imagined futures in their projections from difficult presents and into desired pasts. Parents reported apparently high receptivity to potential future neuroimaging and genetic tests. Yet when they responded, ‘yes, anything that helps’, uncertainty, caution, and resistance were expressed in implicit negotiations over what it means to ‘help’. We situate the discussion of future technologies in the wider context of how a biological approach figures in parents’ understandings of OCD. A biological perspective was prioritised when it facilitated a journey towards understanding-as-acting; the intense gathering of knowledge judged likely to lead to better outcomes. When biological knowledge did not seem likely to lead to or itself constitute action, parents were often reluctant to even discuss it. The perspectives of those who may encounter future technologies are relevant to shaping their

development, but gathering and interpreting such perspectives presents methodological, conceptual, and normative difficulties. These difficulties with time-travelling talk are discussed throughout the paper.

[“Let’s pull these technologies out of the ivory tower”: The politics, ethos, and ironies of participant-driven genomic research](#) (open access)

*Michelle L. McGowan, Suparna Choudhury, Eric T. Juengst, Marcie Lambrix, Richard A. Settersten Jr., Jennifer R. Fishman*

This paper investigates how groups of ‘citizen scientists’ in non-traditional settings and primarily online networks claim to be challenging conventional genomic research processes and norms. Although these groups are highly diverse, they all distinguish their efforts from traditional university- or industry-based genomic research as being ‘participant-driven’ in one way or another. Participant-driven genomic research (PDGR) groups often work from ‘labs’ that consist of servers and computing devices as much as wet lab apparatus, relying on information-processing software for data-driven, discovery-based analysis rather than hypothesis-driven experimentation. We interviewed individuals from a variety of efforts across the expanding ecosystem of PDGR, including academic groups, start-ups, activists, hobbyists, and hackers, in order to compare and contrast how they relate their stated objectives, practices, and political and moral stances to institutions of expert scientific knowledge production. Results reveal that these groups, despite their diversity, share commitments to promoting alternative modes of housing, conducting, and funding genomic research and, ultimately, sharing knowledge. In doing so, PDGR discourses challenge existing approaches to research governance as well, especially the regulation, ethics, and oversight of human genomic information management. Interestingly, the reaction of the traditional genomics research community to this revolutionary challenge has not been negative: in fact, the community seems to be embracing the ethos espoused by PDGR, at the highest levels of science policy. As conventional genomic research assimilates the ethos of PDGR, the movement’s ‘democratizing’ views on research governance are likely to become normalized as well, creating new tensions for science policy and research ethics.

[Mapping Global Health: A network analysis of a heterogeneous publication domain](#)

*George Weisz, Alberto Cambrosio, Jean-Philippe Cointet*

This paper examines one of the most visible but oddly neglected aspects of the rapidly expanding Global Health (GH) enterprise: its vast literature. Basing our data on the PubMed MeSH term “World Health” (changed to “Global Health” in 2015) and utilizing the citation and funding metadata provided by Web of Science, we analyze nearly 20,000 articles using the

software platform CorTexT for the automatic processing of large text corpora. We perform several types of scientometric network analyses, and provide maps displaying inter-citations among journals publishing GH articles, co-authorship among the 292 authors who published 12 or more papers, co-citation analysis of works (articles, books, and reports) cited at least 30 times by the papers in our database, and funding sources since 2008. The maps display the social, cognitive, and funding substructure of the GH publication field. We suggest that this somewhat fragmented and fuzzy domain is held together by (1) a core group of authors who have for some time been co-authoring numerous papers and reports with one another; (2) several central journals, most notably the *Lancet*, addressing wider audiences and transcending the narrow specialization characteristic of scientific and biomedical fields; and (3) a growing body of large-data metrics, most prominently the Global Burden of Disease, which has become a rhetorical resource for numerous groups with different agendas.

[Morally accounting for sex selection online in Turkey](#)

*Burcu Mutlu*

The Internet, beyond providing opportunities for advertising reproductive services, offers people an anonymous social space to exchange information, support, and personal stories regarding their reproductive goals and to enact reproductive moral reasoning regarding controversial biotechnologies in complex ways. Focusing on the online discussion forum of the Turkish web portal *Women's Club*, this article examines the moral negotiations of sex selection by women seeking to legitimize or delegitimize it through rhetorical appeal to a mix of science, religion, gender, ignorance, propitiousness, and modernity. By doing so, it will reveal the ways in which women forum members work to craft not only moral selves and technologies but also a shared space for moral reflection. By examining the discursive content of Turkish women's postings concerning sex selection, I argue that online forums offer these women an anonymous moral space to discuss their reproductive goals, although some family secrets do not escape the moral scrutiny of others even within these forums. The heterogeneity and complexity of women's moral engagements with reproductive technologies on the Internet demonstrates that reproductive issues are moral issues directly related to the expectations for women as gendered beings, as individuals, family members, and as citizens, and also serve to reproduce social relations, including patriarchal inequalities.

