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## In the Journals, March 2014 -- Part II

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By Aaron Seaman

And here is the second part of the March journal roundup!

Once again, there are several special issues, which have been detailed elsewhere on Somatosphere:

[Critique of Anthropology, "Critical Perspectives on Multispecies Ethnography"](#)

[Theory, Culture and Society, "Social Theory after Strathern"](#)

[Global Public Health, "HIV Scale-Up and the Politics of Global Health"](#)

[Science, Technology, & Human Values, "The Conceptual and the Empirical: Expanding STS"](#)

**[Medical Anthropology Quarterly](#)** has a new issue filled with several interesting articles:

[Critical Anthropology of Global Health "Takes a Stand" Statement: A Critical Medical Anthropological Approach to the U.S.'s Affordable Care Act](#)

*Sarah Horton, Cesar Abadía, Jessica Mulligan, and Jennifer Jo Thompson*

The Affordable Care Act (ACA) of 2010—the U.S.'s first major health care reform in over half a century—has sparked new debates in the United States about individual responsibility, the collective good, and the social contract. Although the ACA aims to reduce the number of the uninsured through the simultaneous expansion of the private insurance industry and government-funded Medicaid, critics charge it merely expands rather than reforms the existing fragmented and costly employer-based health care system. Focusing in particular on the ACA's individual mandate and its planned Medicaid expansion, this statement charts a course for ethnographic contributions to the on-the-ground impact of the ACA while showcasing ways critical medical anthropologists can join the

debate. We conclude with ways that anthropologists may use critiques of the ACA as a platform from which to denaturalize assumptions of “cost” and “profit” that underpin the global spread of market-based medicine more broadly.

[Navigating and Circumventing a Fragmented Health System: The Patient's Pathway in the Sierra Madre Region of Chiapas, Mexico](#)

*Rose Leonard Molina and Daniel Palazuelos*

Mexico has implemented several important reforms in how health care for its poorest is financed and delivered. Seguro Popular, in particular, a recently implemented social insurance program, aims to provide new funds for a previously underfunded state-based safety net system. Through in-depth ethnographic structured interviews with impoverished farmers in the state of Chiapas, this article presents an analysis of Seguro Popular from the perspective of a highly underserved beneficiary group. Specific points of tension among the various stakeholders—the government system (including public clinics, hospitals, and vertical programs), community members, private doctors, and pharmacies—are highlighted and discussed. Ethnographic data presented in this article expose distinct gaps between national health policy rhetoric and the reality of access to health services at the community level in a highly marginalized municipality in one of Mexico's poorest states. These insights have important implications for the structure and implementation of on-going reforms.

[Framework Negotiations: Diagnostic Insights among Alternative Medical Practitioners Participating in Integrative Medicine Case Conferences](#)

*Ellen J. Salkeld*

Medical anthropology concerns itself with cultural interpretations of health and illness in complex pluralistic societies whose members incorporate multiple strategies to address health issues. This research explored the variety of complementary and alternative medicine (CAM) topics introduced into biomedically structured clinical evaluation. A field study of routine case conferences held within a clinical fellowship program in integrative medicine (IM) provided the ideal setting to explore contrasting conceptualizations of disease. Study results yielded five core sources of information sought by CAM practitioners, typically not addressed in biomedicine: social relations history within family of origin, emotional health, energetic health, spiritual health, and in-depth nutritional evaluation.

[For the Sake of Others: Reciprocal Webs of Obligation and the Pursuit of Transplantation as a Caring Act](#)

*Laura Lynn Heinemann*

This article highlights reciprocal webs of care and moral obligations toward kin during transplantation, using an expansive notion of “care” to include both its obvious and more hidden forms. Evidence from 24 months of ethnographic fieldwork among transplant patients, their loved ones, and clinical personnel in the U.S. Midwest suggests that patients are simultaneously caregivers to others and are considered vital members of reciprocal webs of care without whom their kin networks could not effectively operate. Transplantation can become a person’s main, perhaps only hope of fulfilling ongoing obligations to others, so pursuing a transplant becomes not a matter of choice, but rather a moral orientation. A potential implication of these findings is that rather quotidian and conventional (even if contested) notions of what kin ought to do and be for each other may be among the underpinnings of high-tech biomedical practices like transplantation.

