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## In the Journals - June 2016, Part I

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By Anna Zogas

Here are some articles published in June that may be of interest. Enjoy!

### [Medical Anthropology Quarterly](#)

[Cancer and the Comics: Graphic Narratives and Biogitimate Lives](#)

*Juliet McMullin*

Cancer graphic narratives, I argue, are part of a medical imaginary that includes representations of difference and biomedical technology that engage Fassin's (2009) concept of biogitimacy. Framed in three parts, the argument first draws on discourses about cancer graphic narratives from graphic medicine scholars and authors to demonstrate a construction of universal suffering. Second, I examine tropes of hope and difference as a biotechnical embrace. Finally, I consider biosociality within the context of this imaginary and the construction of a meaningful life. Autobiographical graphic narrative as a creative genre that seeks to give voice to individual illness experiences in the context of biomedicine raises anthropological questions about the interplay between the ordinary and biogitimate. Cancer graphic narratives deconstruct the big events to demonstrate the ordinary ways that a life constructed as different becomes valued through access to medical technologies.

["Time with Babe": Seeing Fetal Remains after Pregnancy Termination for Impairment](#)

*Lisa M. Mitchell*

Some North American hospitals now offer parents the opportunity to see, hold, and photograph fetal remains after pregnancy loss. I explore the social, material, and interpretive strategies mobilized to create this fetal visibility after second trimester–induced abortion for fetal anomaly. My analysis examines both the discursive framing of fetal remains in practice guidelines on pregnancy loss and the responses of a group of Canadian women to being offered “time with babe.” I show that while guidelines tend to frame contact with fetal remains as a response to women’s desires to see their baby and to feel like mothers, women’s experiences of this contact were shaped by more diverse wishes and concerns as well as by specific abortion practices and practitioner comments and actions.

[“With This You Can Meet Your Baby”: Fetal Personhood and Audible Heartbeats in Oaxacan Public Health](#)

*Rebecca Howes-Mischel*

This article examines how amplified fetal heartbeats may be used to make claims about fetuses’ social presence. These claims are supported by the Mexican Public Health system’s selection of the maternal–child relationship as a key site of clinical intervention, intertwining medical and moral discourses. Drawing on the robust literature on cross-cultural propositions of “fetal personhood,” this analysis uses ethnographic material from public health institutions in Oaxaca, Mexico, to explore how doctors use diagnostic technology to materialize fetuses for their patients. I argue that Spanish’s epistemological distinction between *saber* (to have knowledge about) and *conocer* (to be acquainted with) is key to how diagnostic technologies may be deployed to make social claims. I use one doctor’s attempts to use technology to shift her patient from *saber* to *conocer* as illustrative of underlying cultural logics about fetal embodiment and its proof. Focused on the under-theorized socio–medical deployment of audio fetal heartbeat technology, this article suggests that sound—in addition to sight—is a potent tool for constructing fetal personhood.

[Incertitude, Hepatitis B, and Infant Vaccination in West and Central Africa](#)

*Tamara Giles-Vernick, Abdoulaye Traoré, Louis Bainilago*

This comparative study explores incertitude about hepatitis B (HBV) and its implications for childhood vaccination in Bangui, Central African Republic, and the Cascades region, Burkina Faso. Anthropological approaches to vaccination, which counter stereotypes of “ignorant” publics needing education to accept vaccination, excavate alternative ways of knowing about illness and vaccination. We build on these approaches, evaluating different kinds of incertitude (ambiguity, uncertainty, ignorance) about infancy, HBV, health protection, and vaccination. Using interviews and participant observation, we find that Bangui and Cascades publics framed their incertitude differently through stories of infancy, illness, and protection. We locate different forms of incertitude within their historical contexts to illuminate why vaccination practices differ in the Cascades region and Bangui. A more nuanced approach to incomplete knowledge, situated in political, economic, and social histories of the state and vaccination, can contribute to more appropriate global health strategies to improve HBV prevention.

[Recreating Virginity in Iran: Hymenoplasty as a Form of Resistance](#)

*Azal Ahmadi*

Hymenoplasty is a controversial surgery in Iran, where a woman’s failure to present herself as virginal for marriage may result in severe social

repercussions. Critical literature surrounding this clandestine surgery is sparse. During ethnographic fieldwork in Tehran, I interviewed women who have and have not undergone hymenoplasty and physicians who perform it. Using a Foucauldian framework, I argue that the medicalization of virginity is a form of female social control in Iran. The resulting narratives and discourses suggest that hymenoplasty is a covert form of resistance against socioculturally prescribed sexual inequality that restricts women to the social sphere of premarital chastity. By manipulating the medicalization of virginity, women inadvertently resist dichotomous gendered classifications that constrain them as either the deviant woman who has premarital sex or the normal woman who remains virginal until marriage. These women deviate from a fixed notion of gender embodiment, eroding socioculturally constituted categorical boundary markers regarding femininity.