["I don't have to know why it snows, I just have to shovel it!": Addiction recovery, genetic frameworks, and biological citizenship](#)

*Molly J. Dingel, Jenny Ostergren, Kathleen Heaney, Barbara A. Koenig, Jennifer McCormick*

The gene has infiltrated the way citizens perceive themselves and their health. However, there is scant research that explores the ways genetic conceptions infiltrate individuals' understanding of their own health as it relates to a behavioral trait such as addiction. Do people seeking treatment for addiction ground their self-perception in biology in a way that shapes their experiences? We interviewed 63 participants in addiction treatment programs, asking how they make meaning of a genetic understanding of addiction in the context of their recovery, and in dealing with the stigma of addiction. About two-thirds of people in our sample did not find a genetic conception of addiction personally useful to them in treatment, instead believing that the cause was irrelevant to their daily struggle to remain abstinent. One-third of respondents believed that an individualized confirmation of a genetic predisposition to addiction would facilitate their dealing with feelings of shame and accept treatment. The vast majority of our sample believed that a genetic understanding of addiction would reduce the stigma associated with addiction, which demonstrates the perceived power of genetic explanations in U.S. society. Our results indicate that respondents (unevenly) ground their self-perception of themselves as an addicted individual in biology.

[Young brains at risk: Co-constituting youth and addiction in neuroscience-informed Australian drug education](#)

*Adrian Farrugia, Suzanne Fraser*

This article explores the developing relationship between neuroscientific understandings of 'addiction' and 'youth'. Drawing on science and technology studies theory and social scientific analyses of both these concepts, it identifies a co-constitutive relationship between notions of addiction as a brain disease and of youth as a stage of brain development. These two concepts are then tracked in a series of drug education documents concerned with alcohol and other drug (AOD) use and addiction among young people, and their implications and effects and analysed together. The aim is to investigate the impact on drug education of neuroscientific approaches to youth and addiction. Are new concepts and directions for harm reduction created in the encounters between neuroscience, youth and addiction, or do they simply reinstate and reinforce existing assumptions and judgments? Is drug education shaped by these concepts likely to achieve its aim, that is, to increase young people's sensitivity to harm and safety? The article begins by introducing neuroscientific accounts of youth and addiction, arguing that the two concepts share three key assumptions. First, both emphasise biology and sideline social context in the making of drug use practices and outcomes. Second, both reproduce uncritical treatments of brain scans (PET and fMRI images) as windows into minds and subjects. Third, both understand the brain as ontologically separate from its environment. These assumptions and their implications are then tracked through an analysis of

Australian drug education resources, focusing on how drug education constitutes youthfulness and addiction as pathological disorders. In its reliance on neuroscientific understandings of youth and addiction, we conclude, drug education is unlikely to achieve its goal of reducing drug-related harm.

[Failing, hacking, passing: Autism, entanglement, and the ethics of transformation](#)

*Gregory Hollin*

One of the most notable recent changes in autism science is the belief that autism is a heterogeneous condition with no singular essence. I argue that this notion of 'autistic heterogeneity' can be conceived as an 'agential cut' and traced to uncertainty work conducted by cognitive psychologists during the early 1990s. Researchers at this time overcame uncertainty in scientific theory by locating it within autism itself: epistemological uncertainty was interwoven with ontological indeterminacy and autism became heterogeneous and chance like, a condition determined by indeterminacy. This paper considers not only the conceptual significance of this move but also the impact upon forms of subjectivity. This analysis is undertaken by integrating the agential realism of Karen Barad with the historical ontology of Michel Foucault. I argue that these two approaches are, firstly, concerned with ontologies of emergence and, secondly, foreground the inherently ethical nature of change. As such these theories can be used to articulate an 'ethics of transformation'. I argue that the agential cut which brought about autistic heterogeneity is potentially problematic within an ethics of transformation, limiting the possibility of future change in subjectivity by imagining difference and resistance as properties of autism rather than the individual.