[Nobody’s Child: The Role of Trauma and Interpersonal Violence in Women’s Pathways to Incarceration and Resultant Service Needs](#)

*Catherine Mitchell Fuentes*

With the rate of women’s incarceration significantly outpacing that of men’s, combined with the fact that the United States has the highest incarceration rate in the world, there is an urgent need to delineate incarcerated women’s pathways to crime and subsequent service needs. This article reports findings of modified participant observation and qualitative research conducted from 2008 to 2010 with women incarcerated in a large, county jail in North Carolina addressing these issues. Thirty life history interviews, nine focus groups, and 60 questionnaires reveal the centrality of trauma, particularly in the form of interpersonal violence (i.e., sexual, physical, and/or emotional abuse in adulthood and/or childhood), in incarcerated women’s lives. In the absence of positive resources (e.g., counseling, family/friend support), women’s attempts to cope with trauma increase their risks for incarceration as well as further trauma. In addition to providing trauma-based treatment, decreasing women’s recidivism requires macro-level examinations of policies that marginalize women economically and socially.

[Fallen Uterus: Social Suffering, Bodily Vigor, and Social Support among Women in Rural Mexico](#)

*Vania Smith-Oka*

This article focuses on rural indigenous Mexican women's experiences with uterine prolapse, particularly the illness's expression of social suffering. Drawing on ethnographic research conducted during 2004–2005 and 2007 in a Nahua village in the state of Veracruz, the article analyzes the multifactorial nature of women's social suffering. Results show that the roots of uterine displacement for the women lie in lack of social relations and in perceptions of bodily vigor. Additionally, inequality present in the women's interactions with mainstream Mexico brings into focus the larger structural factors that shape their reproductive health. The implications of research on the effect of social support on women's embodiment of social suffering can extend beyond one illness, linking it to broader issues shaping the health of marginalized populations.

[Definitions and the Experience of Fertility Problems: Infertile and Sub-fertile Women, Childless Mothers, and Honorary Mothers in Two Southern Nigerian Communities](#)

*Bruce Whitehouse and Marida Hollos*

Although infertility causes women considerable grief, social stigma, and economic deprivation, scholars have paid little attention to infertility's definitions that may depart from the standard Western usage and how such definitions influence the way women experience the condition. This article, by listening to individual women's experiences of infertility in two Nigerian communities, examines these definitions and differentiates between culturally salient categories of infertility. In distinguishing between different kinds of childless women and those with low fertility, we intend to enhance understandings of infertility by considering women's subjective understandings of the condition and thus moving beyond the current medical definition. By comparing women's experiences in two different ethnic groups in Nigeria, we show how distinct forms of kinship structures and social organizations shape the ways low fertility is defined, managed, and experienced.

The journal [New Genetics and Society](#) has five new articles to peruse, as well:

[“It's a risk that requires evaluation and rational appraisal”: emotion and](#)

[infectious risk in xenotransplantation](#)

*Peta S. Cook*

Xenotransplantation (XTP) is a potential solution to a variety of human health problems. While immunological disparities between source animals and humans remain significant hurdles to successful XTP, serious concerns have been raised with regard to cross-species viral transfer (zoonosis). This article explores how six male Australian scientists and clinicians working, or with collaborative roles, in the field of XTP construct infectious risk. These negotiations reveal that they primarily focus on known, measured risks, namely that of porcine endogenous retroviruses. This is used to prove zoonotic safety, which marginalizes broader zoonotic concerns. Such assessments heavily rely upon technical, cultural and emotional evaluations to provide an impression of certainty when faced with the potential problematic and uncertain outcomes. The combination of the technical and emotional, or what I call techniemotion, exposes the emotion that is invested in science and integral to science, and operates as part of XTP science.