### [An Elephant in the Consultation Room?: Configuring Down Syndrome in British Antenatal Care](#)

Gareth M. Thomas

This article is based on an ethnographic study of prenatal screening for Down syndrome in two British health care institutions. Drawing on observations of everyday hospital life and interviews with health care professionals, I identify how a discussion of Down syndrome is avoided during prenatal screening consultations. This relative silence is created and upheld because of three things: (1) the British public is considered as knowing what Down syndrome is; (2) the organization of care dictates that the condition is not classified as important enough to justify an explanation within consultations; and (3) professionals frequently admit to having minimal knowledge of Down syndrome. This absence, together with the condition being categorized as a risk or problem, helps produce and uphold its status as a negative pregnancy outcome. I conclude by highlighting the contributions that this article has for anthropologically exploring how ideas around disability intersect with the proliferation of reproductive technologies.

### [Culture and the Immune System: Cultural Consonance in Social Support and C-reactive Protein in Urban Brazil](#)

*William W. Dressler, Mauro C. Balieiro, Rosane P. Ribeiro, José Ernesto dos Santos*

In this article, we examine the distribution of a marker of immune system stimulation—C-reactive protein—in urban Brazil. Social relationships are associated with immunostimulation, and we argue that cultural dimensions of social support, assessed by cultural consonance, are important in this process. Cultural consonance is the degree to which individuals, in their own beliefs and behaviors, approximate shared cultural models. A

measure of cultural consonance in social support, based on a cultural consensus analysis regarding sources and patterns of social support in Brazil, was developed. In a survey of 258 persons, the association of cultural consonance in social support and C-reactive protein was examined, controlling for age, sex, body mass index, low-density lipoprotein cholesterol, depressive symptoms, and a social network index. Lower cultural consonance in social support was associated with higher C-reactive protein. Implications of these results for future research are discussed.

### [American Anthropologist](#)

#### [The Year 2015 in Sociocultural Anthropology: Material Life and Emergent Cultures](#)

*Dolores Koenig*

In this review essay, I explore the implications of renewed anthropological interest in materiality and the cultures that emerge from interaction among humans, nonhuman agents, and the material environment. Drawing upon sociocultural anthropology published primarily in 2015, I focus on five themes: cultures as emergent; bureaucracies in contemporary life; science, measurement, and state policy; affect and emotion in daily life; and multispecies and interspecies studies. Overall, the works I review illustrate the strength of anthropology in rendering visible the contradictions, trade-offs, and unlikely connections of lived experience in a material world. The works also show how cultures become real through people's actions and interactions with others. Nevertheless, sociocultural anthropology continues to face two enduring contradictions: first, attention to inequalities and disadvantages caused by existing structures versus an emphasis on the emergence and consequent unpredictability of social forms, and second, a view of humans as significant causal agents who can harm the natural world versus a perspective that sees humans as influenced by complex environments that include nature, nonhuman living beings, and inanimate objects.

#### [A New Reflexivity: Why Anthropology Matters in Contemporary Health Research and Practice, and How to Make It Matter More](#)

*Svea Closser, Erin P. Finley*

[excerpt] Many of medical anthropology's leading lights are currently lamenting the undervalued place of ethnographic work in public health and medicine. Vincanne Adams argues that in the field of global health, demands for randomized, controlled studies have become an "empirical tyranny" (Adams 2010:48). João Biehl and Adriana Petryna assert that "ethnographic evidence consistently dies within the dominant conceptual paradigms of global health" (Biehl and Petryna 2013:16). This argument

seems incomplete to us. Based on our experience publishing and collaborating with health professionals in two very different arenas—global polio eradication and veteran-oriented health services research—we have come to believe that anthropologists now have an unprecedented opportunity to contribute to the creation of clinical and public health structures more deeply informed by core anthropological concerns. Anthropological theory has a powerful grasp of the connection between broad-scale social structures and intimate lived realities, and its methods are perhaps unequalled in capturing the nuances of context. But making the most of anthropology's particular strengths will require overcoming a series of challenges, particularly in how we as anthropologists communicate with other health professionals. In this commentary, we first discuss our observations on anthropology's unique value in contemporary health research and practice and then offer a few suggestions for how to make the most of our contributions. Ultimately, we contend that making sure that anthropology has a place at the table with public health and medicine will require a new reflexivity, a careful examination of the biases and conventions of our discipline.

## [BioSocieties](#)

### [The normalisation of body gifting in Taiwan](#)

*Hung-Chieh Chang*

The Tzu Chi Foundation has made body gifting, such as body donation, bone marrow donation and cord blood donation, successful in Taiwan. Using Foucault's theoretical framework of governmentality and normalisation, this article discusses how a Buddhist charity, the Tzu Chi Foundation, normalises body gifting in Taiwan through their campaigns, system and philosophy. It argues that Buddhist discourses of karma create a 'benefit-all altruism' in body gifting. Furthermore, the emergence of the Tzu Chi Foundation in the last five decades has been a process of discipline and norm construction. The Tzu Chi Foundation, with its comprehensive missions, builds up an extensive network to spread their philosophy in different fields, from environmental protection and humanity education to medical care. The practice-oriented and community-based volunteer system helps the 'giving' ideology take root in the communities in Taiwan. Finally, through the media and the Internet, the effect goes beyond the institutional boundaries and reaches the public.