[Body & Society](#)

[Exploring the Ineffable in Women's Experiences of Relationality with their Stored IVF Embryos](#)

*Jenni Millbank*

This article contributes to a more nuanced and contextual approach to women's decision-making concerning their stored IVF (in vitro fertilisation) embryos through attempting to craft a space for the expression of the complex, and contradictory, emotions attached to these decisions, unhooked from any notion of abstract moral status inhering in the embryo itself. Women struggle to express the confounding nature of the relationship to the stored IVF embryo as something of-the-body but not within the body, neither self nor other, person nor thing. In order to try to address this sense of the ineffable, I draw in this article upon a series of images by German-born American artist, Kiki Smith. The article explores



three major themes, each alongside one of Smith's artworks connecting to an experience of discomfort or confounding unease.

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

#### [Medical Disease or Moral Defect? Stigma Attribution and Cultural Models of Addiction Causality in a University Population](#)

*Nicole L. Henderson, William W. Dressler*

This study examines the knowledge individuals use to make judgments about persons with substance use disorder. First, we show that there is a cultural model of addiction causality that is both shared and contested. Second, we examine how individuals' understanding of that model is associated with stigma attribution. Research was conducted among undergraduate students at the University of Alabama. College students in the 18–25 age range are especially at risk for developing substance use disorder, and they are, perhaps more than any other population group, intensely targeted by drug education. The elicited cultural model includes different types of causes distributed across five distinct themes: Biological, Self-Medication, Familial, Social, and Hedonistic. Though there was cultural consensus among respondents overall, residual agreement analysis showed that the cultural model of addiction causality is a multicentric domain. Two centers of the model, the moral and the medical, were discovered. Differing adherence to these centers is associated with the level of stigma attributed towards individuals with substance use disorder. The results suggest that current approaches to substance use education could contribute to stigma attribution, which may or may not be inadvertent. The significance of these results for both theory and the treatment of addiction are discussed.

#### [Family Life and Social Medicine: Discourses and Discontents Surrounding Puebla's Psychiatric Care](#)

*Kathryn Law Hale*

Drawing on clinical data from 15 months of on-site participant observation in the only public psychiatric hospital in the state of Puebla, Mexico, this article advances our understanding of globalization in relation to psychiatry. I challenge the construction of psychiatry as only treating the individual patient and provide grounded doctor-patient-family member interaction in a Mexican psychiatric clinic in order to review what happens when doctors cannot interact with patients as atomized individuals even though in theory they are trained to think of patients that way. Challenged by severe structural constraints and bolstered by lessons from other nations' efforts at deinstitutionalization, psychiatrists in Puebla push to keep patients out of the inpatient wards and in their respective communities. To this end, psychiatrists call upon co-present kin who are

identified both as the customer and part of the caretaking system outside the clinic. This modification to the visit structure changes the dynamic and content of clinical visits while doctors seamlessly respond to unspoken beliefs and values that are central to local life, ultimately showing that efforts to define a “global psychiatry” informed by global policy will fail because it cannot exist in a uniform way—interpersonal interaction and personal experience matters.

[Seeing a Brain Through an Other: The Informant’s Share in the Diagnosis of Dementia](#)

*Laurence Anne Tessier*

This article takes up the neuroscientific assumption of our brains as “solitary” and contrasts this understanding with the description of actual clinical practices. Drawing on observations of clinical consultations and team meetings in a world famous US center for the diagnosis of dementia, I examine how the “informant”, a member of the patient’s family, participates in the diagnosis process. Based on specific situations in which the informant is judged to be a “bad” one, I inquire as to how clinicians use what they understand of the affective relationships between the patient and the bad informant in order to make a diagnosis. The diagnosis of dementia in an individual is shown to draw on relational dimensions in the patient’s life, made visible and enunciable only when problematic. This inquiry therefore brings out how these neurologists, even though they are engaged in a neuroscientific paradigm that conceives the brain as a self-sufficient cognitive machinery, nevertheless do consider what links us to the brains sharing our lives, in order to make sense of our networks of neurons.

[Class-Based Chronicities of Suffering and Seeking Help: Comparing Addiction Treatment Programs in Uganda](#)

*Julia Vorhölter*

Based on ethnographic fieldwork, this article looks at changing discourses and practices in the field of mental health care in Uganda. In particular, it analyzes two psychotherapeutic institutions designed to treat drug- and alcohol-addiction, and their accessibility and affordability for people from different class backgrounds. The first center is a high-class residential facility near Kampala which offers state-of-the-art addiction therapy, but is affordable only for the rich. The second center, a church-funded organization in Northern Uganda, cares mainly for people from poor, rural families who cannot afford expensive treatment. Comparing the two centers provides important insights not only into the temporalities of mental illness, substance abuse and mental health care, but also into broader socio-economic dynamics and understandings of suffering in contemporary Uganda. The term ‘class-based chronicities’ refers to the

way both the urgency with which people seek treatment (when has someone suffered enough?) and the length of treatment they receive (when is someone considered 'recovered?') are highly class-dependent. On a theoretical level, the article shows how psychotherapeutic models operate as philosophical systems which not only impact on treatment practices, but also produce different addiction entities and addiction-related subjectivities. As such, it contributes to an emerging anthropology of addiction.