[Prospecting the past: genetic perspectives on the extinction and survival of indigenous peoples of the Caribbean](#)

*Jada Benn Torres*

In this paper, I examine discourses of survival and extinction regarding the fates of indigenous Caribbean peoples and the manner in which genetic ancestry data influences these discourses. I argue that ideas of extinction and survival are intricately tied in places where a hybrid national identity is generally accepted, thus making the incorporation of genetic data into these debates more malleable. Meanwhile, other Caribbean contexts present the possibility for genetic data to significantly affect people's conception of how indigenous people should fit within contemporary conceptualizations of the nation. Secondly, I explore the incongruities between folk and scientific understandings of ancestry as well as how ideologies of race, histories of colonialism, and political economy affect the manner in which researchers present genetic ancestry. Finally, I call for genetic anthropologists to "look beyond the laboratory" and to be prepared and willing to engage in the repercussions of their research. Such an engagement would involve the repudiation of racist applications of genetic ancestry data and making meaningful attempts to include and collaborate with members of the studied communities.

[Streitkultur and the governance of genetic testing and insurance in Germany](#)

*Jonas Lander and Ine Van Hoyweghen*

Rapid developments in genetic testing have given rise to fundamental ethical, legal, and social questions that need to be dealt with in society. Results of genetic tests may be of interest to third parties such as private insurance companies, leading to fears of genetic discrimination. In Germany, the Government adopted the Genetic Diagnosis Act (Gendiagnostikgesetz, GenDG) in 2009 to protect people from, inter alia, genetic discrimination in obtaining life or health insurance. Given the sensitivity of the topic, this legislation was continually revised between 2001 and 2009. In this article, we reconstruct the process of formulating the GenDG with regard to genetics and insurance. The article begins with the parliamentary Enquete Commission in 2000 to develop a strategy and recommendations for the governance of genetic diagnostics, and analyzes how these recommendations were applied during the legislative process. We demonstrate that the legislative process of GenDG was largely determined by conventional methods of governance, rather than Streitkultur called for by the Enquete Commission in 2002. We conclude that though Streitkultur was defined as a mechanism to develop a robust approach to the governance of genetic diagnostics, it failed to influence a crucial element in genetic testing and insurance; namely, to fully protect insurees from genetic discrimination.

[Autobiologies on YouTube: narratives of direct-to-consumer genetic testing](#)

*Anna Harris, Susan E. Kelly, and Sally Wyatt*

Despite a growing personal genomics market, little is known about how people engage with the possibilities offered by direct-to-consumer (DTC) genetic testing. In order to help address this gap, this study deploys narrative analysis of YouTube videos posted by individuals who have purchased DTC genetic testing for disease. Genetic testing is said to be contributing to new states of illness, where individuals may become “patients-in-waiting.” In the videos analyzed, we found a new form of storytelling about this ambiguous state of illness, which we refer to as autobiography. Autobiology – the study of, and story about, one’s own biology – concerns narratives of sense-making through forms of biological practice, as well as wayfaring narratives which interweave genetic markers and family histories of disease. These autobiologies – part of a broader shift toward public stories about genetics and other

healthcare technologies – exhibit playfulness, as well as being bound with consumerist practices.

[Implicit and explicit notions of valorization in genomics research](#)

*Dirk Stemerding and Roel Nahuis*

Valorization of knowledge has been defined as a major challenge in the context of genomics as an emerging strategic research field. Valorization is a Dutch science-policy concept for what is elsewhere called science impact or the third mission of universities. This article describes the institutionalization of valorization policy in the Dutch genomics research system as a specific manifestation of a changing social contract between science and society, which mainly targets economic value creation and the stimulation of entrepreneurship. A societal debate has emerged in which this focus on economic aspects has been strongly criticized as one-sided. In response, policy-makers are willing to adopt a broader definition of valorization. On the basis of an analysis of valorization policies and practices in Dutch medical genomics, this article draws attention to two myths in this valorization debate.

[Philosophy, Ethics, and Humanities in Medicine](#) has posted a new article online this month:

[The epistemological role of empathy in psychopathological diagnosis: a contemporary reassessment of Karl Jaspers' account](#)

*Panagiotis Oulis*

Introduction:

In his classic essay “The phenomenological approach to psychopathology”, Karl Jaspers defended the irreducible reality of the “subjective” mental symptoms and stressed the pivotal role of empathy in their diagnostic assessment. However, Jaspers’ account of the epistemological role of empathy in psychopathological diagnosis was far from clear: whereas at several places Jaspers claimed that empathy provides a direct access to patients’ abnormal mental experiences, at other places he stressed that it did so only indirectly, through a whole battery of their observable clinical indicators. The aim of this paper is to reassess Jaspers’ account of the epistemological role of empathy in psychopathological diagnosis.