### [Vaccine resistances reconsidered: Vaccine skeptics and the Jenny McCarthy effect](#)

*Samantha D Gottlieb*

Recent data and increased vaccine-preventable disease outbreaks suggest that a growing number of US parents choose not to vaccinate

their children. Popular media have responded to this phenomenon by emphasizing refusers' moral failings and irrational fears. This article explores vaccine skeptics' objections and argues that their critics miss fundamental reasons for resistances. Drawing on ethnographic research with a community of vaccine skeptics in southern California, a consideration of a leading vaccine researcher's responses to vaccine critics and an analysis of Jenny McCarthy's condemnation of current vaccine practices, this research considers why even parents who have accepted some vaccines, but not all, distrust vaccines and their proponents. Parents' skepticism merits new forms of engagement by physicians and other vaccine advocates. As with any health intervention, vaccines can present some risks to a small number of recipients; when public health and clinical messages minimize parents' fears, they may increase parental doubt. The voices of parents who choose to opt out of or to alter the normal vaccine schedule reveal important expressions of biomedical resistance.

[Our circuits, ourselves: What the autism spectrum can tell us about the Research Domain Criteria Project \(RDoC\) and the neurogenetic transformation of diagnosis](#)

*Elizabeth Fein*

The Research Domain Criteria (RDoC) project is an ambitious new initiative by the National Institute of Mental Health that aims to comprehensively redefine mental illnesses as problems of neurogenetic 'circuitry'. This essay explores potential implications of this nascent approach. Drawing on data from two studies that examine the diagnosis of autism spectrum disorder, itself recently reconceptualized along lines similar to this new diagnostic paradigm, I argue that such 'circuit disorders' differ from their predecessors in two significant ways. First, while psychiatric disease entities under the previous paradigm were understood as fundamentally separable from the affected person, circuit disorders are bound up in intimate neuropsychological processes such as memory, perception and desire; they are thus often experienced as constitutive of identity by those living under their description. Second, rather than being limited to matters of 'clinically significant impairment', circuit disorders are multivalent, encompassing valued as well as devalued traits. Given that one major aim of the RDoC is to allow for pre-emptive biomedical intervention upon pre-symptomatic states, these emergent qualities of circuit disorders raise complex ethical concerns. I conclude by illustrating the way these concerns become obscured in the transition to an ostensibly value-neutral biophysiological paradigm.

["You're not just a paid monkey reading slides": How key opinion leaders explain and justify their work](#)

*Sergio Sismondo, Zdenka Chloubova*

Key opinion leaders (KOLs) are physicians and researchers engaged by pharmaceutical companies, most often to speak to audiences of other physicians. This article provides some background information on the structures of pharmaceutical company influence on and control over KOLs. The primary focus of this article, though, is on KOLs' explanations and justifications of their paid work for the companies, on the basis of, among other sources, 13 interviews with high-earning KOLs. Among KOLs' important justifications are ones in terms of the educational value of the talks they give and the benefits gained by patients; these are buttressed by claims about the integrity of the speakers. However, those justifications rarely address pharmaceutical companies' use of KOLs, or larger issues to do with the general influence that pharmaceutical companies have on medical knowledge.

[Local biologicals and the politics of standardization: Making ethical pluripotent stem cells in the United Kingdom and Japan](#) (*open access*)

*Koichi Mikami, Neil Stephens*

In 2003, the United Kingdom and Japan had adopted relatively similar approaches to human embryonic stem cells science. The decade since has witnessed significant divergence in their national policies as differing responses to ethical questions about research use of human embryos emerged. The United Kingdom pursued a vision of 'institutionally accredited stem cells' by reconfiguring the role of the Human Fertilisation and Embryology Authority and establishing the UK Stem Cell Bank. In contrast, Japan followed a vision of 'technically advanced stem cells' by developing induced pluripotent stem cells and supporting its research programs enthusiastically. Our research – drawing upon extensive fieldwork in both countries – demonstrates the socio-technical arrangements developed to instantiate these visions and articulates their divergence while at the same time revealing their connectedness. This relationship becomes progressively evident as the two visions face each other in the politics of standardization in global stem cell science. Drawing on Franklin's concept of local/global biological, we discuss the connectedness of the two local arrangements. In so doing, we explicate the future challenges for both countries as they need to demonstrate the significance of their visions in this global enterprise, while the success of one would likely undermine the significance of the other.