[Insuring Care: Paperwork, Insurance Rules, and Clinical Labor at a U.S. Transgender Clinic](#)

*Marieke van Eijk*

What is a clinician to do when people needing medical care do not have access to consistent or sufficient health insurance coverage and cannot pay for care privately? Analyzing ethnographically how clinicians at a university-based transgender clinic in the United States responded to this challenge, I examine the U.S. health insurance system, insurance paperwork, and administrative procedures that shape transgender care delivery. To buffer the impact of the system's failure to provide sufficient health insurance coverage for transgender care, clinicians blended administrative routines with psychological therapy, counseled people's minds and finances, and leveraged the prestige of their clinic in attempts to create space for gender nonconforming embodiments in gender conservative insurance policies. My analysis demonstrates that in a market-based health insurance system with multiple payers and gender binary insurance rules, health care may be unaffordable, or remain financially challenging, even for transgender people with health insurance. Moreover, insurance carriers' "reliance" on clinicians' insurance-related labor is problematic as it exacerbates existing insurance barriers to the accessibility and affordability of transgender care and obscures the workings of a financial payment model that prioritizes economic expediency over gender nonconforming health.

[Global Mental Health and Adolescent Anxiety: Kin, Care and Struggle in New Mexico](#)

*Janis H. Jenkins, Annika Stone*

While recent developments within the field of global mental health have illuminated the reality of serious mental health difficulties worldwide, particularly in low-income settings, research that focuses on children and adolescents remains underdeveloped. This is especially the case with respect to ethnographic studies of lived experience of adolescents diagnosed with serious mental health conditions. Drawing from an interdisciplinary study of adolescents in New Mexico who were afflicted with a broad range of disorders according to contemporary research

diagnostic criteria, this article focuses on anxiety-related conditions with respect to subjective experience and social–ecological contexts of living with such conditions. We offer preliminary observations regarding the value of linking ethnographic and research diagnostic data to address questions of resilience, endurance, capacity and struggle. These observations are intended as the basis for the formulation of more precise hypotheses about adolescent anxiety, kin, and care under conditions of structural violence marked by psychological, residential, and intergenerational adversity.

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

#### [Postcolonial Biotech: Taiwanese Conundrums and Subimperial Desires](#)

(open access)

*Jennifer A. Liu*

Where most accounts of biotech in Taiwan—indeed, globally—focus on its economic potential and its potential to heal various ills, a postcolonial and subimperial framing insists on attention to often underexamined aspects, for example, how biotech practices reflect specific nationalist desires and rely on forms of exploitation. A postcolonial and subimperial framing insists on the inclusion of other stories. Drawing Taiwan’s nanxiang (southward) policies and Indigenous rights into a biotech frame, I suggest that such policies and desires create potential contradictions that are not easily resolved. For example, hard-won policies preventing the collection of Indigenous genetic samples may foreclose studies that might address pronounced health disparities. And the scope of a national biobank project aimed toward a global Chinese ethnic community is limited by competing claims of Taiwanese genetic uniqueness. One possible resolution envisions Taiwan biotech as a site for imagining possible futures outside enduring colonial influences and subimperial desires.

### [Ethos](#)

#### [Dinámicas Ocultas: Culture and Psy-Sociality in Mexican Family Constellations Therapy](#)

*Whitney L. Duncan*

This article takes the ethnographic case of Family Constellations therapy in Oaxaca, Mexico, to demonstrate how a nonnative therapeutic practice articulates with local cultural frameworks to foster novel forms of therapeutic experience and sociality. Family Constellations in Oaxaca promotes particular forms of what I call “psy-sociality,” or sociality generated by globalizing psy concepts, diagnoses, and practices, which produce new sites for self-work and subject-formation, but also for jointly processing social suffering, familial conflict, and psychological distress in

culturally salient ways. First, participants socialize in a structured way that promotes embodied connection to others. Second, participants are socialized into gendered ways of speaking, knowing, interpreting, and acting upon the self and the family. Finally, participants are also given explicit guidance for how to confront current sociofamilial conflicts with which they are grappling. In the process, participants localize this foreign therapy according to the context of present-day Mexico.