Methods:

I examine thoroughly Jaspers’ assertions on in the role of

empathy in the diagnosis of “subjective” symptoms. Moreover, I explicate briefly the epistemological status of psychopathological diagnostic examination with the aid of the distinction between direct and indirect observation.

#### Results:

Diagnostic assessment of “subjective” mental symptoms involves necessarily indirect psychopathological observation. Jaspers’ ambiguity is traced to his failure to distinguish clearly between direct and indirect psychopathological observation along with his excessive reliance on empathy. Relatedly, Jaspers’ ambiguity is also traced to his conflation of the semantics with the epistemology of psychopathological concepts representing patients’ “subjective” mental symptoms. These results apply also to contemporary phenomenological approaches to psychopathological diagnostic examination which maintain that patients’ abnormal mental experiences are invariably expressed in their overt behavior.

#### Conclusions:

Jaspers was right in stressing that psychopathological concepts of subjective mental symptoms represent patients’ genuine abnormal experiences irreducible to concepts representing their associated behavioral manifestations. Moreover, he was right in stressing the importance of the empathic ‘second person’ approach to patients’ mental experiences. However, he failed to recognize unambiguously that the epistemological access to patients’ mental symptoms, though enormously aided by empathy, remains mainly indirect and thus requires also a ‘third person’ approach to them. Overall then, clinical psychopathological examination requires both a ‘second’ and a ‘third’ person approach, as well as their judicious alternation during the diagnostic interview. Although focused on Jaspers’ essay, my critical analysis is also highly relevant to contemporary psychopathological approaches aiming to overcome the serious limitations of currently prevailing systems of diagnostic criteria of mental disorders.

## **Science as Culture**

### **[Bioethics in the Making: “Ideal Patients” and the Beginnings of Face Transplant Surgery in Mexico](#)**

*Samuel Taylor-Alexander*

Medical teams around the world are increasingly gaining ethical clearance to utilise face transplant surgery as a reconstructive



surgical procedure. Analysis of the beginnings of the operation in Mexico vis-à-vis the early uptake of the procedure in France reveals that this controversial experimental medical field has become loaded with national significance. The primary issue of dispute has been the dependence on life-threatening immunosuppressant therapy in a procedure that treats otherwise biologically healthy people. Attempts to resolve related debate has resulted in the emergence of what my interlocutors refer to as an “ideal patient”, a person whose particular state of health and suffering render them operable within the current biomedical constraints. Drawing together the idiom of coproduction with the concept of sociotechnical imaginaries shows how this imagined patient category was refracted and stabilised as it entered into the Mexican context whilst producing patients and surgical experts as particular types of bioethical subjects. The flexibility and normative value of the “ideal patient” mobilises and is mobilised by surgeons, who themselves emerge as national bioethical subjects responsible for saving the face of nations in the midst of broader changes surrounding how State’s should respond to medical advancement.

### **Science in Context**

#### **[The Endurance of Uncertainty: Antisociality and Ontological Anarchy in British Psychiatry, 1950–2010](#)**

*Martyn Pickersgill*

Research into the biological markers of pathology has long been a feature of British psychiatry. Such somatic indicators and associated features of mental disorder often intertwine with discourse on psychological and behavioral correlates and causes of mental ill-health. Disorders of sociality – particularly psychopathy and antisocial personality disorder – are important instances where the search for markers of pathology has a long history; research in this area has played an important role in shaping how mental health professionals understand the conditions. Here, I characterize the multiplicity of psychiatric praxis that has sought to define the mark of antisociality as a form of “ontological anarchy.” I regard this as an essential feature of the search for biological and other markers of an unstable referent, positing that uncertainties endure – in part – precisely because of attempts to build consensus regarding the ontology of antisociality through biomedical means. Such an account is suggestive of the co-production of biomarkers, mental disorder, and psychiatric institutions.