[Therapeutic governmentality and biopower in a Canadian mental health court](#)

*Anne Nordberg*

Mental health courts (MHCs) are a response to the structural violence experienced by people with severe mental illness (SMI) involved in the criminal justice system. My ethnographic research of an MHC in urban

Canada serves as the foundation for a discussion of court processes that are an example of biopower. The purpose of this article is to demonstrate how strategies for intervention in the name of life and health, truth discourses and forms of self-governance operate among criminal justice-involved individuals with SMI. This study reveals the tensions between the intense forensic gaze and invisibility and between treatment strategies that are beneficial for some people with SMI yet ultimately coercive and oppressive. The governance of this population is discussed, as well as what happens to people who fail or refuse to self-govern as the court compels them.

This issue of **BioSocieties** also has a Book Forum about recent literature on the so-called obesity epidemic. The forum is introduced by *Nicolas Langlitz* here: [Biosociological weight watching: From European famines to Guatemalan love handles](#) (*open access*).

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

#### [Obligatory Effort \[Hishtadlut\] as an Explanatory Model: A Critique of Reproductive Choice and Control](#)

*Elly Teman, Tsipy Ivry, Heela Goren*

Studies on reproductive technologies often examine women's reproductive lives in terms of choice and control. Drawing on 48 accounts of procreative experiences of religiously devout Jewish women in Israel and the US, we examine their attitudes, understandings and experiences of pregnancy, reproductive technologies and prenatal testing. We suggest that the concept of hishtadlut—"obligatory effort"—works as an explanatory model that organizes Haredi women's reproductive careers and their negotiations of reproductive technologies. As an elastic category with negotiable and dynamic boundaries, hishtadlut gives ultra-orthodox Jewish women room for effort without the assumption of control; it allows them to exercise discretion in relation to medical issues without framing their efforts in terms of individual choice. Haredi women hold themselves responsible for making their obligatory effort and not for pregnancy outcomes. We suggest that an alternative paradigm to autonomous choice and control emerges from cosmological orders where reproductive duties constitute "obligatory choices."

### [Disability Studies Quarterly \(Open Access\)](#)

#### [Being Disoriented: Uncertain Encounters with Disability](#) (*open access*)

*Ryan C. Parrey*

Disorienting encounter with disability are those in which the meaning of disability is an open question, and in which our relation to it is



questionable. This essay explores the relationship between disability and disorientation on conceptual but also concrete levels. First, I examine the connection between disability and disorientation within disability studies. Second, I provide a preliminary sketch of disorientation through what I call ontic disruption and ontological disorientation. Third, I take up Leder's (1990) articulation of bodily disappearance and embodied disappearance to address ableist violence. Finally, I develop the notion of dysorientation — a prolonged, persistent or recurrent sense of disorientation — as a useful concept for understanding experiences of ableism but also as a significant meeting point between impairment and disability.

[Beyond the Feeble Mind: Foregrounding the Personhood of Inmates with Significant Intellectual Disabilities in the Era of Institutionalization](#) (*open access*)

*Holly Allen, Erin Fuller*

This essay explores the experiences of persons with significant intellectual disabilities at the Vermont State School for Feebleminded Children (later Brandon Training School) in the period 1915-1960. We discuss the limits of existing histories of intellectual disability in accounting for the distinct experiences of significantly intellectually disabled people. This essay works to correct the tendency to define the nominal intellectual disability of “morons” and “borderline” cases—both in the past and in disability historiography of the past—against the abject, embodied difference of the “low-grade idiot” or “imbecile.” The history we offer has implications for the present-day disability rights movement.

[Implementing universal design in a Norwegian context: Balancing core values and practical priorities](#) (*open access*)

*Inger Marie Lid*

How can urban planning processes include perspectives from people with disabilities? This paper discusses the implementation of universal design (UD) and accessibility in a local urban context. Universal design consists of both core values, such as inclusion and equal status, and specific design initiatives, such as design of pavement surfaces and benches. The aim of implementing universal designing strategies is to achieve equal access for all citizens. The paper interprets the urbanist Henri Lefebvre's notion of the right to the city as a right to participate in urban life and thus a dimension of equal citizenship on a very concrete level. The right to participate in urban life is closely linked to access to the built environment. Based on an empirical study of an urban redesign project, I argue that equal access must imply both access to public places and to political processes.

[Explanation not Excuse: Attention Deficit Disorder, Collegiality and](#)

[Coalition](#) (open access)*David P. Terry*

This ethnopoetic essay performs some of the professional, interpersonal and political challenges presented by ADHD and some of the ways in which non-visible disabilities intersect with other axes of privilege and accessibility.

[Health & Place](#)[“I’m stronger than I thought”: Native women reconnecting to body, health, and place](#)*Katie Schultz, Karina L. Walters, Ramona Beltran, Sandy Stroud, Michelle Johnson-Jennings*

This community-based research applied principles of wilderness experience programming and Indigenous knowledges in an exploratory intervention designed to address health disparities in a tribal community. Drawing on historical trauma frameworks, tribal members rewalked the Trail of Tears to consider its effect on contemporary tribal health. Qualitative data from tribal members suggest that engagement with place and experiential learning, particularly the physical and emotional challenge of the Trail, facilitated changes in health beliefs, attitudes, and behaviors. Deep engagement outside of traditional health service settings should be considered in interventions and may be particularly effective in promoting positive health behaviors in Native communities.