### [Journal of the Royal Anthropological Institute](#)

#### ['Black' and 'white' death: burials in a time of Ebola in Freetown, Sierra Leone](#)

*Jonah Lipton*

The article examines experiences of the 2014-15 Ebola crisis in Freetown, Sierra Leone, through an analysis of the performance of burials. While most of the city's residents had no contact with the virus, 'Ebola' was inescapable, owing to the onerous state of emergency regulations imposed by national and international authorities. All burials, regardless of the cause of death, were to be performed by newly established official teams operating according to unfamiliar biomedical and bureaucratic protocols. Burials became emblematic of the crisis through presenting a conflict between local practices and novel procedures, which was coded locally in a complex racial language of 'black' and 'white', recalling a long regional history of violent integration into the Atlantic World. Building on long-standing anthropological discussion on the relationship between 'good' death and social order, the article explores how burials became sites around which opposing 'orders' were experienced, negotiated, and reconciled in locally meaningful ways.

### [Medicine Anthropology Theory](#) (Open Access)

#### [Anthropological approaches to medical humanitarianism](#)

*Isabel Beshar, Darryl Stellmach*

Despite broadly shared interest in the welfare of 'precarious lives', medical anthropology and medical humanitarianism are too often in tension. In this survey, we sketch a history of the two disciplines, then track three major patterns through which anthropologists approach the analysis of medical humanitarian efforts. Our three patterns frame medical anthropology as: 1) a critique of medical humanitarianism and its ties to colonialism and globalization, 2) a translation of medical humanitarianism and its associated lexicon, 3) and a reform of medical humanitarianism from the inside out. In highlighting the individual strengths of these three approaches, we argue for the value of medical anthropology – as both a mindset and a method – in health and humanitarian emergencies.

[The program is perfect: Narcotics Anonymous and the managing of the American addict](#)

*Paul Christensen*

This article examines Narcotics Anonymous (NA) membership in two ways: how blame for failure is displaced from the 'perfect' organizational program and onto the individual addict working to remain sober and how this displacement is accompanied by notions of individual responsibility and work. These discourses illustrate the influence of a neoliberal outlook on the life course among 'clean' NA members, particularly as the social safety net in the United States has been systematically reduced and replaced by a system that focuses attention on personal responsibility. I show how NA's ideological approach blinds group members and the larger public to the complexity of addiction, turning addicts who struggle with recovery into failures, through internalized ideological trajectories that root responsibility in the self while discounting context.

[In search of trust and efficacy: Tibetan medicine in multiethnic Rebgong, Qinghai, China](#)

*Nianggajia, Heidi Fjeld*

This article describes how Tibetan medicine, traditionally an ethnomedicine indigenous to Tibetan areas, travels across cultural boundaries in a multiethnic region, presenting empirical findings from Rebgong (Ch. Tongren) in Qinghai province, People's Republic of China. Focusing on Muslim Hui and Han Chinese citizens, we describe how these patients smoothly engage with Tibetan medicine. This, we argue, is enabled by a strong sense of trust in distinguished Tibetan doctors, or 'lineage doctors', and their privately produced Tibetan medicines, and by shared understandings of the patient role. Contemporary medical pluralism in Rebgong invites us to revisit classic themes in medical anthropology as it brings the study of ethnomedicine into the context of a reconfigured instrumentalized public health system and ethnic relations, in which trust is a rare and treasured quality.

[Pathways, intersections, and hotspots: Multisited fieldwork and the South African HIV/AIDS policy process](#)

*Theodore Powers*

Since the late apartheid era, the South African HIV/AIDS movement has mobilized infected and affected communities and cultivated alliances to establish and expand a national HIV/AIDS response that is based on human rights. In doing so, HIV/AIDS activists have actively engaged with political dynamics across the institutional domains of the state. Participant observation research with South African HIV/AIDS activists and analyses of the South African HIV/AIDS policy process therefore necessitate

following the movement of research participants across many sites. Bringing together existing approaches to multisited research, the concepts of pathways, intersections, and hot spots are utilized to represent the social and spatial experiences of HIV/AIDS activists, state health administrators, and other policy actors within a unified conceptual framework.

Photo Essay: [Diabetes in Senegal](#)

*Steven Rubin, Rhonda BeLue*

Saharan Africa is faced with a significant and increasing burden of noncommunicable diseases, including type 2 diabetes mellitus. The incidence of diabetes is growing; however, insufficient resources are available for prevention efforts and disease management. Diabetes affects people living with the disease, their families and communities, and the multiple health care systems with which they interface.