And, finally, a selection of the articles from the two issues ([here](#) and [here](#)) of **Social Science & Medicine**.

["I didn't think I could get out of the fucking park." Gay men's retrospective accounts of neighborhood space, emerging sexuality and migrations](#)

*Victoria Frye, James E. Egan, Hong Van Tieu, Magdalena Cerdá, Danielle Ompad, and Beryl A. Koblin*

Young, African American and Latino gay, bisexual and other men who have sex with men (MSM) are disproportionately represented among new HIV cases according to the most recent national surveillance statistics. Analysts have noted that these racial/ethnic disparities in HIV among MSM exist within the wider context of sexual, mental and physical health disparities between MSM and heterosexuals. The intercorrelation of these adverse health outcomes among MSM, termed syndemics, has been theorized to be socially produced by a heterosexist social system that marginalizes lesbian, gay, bisexual, MSM and other sexual minorities. African American and Latino MSM experience overlapping systems of oppression that may increase their risk of experiencing syndemic health outcomes. In this paper, using data from twenty in-depth qualitative interviews with MSM living in four New York City (NYC) neighborhoods, we present accounts of neighborhood space, examining how space can both physically constitute and reinforce social systems of stratification and oppression, which in turn produce social disparities in sexual health outcomes. By analyzing accounts of emerging sexuality in neighborhood space, i.e. across time and space, we identify pathways to risk and contribute to our understanding of how neighborhood space is experienced by gay men, adding to our ability to support young men as they emerge in place and to shape the social topography of urban areas.

[Fast, cheap, and out of control? Speculations and ethical concerns in the conduct of outsourced clinical trials in India](#)

*Vinay R. Kamat*

The globalization of biopharmaceutical clinical trials and their offshore outsourcing, from the West to low and middle-income countries, has come under increasing scrutiny from academic scholars, practitioners, regulatory agencies and the media. This article reports the results of a study conducted in Bangalore and Hyderabad between 2007 and 2009, to elicit the perspectives of

stakeholders, concerning media representations of their work and the ethical issues that emanate from their engagement in the clinical trials enterprise. In acknowledging the inherently problematic nature of the outsourcing of clinical trials to low income countries, I argue that the practice of not prioritizing research on diseases that are most prevalent among communities, from which subjects are recruited, demands a coordinated and sustained critique. I propose that the critical discourse on the outsourcing of clinical trials should not only emphasize the perils of this practice, but also address some broader issues of equity and distributive justice that determine people's access to basic health care in low income countries. Close attention to the specific context of clinical trials in an increasingly neoliberal medical and health environment in emerging economies such as India can provide critical insights into the on-the-ground complexities and challenges of outsourced global clinical trials.

[Choose and Book: A sociological analysis of 'resistance' to an expert system](#)

*Trisha Greenhalgh, Rob Stones, and Deborah Swinglehurst*

In 2004, the English Department of Health introduced a technology (Choose and Book) designed to help general practitioners and patients book hospital outpatient appointments. It was anticipated that remote booking would become standard practice once technical challenges were overcome. But despite political pressure and financial incentives, Choose and Book remained unpopular and was generally used reluctantly if at all. Policymakers framed this as a problem of 'clinician resistance'. We considered Choose and Book from a sociological perspective. Our dataset, drawn from a qualitative study of computer use in general practice, comprised background documents, field notes, interviews, clinical consultations (directly observed and videotaped) and naturally occurring talk relating to referral to hospital in four general practices. We used strong structuration theory, Giddens' conceptualisation of expert systems, and sensitivity to other sociological perspectives on technology, institutions and professional values to examine the relationship between the external environment, the evolving technology and actions of human agents (GPs, administrators, managers and patients). Choose and Book had the characteristics of an expert system. It served to 'empty out' the content of the consultation as the abstract knowledge it contained was assumed to have universal validity and to over-ride the clinician's application of local knowledge and practical wisdom. Sick patients were incorrectly

assumed to behave as rational choosers, able and willing to decide between potential options using abstracted codified information. Our analysis revealed four foci of resistance: to the policy of choice that Choose and Book symbolised and purported to deliver; to accommodating the technology's socio-material constraints; to interference with doctors' contextual judgements; and to adjusting to the altered social relations consequent on its use. We conclude that 'resistance' is a complex phenomenon with socio-material and normative components; it is unlikely to be overcome using the behaviourist techniques recommended in some health informatics and policy literature.