[Recovering mental health across outdoor places in Richmond, London: Tuning, skill and narrative](#)*Krzysztof Bierski*

Both scientific and popular discourses assume that the environment can exert an influence on human health. Drawing on anthropological research conducted alongside mental health activists in the United Kingdom, I discuss how people affected by mental health problems sought to recover by visiting outdoor places in the London Borough of Richmond. Their intentional movement and stillness in the world involved tuning and narrative orientation, which, over time, became skilled. Recovery from mental ill-health was not an outcome of merely being in a particular place, but rather emerged as an ongoing process of relearning how to live in and as part of the environment.

[Journal of the Royal Anthropological Institute](#)[Patient waiting: care as a gift and debt in the Thai healthcare system](#)*Bo Kyeong Seo*

Drawing on fieldwork in Chiang Mai during 2010 and 2012, I examine poor Thais' and Shan migrants' experiences of receiving healthcare from a public hospital, and, in parallel, care from the state. While universal health coverage has become a way in which the state finds legitimacy in people's lives through giving care, being a recipient of state aid is implicated in the emotive domain of waiting. By focusing on how people feel and think of a gift and debt of care, I suggest that flows of affects that loom large in social interactions within the public hospital denote not only poor people's subordinate position but also their effort to achieve a sense of mutuality and moral autonomy. This study contributes to a broader understanding of experiences of paternalism, inequality, and dependence by illuminating people's agentic submission into relations of care.

### **[Medical Humanities](#)**

#### **[Gastroenvironmental distress: metaphorical antecedents of the gut microbiome](#)**

*Nitin K Ahuja, Amisha Ahuja*

The human gut has been viewed for centuries as a potential mediator of systemic disease. The theory of auto-intoxication, which found its clearest articulation in the late nineteenth and early twentieth centuries, focused on altered bowel habits as the cause of widespread physical decay and advocated for the pursuit of health through regular defecation. More recently, under the banner of the microbiome, research on commensal bacteria makes a similar case for associations between alimentary dynamics and illness manifestations far outside the gastrointestinal tract. Surface distinctions between these two conceptual frameworks are apparently antipodal, the former championing emptiness and sterility, the latter abundance and restoration. Within both models, however, persists a common anxiety about the detrimental effects of civilisation on the body in relation to the natural world. As scientific understanding of the microbiome continues to mature, acknowledging the historical and moral parameters of its borrowed ecological idiom may facilitate critical distinctions between what is true and what feels like it should be.

#### **[Empathy and affect: what can empathied bodies do?](#)**

*George Robert Ellison Marshall, Claire Hooker*

While there has been much interest in the apparent benefits of empathy in improving outcomes of medical care, there is continuing concern over the philosophical nature of empathy. We suggest that part of the difficulty in coming to terms with empathy is due to the modernist dichotomies that have structured Western medical discourse, such that doctor and patient, knower and known, cognitive and emotional, subject and object are situated in oppositional terms, with the result that such accounts cannot

coherently encompass an emotional doctor, or a patient as knower, or empathy as other than a possession or a trait. This paper explores what, by contrast, a radical critique of the Cartesian world view, in the form of a Deleuzian theoretical framework, would open up in new perspectives on empathy. We extend the framework of emotional geography to ask what happens when people are affected by empathy. We suggest that doctors and patients might be more productively understood as embodied subjects that are configured in their capacities by how they are affected by singular 'events' of empathy. We sketch out how the Deleuzian framework would make sense of these contentions and identify some possible implications for medical education and practice.

[The anonymity paradox in patient engagement: reputation, risk and web-based public feedback](#)

*Ewen Speed, Charlie Davison, Caroline Gunnell*

The UK National Health Service (NHS) has long espoused patient and public engagement. Recent years have seen increasing use of internet-based methods of collecting feedback about patient experience and public and staff views about NHS services and priorities. Often hailed as a means of facilitating participative democratic patient engagement, these processes raise a number of complex issues. A key aspect of it is the opportunity for comment to be made anonymously. Our research reveals an anonymity paradox whereby patients clearly demonstrate a perception that anonymity is a prerequisite for effective use of these feedback processes, whereas professionals demonstrate a perception that patient anonymity is a barrier to effective use. The risks of anonymity are constructed very differently by patients and professionals. Patient concerns around anonymity were not motivated by a general concern about a loss of privacy, but more that a positive identification might compromise future care. For professionals, concerns were voiced more around risks of reputational damage for specific practitioners or practices (in that anyone could say anything) and also that this anonymous feedback was available publicly and that it might go against the medical opinion of the professional. These concerns pointed to important differences in perceptions of patient and professional vulnerability. In the qualitative analysis that follows the key finding was that while anonymity makes service users feel less vulnerable, it can have the opposite effect on managers and clinical staff. This raises important implications for the use and utility of internet-based methods of collecting patient feedback.