The prevention and management of diabetes extend well beyond the walls of health care facilities; they are embedded within and influenced by family, community, cultural, and economic contexts. Adopting a socioecological lens (Hill et al. 2013), we use photography to explore diabetes-related behaviors such as diet and physical activity in the context of family, community, and other emplaced interactions. Our images make visible the management and effects of diabetes within the intimate daily lives and spaces of people living with the disease in the Thiès region of Senegal.

Photography as a tool of ethnographic research can exacerbate power differentials between observer and observed, particularly when used with vulnerable populations. However, the creation and dissemination of images also provide an opportunity to make visible a noncommunicable disease like diabetes, which continues to be dangerously underfunded internationally (Bloomberg 2017). Diabetes in sub-Saharan Africa, in particular, remains insufficiently researched and scarcely represented, rendering invisible both the people (patients and health care providers) and places involved in the prevention and management of the disease.

### [Social Science & Medicine](#)

[Justification and authority in institutional review board decision letters](#)

(open access)

*Justin T. Clapp, Katharine A. Gleason, Steven Joffe*

While ethnographic study has described the discussions that occur during human subjects research ethics review, investigators have minimal access to the interactions of ethics oversight committees. They instead receive

letters stipulating changes to their proposed studies. Ethics committee letters are central to the practice of research ethics: they change the nature of research, alter the knowledge it produces, and in doing so construct what ethical research is and how it is pursued. However, these letters have rarely been objects of analysis. Accordingly, we conducted a qualitative analysis of letters written by American institutional review boards (IRBs) overseeing biomedical and health behavioral research. We sought to clarify how IRBs exercise their authority by assessing the frequency with which they provided reasons for their stipulations as well as the nature of these reasons. We found that IRBs frequently do not justify their stipulations; rather, they often leave ethical or regulatory concerns implicit or frame their comments as boilerplate language replacements, procedural instructions, or demands for missing information. When they do provide justifications, their rationales exhibit substantial variability in explicitness and clarity. These rhetorical tendencies indicate that the authority of IRBs is grounded primarily in their role as bureaucratic gatekeepers. We conclude by suggesting that greater attention to justification could help shift the basis of the IRB-researcher relationship from compliance to mutual accountability.

[The oughtness of care: Fear, stress, and caregiving during the 2000–2001 Ebola outbreak in Gulu, Uganda](#)

*Sung-Joon Park, Grace Akello*

In this article we introduce the term *oughtness of care* to show how caring for sick relatives was experienced in the context of the Ebola outbreak in Gulu, Uganda, in 2000–2001. We conducted fieldwork over a nine month period from July 2016 to March 2017 in the suburbs of Lacor, Bardege, Pece Lukung, Kasubi, Limu, and Kanyagoga Koro Layibi, Rwot Obilo, all of which were epicenters for Ebola. In addition, we conducted interviews in the districts of Amuru, Kitgum, and Lamwo, where some interlocutors had resettled following the end of the war that was affecting Gulu at the time of the Ebola outbreak. Of the 198 interlocutors in the focus group discussions, we followed up on 98 for further group and individual interviews. Our analysis principally provides a retrospective ethnographic study of caregivers' moral experiences of the need to care for sick relatives during the outbreak. In our study, respondents argued that they would rather respond to the compelling need to offer care for intimate others at home or in a healthcare institution, rather than listen to sensitization messages not to touch sick patients. We introduce the term *oughtness of care* to enable us to understand how caregiving, which caregivers experienced as a moral logic draws its justification from the specific situation of radical insecurity which they were thrown into. We argue that this caregiving has its own logic, which is insufficiently captured by conventional public health approaches to containing Ebola outbreaks. Caregivers are, in consequence, not recognized as ethical subjects by



such public health interventions. By providing an understanding of the moral experience of caregiving and the distinct logic of care, our analysis contributes to the development of relevant and effective public health responses to Ebola epidemics.

[Medical egg freezing and cancer patients' hopes: Fertility preservation at the intersection of life and death](#)

