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In the Journals--March 2017, Part II

2017-04-03 12:00:32

By Julia Kowalski

This is Part II of March's article round-up. You can find [part I here](#).

In addition to the articles below, Theory, Culture and Society features [an interview with Michel Foucault from 1983](#).

[New Genetics and Society](#)

[Everything and nothing: regulating embryo research in Canada](#)

Alana Cattapan & Dave Snow

This article examines how medical and scientific professionals experience and engage with the governance of embryo research in Canada. Drawing on the history of embryo regulation in Canada and the findings of a survey conducted with lab directors in Canadian fertility clinics, we identify a disjuncture between the rules established by legislation, regulations, and research ethics guidelines and the real-life experiences of professionals in the field. This disjuncture, we argue, is the result of both the absence of implementation mechanisms that would give substance to the governing framework, as well as an inability on the part of medical and scientific professionals to engage in robust self-regulation. Overall, we demonstrate that in an ethically charged and highly technical area of policy-making like embryonic research, clarity about the roles and responsibilities of government and professionals in policy-making and implementation is critical to effective governance.

[Not just about "the science": science education and attitudes to genetically modified foods among women in Australia](#)

Heather J. Bray & Rachel A. Ankeny

Previous studies investigating attitudes to genetically modified (GM) foods suggest a correlation between negative attitudes and low levels of science education, both of which are associated with women. In a qualitative focus group study of Australian women with diverse levels of education, we found attitudes to GM foods were part of a complex process of making "good" food decisions, which included other factors such as locally

produced, fresh/natural, healthy and nutritious, and convenient. Women involved in GM crop development and those with health science training differed in how they used evidence to categorize GM foods. Our findings contribute to a deeper understanding of how GM food, and the role of science and technology in food production and consumption more broadly, is understood and discussed amongst diverse “publics” and across different “sciences,” and to research related to deepening public engagement at the intersection of science and values.

[Bench, bedside, boardroom: negotiating translational gene therapy](#)

Courtney Addison

This article presents ethnographic material from a London-based group of gene therapists who received the opportunity to trial a device that, its makers claimed, would expedite and improve their cell work. The Vanguard cell processor elicits both enthusiasm and ambivalence from group members, which I seek to understand by examining the group’s current manner of working alongside the device and its purported virtues. I show that cell processing currently involves complex practices of recognition, attention, care, and involvement, which answer to both the liveliness of cells and the experimentality of gene therapy. I read these practices as a well-honed configuration of productive engagements and detachments, which the Vanguard would thoroughly rearticulate. I thus argue that translational gene therapy is a site at which private and academic interests meet, and that translation more generally might be seen as a space where the relational format of science is renegotiated.

[Science as Culture](#)

[Problematisations of Complexity: On the Notion and Production of Diverse Complexities in Healthcare Interventions and Evaluations](#)

Tineke Broer, Roland Bal & Martyn Pickersgill

Within the literature on the evaluation of health (policy) interventions, complexity is a much-debated issue. In particular, many claim that so-called ‘complex interventions’ pose different challenges to evaluation studies than apparently ‘simple interventions’ do. Distinct ways of doing evaluation entail particular ontologies and epistemologies of complexity. They differ in terms of whether they define complexity as a quantitative trait of interventions, whether they see evaluation as part of or outside the intervention, and whether complexity can be regarded as an emergent property of the intervention and its evaluation. In practice, evaluators and

commissioners of large health care improvement programmes rely on different, sometimes contradictory, repertoires about what it means to conduct a 'good' evaluation. This is an ongoing matter negotiated between and among commissioners, researchers, and—sometimes—programme managers. In particular, notions of evaluability, usefulness and distance/independence are problematised in different ways and with diverse consequences, which, in turn, produce other notions and layers of complexity such as temporal, institutional and affective complexities. When (social science) researchers claim that one method or another is better able to grasp complexity, they elide the issue that any methodological choice emphasises some complexities and lets others fade into the background. Analysing the practicalities and emotions involved in evaluation studies opens up the notion of complexity to analytical scrutiny, and suggests a basis for co-theorising between biomedical, public health and social scientists (including Science and Technology Studies scholars).

[Contesting a Pandemic: The WHO and the Council of Europe](#)

Sudeepa Abeysinghe

Contemporary risks are often understood as fundamentally uncertain. This uncertain status can be mobilized within political debates surrounding risks. Such a challenge serves to destabilize scientific claims. The World Health Organization's (WHO) management of the 2009/10 spread of the H1N1 virus became a site of one such contestation. Debate within the Council of Europe particularly served to criticize the action of the WHO. This resulted in a definitional and policy contestation between the two institutions. The WHO accounted for its actions through allusions to (seemingly stable) scientific facts, using epidemiological evidence of influenza and its management based on normal science. In contrast, in criticizing public expenditure and panic, the Council of Europe critics problematized the stability of the science employed by the WHO. This included fundamental aspects of scientific knowledge such as the measurability of morbidity and mortality caused by H1N1 and the effect of vaccination against influenza viruses. This criticism relied upon the ability to destabilize the WHO's scientific knowledge, a process made possible through understandings of the uncertain nature of the science of risk (post-normal science). The case study illustrates that potential for previous-established and seemingly stable scientific facts to become destabilized and problematized during contestations of risk management.