[Science in Context](#)

[Advocating Inoculation in the Eighteenth Century: Exemplarity and Quantification](#)

*Anne Eriksen*

Smallpox inoculation was introduced in Europe in the early eighteenth century and has been considered the first mass treatment of disease based on practical use of probability calculations and mathematical tools of computation. The article argues that these new approaches were deeply entangled with other rationalities, most emphatically that of exemplarity. Changes in inoculation methods around mid-century gradually changed the conceptualization of disease, seeing all cases as fundamentally equal, and thus making it more relevant to count them. Arithmetic changed the ways of thinking about smallpox epidemics, but new ways of conceptualizing disease were vital to making it a matter of arithmetic at all. The article investigates what happened when numbers and figures were introduced into medical matters: Who did the figures really concern, and what types of argument were they fitted into? How were numbers transformed into metaphors, and how did quantitative argument work together with arguments from exemplarity?

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

[Patient education as a status passage in life – An ethnographic study exploring participation in a Danish group based patient education programme](#)

*Tine Mechlenborg Kristiansen, Rasmus Antoft*

In this paper, we apply the theory of status passage to the empirical field of group-based patient education. On the basis of ethnographic fieldwork carried out in the context of a local Danish patient education programme aimed at people diagnosed with rheumatoid arthritis, we illustrate how participation in the programme for the recently diagnosed is a regularised status passage symbolising a transition in life from a novice to a more experienced person with chronic illness. We demonstrate how central properties of status passage are at play and how they are shaped by interactions among the different agents: participants, lay experts and health professionals. We highlight how the unique biographical situation of the individual and the individual timing of participation is an important factor affecting whether the patient education programme succeeds in regularising the status passage. We highlight the ambiguity of the role of the health professionals in directing the status passage of the recently diagnosed. On one hand, health professionals empowered the participants by giving them access to professional knowledge and guidance and thereby supporting the status passage. On the other hand, the effort to direct responsibility back to the participants did not consider individual biographical situations, and thereby risked leaving the participants frustrated and unable to pass. Further, we point to the special significance of the socialising process between the participants, with the recently diagnosed being the novices asking questions and seeking guidance and the lay experts and the experienced participants taking the role of

coaches, guiding the recently diagnosed managing the status passage into chronic illness.

[The uncertainty of treatment: Women's use of HIV treatment as prevention in Malawi](#)

*Amy Zhou*

In countries throughout sub-Saharan Africa, antiretroviral therapy is seen as the solution to not only treat existing patients, but also to prevent the future spread of HIV. New policies for the prevention of mother-to-child transmission place women on lifelong treatment as soon as they are tested HIV positive. This article looks at how women understand this prescription for lifelong treatment. Drawing on interviews with HIV-positive women in Lilongwe, Malawi (N = 65) during July–September 2014, I examine the process of making treatment decisions, and why – despite increased access – women refuse or stop treatment. Using treatment for preventative purposes transforms the experience of HIV from an acute to a chronic condition where both the symptoms of disease and the efficacy of treatment are unclear. Women look for evidence of the cost and benefit of treatment through their personal experiences with illness and drug-taking. For some women, the benefits were clearer: they interpreted past illnesses as signs of HIV infection, and felt healthier and more economically productive afterwards. For others, taking treatment sometimes led to marital problems, and side effects made them feel worse and disrupted their ability to work. While women understand the health benefits of antiretroviral therapy, taking treatment does not always make sense in their present circumstances when there are costly physical and economic repercussions. This study builds on existing sociological research on medical decision-making by situating decisions in a broader political economy of changing HIV policies, economic conditions, and everyday uncertainty.

[Fostering reflective trust between mothers and community health nurses to improve the effectiveness of health and nutrition efforts: An ethnographic study in Ghana, West Africa](#)

*Nana M. Ackatia-Armah, Nii Antiaye Addy, Shibani Ghosh, Laurette Dubé*

As the global health agenda shifts from the Millennium Development Goals (MDGs) to Sustainable Development Goals (SDGs), the need for effective preventive health efforts has gained prominence, particularly in low-income regions with poor health and nutrition outcomes. To address needs in communities with limited access to health services and personnel, it is important to develop strategies that can improve the effectiveness of nurses as they interact with the populations they serve. We contribute to informing such strategies by explaining how mothers' "reflective trust" in community health nurses develops as a key influencer

in their health-related decision-making and behavior. Between December 2012 and June 2013, our ethnographic study gathered data in three adjacent rural and semi-rural communities in Ghana's Eastern Region, using interviews with 39 nursing mothers, three focus groups – with mothers, health-workers, and community leaders – as well as 941 h of participant observation. We focused on interactions between mothers and nurses, highlighting tensions between communities' traditions and messages that nurses bring, which are often based on modern science. We also investigated how mothers come to exhibit reflective trust in the nurses to make sense of traditional and scientific knowledge on infant feeding, and integrate them into their own feeding decisions. Our findings have global implications for effectively sustaining and scaling health and nutrition efforts through community approaches.