*Marcia C. Inhorn, Daphna Birenbaum-Carmeli, Pasquale Patrizio*

Egg freezing (i.e., oocyte cryopreservation) is a new reproductive technology that allows women's eggs to be frozen and stored for future use. Over the past five years, so-called "medical egg freezing" (MEF) has begun to play a major role as a form of fertility preservation for young women with cancer and other fertility-threatening medical conditions. Indeed, women who are candidates for MEF are often facing the "double jeopardy" of fertility loss and potential death. In this article, we examine the experiences of the first generation of women to use MEF in the United States and Israel, two countries where experimental use of MEF began early, and where MEF is now offered clinically in many in vitro fertilization (IVF) clinics. Through an ethnographic, interview-based study carried out between June 2014 and August 2016 with 45 women (33 American, 12 Israeli) who had completed at least one cycle of MEF, we highlight women's reflections on their egg freezing experiences, and their considerable hopes for future recovery and motherhood. However, MEF is a Janus-faced new "hope technology." On the one hand, it holds out the promise of life in terms of recovery and future childbearing. As such, women's reflections on MEF reveal hope and gratitude for the technology's existence. However, as with IVF itself, future motherhood can never be guaranteed. This is especially true for women facing death from advanced or aggressive forms of cancers. Three ethnographic case studies of cancer patients, two from the US and one from Israel, highlight how MEF offers hope for life among women confronted with a deadly disease.

[What if the baby doesn't survive? Health-care decision making for ill newborns in Ethiopia](#)

*Kristine Husøy Onarheim, Mitike Molla Sisay, Muluken Gizaw, Karen Marie Moland, Ingrid Miljeteig*

Despite efforts to improve access to and quality of care for newborns, the first month after birth remains the most dangerous period of life. Given high neonatal mortality in low-income countries, saving newborn lives is a key priority for global and national health policy agendas. However, little is known about how these policies resonate with local understandings, experiences and household priorities. In this qualitative study we examined families' decision making and health-care-seeking in Butajira,

Ethiopia. Data were collected through observation in hospital, in-depth interviews (41), and focus group discussions (7) with family members, health-care workers, and community members (October–November 2015). Transcripts and field notes were analyzed inductively using qualitative content analysis. Findings indicate that newborn health was not always the family's priority. Local perceptions of newborns as not yet useful members of the household alongside costly health-care services delayed decision making and care-seeking. While sickness was recognized as dangerous for the ill newborn, seeking health-care could be harmful for the economic survival of the family. In a resource-constrained setting, families' focused on productive assets in order to minimize long-term risks, and waited before seeking newborn health-care services. Until the baby had survived the first vulnerable weeks and months of life, the unknown newborn was not yet seen as a social person by the community. Personhood evolved progressively as the baby became a part of the family. A newborn death was surrounded by silence, and families received minimal support from traditional financial associations, *iddirs*. Decisions regarding health-care were contingent upon families' understandings of newborns and their resource-constrained circumstances. Improving newborn health involves recognizing why families choose to (not) seek health-care, and their actual opportunities and constraints in making such decisions. The everyday realities of vulnerable newborns must be at the center of global and national policy discussions and local implementation.

[Catalyst: Feminism, Theory, Technoscience](#) (Open Access)

[Toxic Shock Syndrome, Tampon Absorbency, and Feminist Science](#) (open access)

*Sharra Vostral*

Tampon-associated toxic shock syndrome (TSS) has disproportionately affected women, and specifically, menstruators. By 1980, the Centers for Disease Control recommended that women limit their use of superabsorbent tampons since the risk for TSS increased with greater levels of absorption. However, women had no way of following this advice since products did not have consistent absorbency labels. A standard to set absorptive capacity as well as nomenclature was required, and the consensus process to do so was governed by ASTM (American Society for Testing and Materials). Esther Rome from the Boston Women's Health Book Collective participated as a consumer representative, and solicited feminist scientist Nancy Reame to help generate data on their behalf. Importantly, they rejected the use of blue saline and "blue goo" as a menstrual fluid in the syngyna—the synthetic vagina simulacrum lab instrument—to test tampon absorbency, and insisted upon heparinized blood instead. They challenged the process by which a standard is established, the method by which variables are controlled, and the erasure

of menstrual fluid from tests about tampon absorbency. The feminist science yielded both usable and valid outcomes, with results that challenged the design of the experiment upon which standards were to be based.

### [Philosophy, Psychiatry, & Psychology](#)

#### [Liberal Individualism and Deleuzean Relationality in Intellectual Disability](#)

*Jennifer Clegg, Elizabeth Murphy, Kathryn Almack*

Successful critiques of health policies for people with impaired cognition identify a need for alternatives that go beyond individualism. ‘Choice’ policy was examined as young people with severe intellectual disabilities moved from special schools to adult services. We draw on three cases from a longitudinal cohort study to examine the way decisions with and for these young people were made and accounted for. It was not a simple matter of parents and transition workers hearing about these young people’s choices and facilitating what they wanted. The data raise questions about discourses of choice in ID when referring to people with severe intellectual disabilities: few ‘choices’ could be considered informed nor made by young people with capacity to make them and many decisions were informed by other ethics. Findings were interpreted through a Deleuzean ethical–relational lens. We identify implications for theory and practice to show how Deleuzean thinking can reinvigorate intellectual disability.