[Institutional ethical review and ethnographic research involving injection drug users: A case study](#)

*Will Small, Lisa Maher, and Thomas Kerr*

Ethnographic research among people who inject drugs (PWID) involves complex ethical issues. While ethical review frameworks have been critiqued by social scientists, there is a lack of social science research examining institutional ethical review processes, particularly in relation to ethnographic work. This case study describes the institutional ethical review of an ethnographic research project using observational fieldwork and in-depth interviews to examine injection drug use. The review process and the salient concerns of the review committee are recounted, and the investigators' responses to the committee's concerns and requests are described to illustrate how key issues were resolved. The review committee expressed concerns regarding researcher safety when conducting fieldwork, and the investigators were asked to liaise with the police regarding the proposed research. An ongoing dialogue with the institutional review committee regarding researcher safety and autonomy from police involvement, as well as formal consultation with a local drug user group and solicitation of opinions from external experts, helped to resolve these issues. This case study suggests that ethical review processes can be particularly challenging for ethnographic projects focused on illegal behaviours, and that while some challenges could be mediated by modifying existing ethical review procedures, there is a need for legislation that provides legal protection of research data and participant confidentiality.

[Hospitals as a 'risk environment': An ethno-epidemiological study of voluntary and involuntary discharge from hospital against medical advice among people who inject drugs](#)

*Ryan McNeil, Will Small, Evan Wood, and Thomas Kerr*

People who inject drugs (PWID) experience high levels of HIV/AIDS and hepatitis C (HCV) infection that, together with injection-related complications such as non-fatal overdose and injection-related infections, lead to frequent hospitalizations. However, injection drug-using populations are among those most likely to be discharged from hospital against medical advice, which significantly increases their likelihood of hospital readmission, longer overall hospital stays, and death. In spite of this, little research has been undertaken examining how social–structural forces operating within hospital settings shape the experiences of PWID in receiving care in hospitals and contribute to discharges against medical advice. This ethno-epidemiological study was undertaken in Vancouver, Canada to explore how the social–structural dynamics within hospitals function to produce discharges against medical advice among PWID. In-depth interviews were conducted with thirty PWID recruited from among participants in ongoing observational cohort studies of people who inject drugs who reported that they had been discharged from hospital against medical advice within the previous two years. Data were analyzed thematically, and by drawing on the ‘risk environment’ framework and concepts of social violence. Our findings illustrate how intersecting social and structural factors led to inadequate pain and withdrawal management, which led to continued drug use in hospital settings. In turn, diverse forms of social control operating to regulate and prevent drug use in hospital settings amplified drug-related risks and increased the likelihood of discharge against medical advice. Given the significant morbidity and health care costs associated with discharge against medical advice among drug-using populations, there is an urgent need to reshape the social–structural contexts of hospital care for PWID by shifting emphasis toward evidence-based pain and drug treatment augmented by harm reduction supports, including supervised drug consumption services.

[“But we’re not hypochondriacs”: The changing shape of gluten-free dieting and the contested illness experience](#)

*Lauren Renée Moore*

“Gluten free” exploded onto the American foodscape in recent years: as of January 2013, 30 percent of U.S. adults reported reducing or eliminating gluten in their diets. How do individuals participate in the expansion of gluten-free dieting, and what are the

implications of that expansion? This article is based on 31 in-depth, semi-structured interviews conducted between May and October 2012 with gluten-free and -restricted persons. I identify three interrelated factors contributing to the expansion of gluten-free dieting among non-celiacs. Participants broaden the lay understanding of gluten-related disorders, undermine biomedical authority, and diagnose others. Such participant-driven change, termed self-ascriptive looping, is one factor in the diet's rapid popularization. I show how participants question the doctor-patient relationship and increase social contestability for other dieters. My findings challenge previous work on contested illness and suggest food intolerances may require a reconceptualization of contested illness experience.

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