[After geneticization](#) (*open access*)

*Michael Arribas-Ayllon*

The concept of geneticization belongs to a style of thinking within the social sciences that refers to wide-ranging processes and consequences of genetic knowledge. Lippman's original use of the term was political, anticipating the onerous consequences of genetic reductionism and determinism, while more recent engagements emphasise the productivity and heterogeneity of genetic concepts, practices and technologies. This paper reconstructs the geneticization concept, tracing it back to early political critiques of medicine. The argument is made that geneticization belongs to a style of constructionist thinking that obscures and exaggerates the essentializing effects of genetic knowledge. Following Hacking's advice, we need a more literal sense of construction in terms of 'assembly' to give a clearer account of the relationship between processes and products. Using the 'assemblage' concept to explore the social ontology of genetics, the paper reviews three areas of the empirical literature on geneticization – disease classification, clinical practice and biosociality – to show that a new style of thinking has appeared within the social sciences. In the final assessment, the conditions that gave rise to geneticization are now obsolete. While it may serve as a useful ritual of debate, conceptually geneticization offers a limited account of the heterogeneity of socio-technical change.

[Understanding global health and development partnerships: Perspectives from African and global health system professionals](#)

*Amy Barnes, Garrett W. Brown, Sophie Harman*

Partnership is a key idea in current debates about global health and development assistance, yet little is known about what partnership means to those who are responsible for operationalising it or how it is experienced in practice. This is particularly the case in the context of African health

systems. This paper explores how health professionals working in global health hubs and the health systems of South Africa, Tanzania and Zambia understand and experience partnership. Drawing on semi-structured interviews with 101 professionals based in each country, Washington DC and Geneva between October 2012 and June 2013, the paper makes four key arguments. First, partnership has a legitimating function in global health policy processes for international development institutions, government agencies and civil society organisations alike. Second, the practice of partnership generates idiosyncratic and complicated relationships that health professionals have to manage and navigate, often informally. Third, partnership is shaped by historical legacies, critical events, and independent consultants. Fourth, despite being an accepted part of global health policy, there is little shared understanding of what good partnership is meant to include or resemble in practice. Knowing more about the specific socio-cultural and political dynamics of partnership in different health system contexts is critical to equip health professionals with the skills to build the informal relations that are essential to effective partnership engagement.

[Rethinking the antivaccine movement concept: A case study of public criticism of the swine flu vaccine's safety in France](#)

*Jeremy K. Ward*

In this article I discuss the definition of “the Antivaccine Movement” using the case of the French controversy over the safety of the 2009 pandemic flu vaccine. I show that the group of main actors who criticized the vaccine's safety is heterogeneous. This heterogeneity can be found in the type of arguments mobilized to question the vaccine's safety and in these actors' likelihood of being involved in any vaccine-related controversies. I show that only a minority of these actors rejected vaccination in general and mobilized against all vaccination campaigns. Most of these actors only occasionally mobilized against a given vaccine or vaccination campaign and they did so to promote a political or cultural agenda that went beyond the vaccine itself. Using these results, I argue that in order to better understand how vaccine-related controversies emerge and why some activists devote time and resources to spread vaccine-critical arguments, social scientists should use three distinct concepts to refer to vaccine criticism: The Antivaccine Movement, the Marginally Antivaccine Movements and the Occasionally Vaccine Critical Movements. To do so would enable social scientists and public health experts to better understand the different ways in which vaccination can become politicized and the evolution of this politicization.

[The doctor-patient relationship as a toolkit for uncertain clinical decisions](#)

*Lauren Diamond-Brown*



Medical uncertainty is a well-recognized problem in healthcare, yet how doctors make decisions in the face of uncertainty remains to be understood. This article draws on interdisciplinary literature on uncertainty and physician decision-making to examine a specific physician response to uncertainty: using the doctor-patient relationship as a toolkit. Additionally, I ask what happens to this process when the doctor-patient relationship becomes fragmented. I answer these questions by examining obstetrician-gynecologists' narratives regarding how they make decisions when faced with uncertainty in childbirth. Between 2013 and 2014, I performed 21 semi-structured interviews with obstetricians in the United States. Obstetricians were selected to maximize variation in relevant physician, hospital, and practice characteristics. I began with grounded theory and moved to analytical coding of themes in relation to relevant literature. My analysis renders it evident that some physicians use the doctor-patient relationship as a toolkit for dealing with uncertainty. I analyze how this process varies for physicians in different models of care by comparing doctors' experiences in models with continuous versus fragmented doctor-patient relationships. My key findings are that obstetricians in both models appealed to the ideal of patient-centered decision-making to cope with uncertain decisions, but in practice physicians in fragmented care faced a number of challenges to using the doctor-patient relationship as a toolkit for decision-making. These challenges led to additional uncertainties and in some cases to poor outcomes for doctors and/or patients; they also raised concerns about the reproduction of inequality. Thus organization of care delivery mitigates the efficacy of doctors' use of the doctor-patient relationship toolkit for uncertain decisions. These findings have implications for theorizing about decision-making under conditions of medical uncertainty, for understanding how the doctor-patient relationship and model of care affect physician decision-making, and for forming policy on the optimal structure of medical work.