### [Health, Risk & Society](#)

#### [Responsible use to responsible harm: illicit drug use and peer harm reduction in a darknet cryptomarket](#)

*Angus Bancroft*

Sale of illicit drugs through online ‘cryptomarkets’ is a notable innovation in the illicit drug market. Cryptomarkets present new ways of configuring risk and harm in relation to drug use. I examine the kinds of knowledge and discourses users employed to do this. I argue that the lay/expert divide that creates a hierarchy of knowledge around drug use and harms is increasingly undermined by the creation of knowledge communities by drug users who make drug use work effectively for them. I draw on the discussion forum of a now defunct English language focused cryptomarket, anonymised as ‘Merkat’, collected between 2015 and 2016. Typically, vendors in the major cryptomarkets are based in the USA, UK, China, the Netherlands and Australia. Buyers were mainly located in the USA, UK, Australia and Western Europe. I scraped the market forum threads and coded on emergent themes. I found that risk worked along four axes, cultural normalisation/pathologisation, chemical potency,

legal/policy and market, each of which required a set of practices and orientations to manage successfully. Users indicated that they had adapted many harm reduction practices, while also promoting a 'responsible harm' orientation where they sought to own and take charge of harm. The support infrastructure drew on knowledge from drug users, vendors and interested professionals. I conclude that cryptomarkets can provide a community infrastructure that supports the exchange of drugs and configures them as risky but manageable objects.

[Risk as a relational phenomenon: a cross-cultural analysis of parents' understandings of child food allergy and risk management](#)

*Marie-Louise Stjerna, Allison Worth, Jeni Harden & Sonja Olin Lauritzen*

Western culture can be seen as permeated by risk-consciousness. In particular, parents are under scrutiny in their roles as risk managers. In this article, we address parental experiences of children more at risk than other children, children with food allergy, and the management of allergy risk in everyday life. Drawing on a notion of risk as 'situated' in local everyday life, we argue that a further exploration of parental understandings of child food allergy risk would benefit from an analysis of studies across different local contexts. In this article, we draw on a secondary qualitative cross-cultural analysis of interview data from several studies of parents in Sweden and Scotland through 2006–2010, which focused on parents' understandings of the nature of food allergy and the children's management of the allergy risk. We found some common themes in the different data sets. First, parents depicted food allergy as life-threatening, a 'death risk' lurking in the background, more or less constantly present in different everyday situations, amounting to an existential condition in parenting. Second, they talked about food allergy risk as a relational phenomenon, meaning that the risk emerged in the encounter between the young person's individual competence to manage allergy risk and the understandings of allergy risk in others – thus depending on contexts and interaction between several actors. Finally, the analysis showed that unpredictability and risk in constant flux are the prominent aspects of living with food allergy. We also discussed the ways risk and trust are related, as well as how the involvement of others can be seen as both a risk and a safeguard.

['You don't know what's going on in there': a discursive analysis of midwifery hospital consultations](#)

*Danielle Ferndale, Renata F.I Meuter, Bernadette Watson & Cindy Gallois*

In contemporary Western society, the concept of risk is mostly linked related to negative or undesirable outcomes and used to explain unusual or abnormal events that have harmful consequences. Working in a poststructuralist framework, in this article we examine how risk shapes

interactions between midwives and pregnant women in the context of public hospitals in Australia. We draw on data from an observational study of clinical encounters in three Australian hospitals between October 2014 and July 2015. The research teams recorded 83 health encounters and in this paper we draw on data from the recordings of 10 clinical consultations between 8 midwives and 10 pregnant women at various stages of gestation. We used these data to explore how a discourse of risk was mobilised through rhetorical strategies and practices of 'hunting' for the abnormal and attempts to control the body. Our findings demonstrate how a discourse of pregnancy and birth as risky operates within public hospital midwifery consultations. We found that in the midwifery consultations we recorded, pregnancy was constructed as a period of vulnerability and unpredictability. It was normalised through discursive practices of hunting for the abnormal and rhetorical strategies of attempting to control the body. Within this discourse, midwives occupied conflicting positions. They asserted that women, with the right support, were capable of spontaneous and intervention-free (pregnancy and) birth. Yet, they acted to enable medical professionals to assess a woman's ability to give birth (un)assisted, or the potential for an adverse event. The women, while positioned as passive within the public health system, were positioned as active in surveilling themselves and responsible for taking steps to mitigate against adverse events.

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