## [Sociology of Health & Illness](#)

### [Con-forming bodies: the interplay of machines and bodies and the implications of agency in medical imaging](#)

*Lisa A. Wood*

Attending to the material discursive constructions of the patient body within cone beam computed tomography (CBCT) imaging in radiotherapy treatments, in this paper I describe how bodies and machines co-create images. Using an analytical framework inspired by Science and Technology Studies and Feminist Technoscience, I describe the interplay between machines and bodies and the implications of materialities and agency. I argue that patients' bodies play a part in producing scans within acceptable limits of machines as set out through organisational

arrangements. In doing so I argue that bodies are fabricated into the order of work prescribed and embedded within and around the CBCT system, becoming, not only the subject of resulting images, but part of that image. The scan is not therefore a representation of a passive subject (a body) but co-produced by the work of practitioners and patients who actively control (and contort) and discipline their body according to protocols and instructions and the CBCT system. In this way I suggest they are 'con-forming' the CBCT image. A Virtual Abstract of this paper can be found at: <https://youtu.be/qysCcBGuNSM>.

[Between disruption and continuity: challenges in maintaining the 'biographical we' when caring for a partner with a severe, chronic illness](#)  
*Gunvor Aasbø, Kari Nyheim Solbrække, Ellen Kristvik, Anne Werner*

Chronic obstructive pulmonary disease (COPD) is a progressive illness that changes the lives of patients and their spouses dramatically. The aim of this paper is to show how spouses of COPD patients integrate their tasks as informal carers with their role as spouses and the tensions and challenges involved in this. The study draws on qualitative interviews with spouses of COPD patients, recruited from the patient pool of ambulatory pulmonary services of two hospitals in Oslo, Norway. The spouses described their great efforts to re-establish normality and continuity in their everyday lives. Accomplishing this was a delicate process because they faced several dilemmas in this work. They balanced the need to sustain the independence and integrity of both parties against the need to ensure safety and deal with the progression of the illness. We propose 'biographical we' as a concept that can highlight the great effort spouses put into establishing a sense of continuity in their lives. In times when healthcare policy involves mobilising informal caregiving resources, an awareness of the complexity of caregiving relationships is crucial when developing appropriate support for informal carers.

[Social inclusion and the Fatosphere: the role of an online weblogging community in fostering social inclusion](#)

*Marissa Dickins, Colette Browning, Susan Feldman, Samantha Thomas*

Overweight and obesity are one of the most salient issues within society today, and the stigmatisation of overweight individuals is prevalent and widespread. Utilising interviews with 44 individuals who blog within an online fat acceptance community known as the Fatosphere, participants' perceptions of inclusion and exclusion were examined within their offline and online environments. Additionally, the effect this had on their offline lives was examined. Participants described a profound sense of exclusion within their offline lives through three agencies: the medicalisation of 'fatness', the weight loss industry and the media, which echoed descriptions of moral judgement. Furthermore, a sense of inclusion was

described within the Fatosphere through the protection and support that they found within this 'safe space'. The effects of the Fatosphere influenced their lives in both negative and positive ways, allowing them to better deal with stigma and discrimination, but sometimes effecting their offline relationships in a negative manner. The Fatosphere provides a unique opportunity for corpulent individuals to engage in a community that is removed from the prominent weight-related discourse within modern society.

['Coz football is what we all have': masculinities, practice, performance and effervescence in a gender-sensitised weight-loss and healthy living programme for men](#) (open access)

*Christopher Bunn, Sally Wyke, Cindy M. Gray, Alice Maclean, Kate Hunt*

In this paper we use a social practice approach to explore men's experience of Football Fans in Training (FFIT), a group-based weight management programme for men that harnesses men's symbolic attachment to professional football clubs to engage them in lifestyle change. FFIT is delivered by community coaches in clubs' stadia and is gender-sensitised in relation to context, content and style of delivery. Using a 'toolkit' of concepts from the work of Bourdieu, Goffman and Durkheim we analysed data from 13 focus group discussions with participants, and fieldwork notes from programme observations to investigate the appeal and success of FFIT, and how it worked to support change. Our analysis builds on our work on the importance of shared symbolic commitment to the football club and being with 'men like me' to understand how the interaction context facilitated 'effervescent' experiences. These experiences encouraged men to make changes to their diet and physical activity, talk about them, practice performing them and implement them in their lives. Thus a social practice approach illuminated the social processes through which lifestyle change was achieved, and we argue that it can deepen and enrich both intervention design and evaluation.

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