[Autistic Heterogeneity: Linking Uncertainties and Indeterminacies](#)

Gregory Hollin

Autism is a highly uncertain entity and little is said about it with any degree of certainty. Scientists must, and do, work through these uncertainties in the course of their work. Scientists explain uncertainty in autism research through discussion of *epistemological uncertainties* which suggest that diverse methods and techniques make results hard to reconcile, *ontological uncertainties* which suggest doubt over taxonomic coherence, but also through reference to autism's *indeterminacy* which suggests that the condition is inherently heterogeneous. Indeed, indeterminacy takes two forms—an inter-personal form which suggests that there are fundamental differences between individuals with autism and an intra-personal form which suggests that no one factor is able to explain all features of autism within a given individual. What is apparent in the case of autism is that scientists put uncertainty and indeterminacy into discussion with one another and, rather than a well-policed epistemic-ontic boundary, there is a movement between, and an entwinement of, the two. Understanding scientists' dialogue concerning uncertainty and indeterminacy is of importance for understanding autism and autistic heterogeneity but also for understanding uncertainty and 'uncertainty work' within science more generally.

[From Standardization to Adaptation: Clinical Trials and the Moral Economy of Anticipation](#)

Catherine M. Montgomery

Hailed as the gold standard, the randomized controlled trial (RCT) occupies a hegemonic position at the top of evidence-based medicine's hierarchy of knowledge. It is testament to the methodology's capacity for standardization that it can so readily be spoken of in the singular: the RCT. Under what conditions, then, is it possible to speak of change in the gold standard? Since the 1950s, alternative versions of the RCT have been advocated for under the banner of 'adaptive design'. Adaptive designs allow investigators to make pre-planned changes to a trial on the basis of accruing information while the experiment is ongoing. Initially a niche topic of methodological debate among biostatisticians, the approach is becoming widespread in mainstream drug development. A genealogical analysis exposes the discursive moves used to justify and popularize adaptation, from a focus on patient well-being and the greater good in the 1960s and 1970s, to efficiency and virtualism in the 1990s and 2000s. Changing discourses of time and patienthood have facilitated a move away from standardization as the singular logic of trials towards an appreciation of flexibility, undergirded by probabilistic methodologies. Adams *et al.*'s [(2009). Anticipation: Technoscience, life, affect, temporality, *Subjectivity*, 28, pp. 246–265] conceptual framework of anticipation illuminates this evolving moral economy of medical research, in which modes of knowledge production which claim to know the future

are supplanting the traditional certainties of fixed and standardized experimental designs. Predictable uncertainty is the currency of this emerging economy, which capitalizes on computer simulation and ever more sophisticated tools of prediction to leverage credibility.

[Science in Context](#)

[Meanings of Waves: Electroencephalography and Society in Mexico City, 1940–1950](#)

Nuria Valverde Pérez

This paper focuses on the uses of electroencephalograms (EEGs) in Mexico during their introductory decade from 1940 to 1950. Following Borck (2006), I argue that EEGs adapted to fit local circumstances and that this adjustment led to the consolidation of different ways of making science and the emergence of new objects of study and social types. I also maintain that the way EEGs were introduced into the institutional networks of Mexico entangled them in discussions about the objective and juridical definitions of social groups, thereby preempting concerns about their technical and epistemic limitations. This ultimately enabled the use of EEGs as normative machines and dispositifs. To this end, the paper follows the arrival of EEGs and the creation of institutional networks then analyzes the extent to which the styles of thinking behind the uses of EEGs and attempts to reify a notion of normal electrical brain behavior—particularly by applying EEGs to a community of Otomí Indians—correlated with the difficulties of defining the socio-anthropological notions that articulated legal and disciplinary projects of the time. Finally, it unveils the shortcomings of alternative attempts to define a brain model and to resist the production of ontological determinations.

[Science, Technology, & Human Values](#)

[How Does One “Open” Science? Questions of Value in Biological Research](#)

Nadine Levin and Sabina Leonelli

Open Science policies encourage researchers to disclose a wide range of outputs from their work, thus codifying openness as a specific set of research practices and guidelines that can be interpreted and applied consistently across disciplines and geographical settings. In this paper, we

argue that this “one-size-fits-all” view of openness sidesteps key questions about the forms, implications, and goals of openness for research practice. We propose instead to interpret openness as a dynamic and highly situated mode of valuing the research process and its outputs, which encompasses economic as well as scientific, cultural, political, ethical, and social considerations. This interpretation creates a critical space for moving beyond the economic definitions of value embedded in the contemporary biosciences landscape and Open Science policies, and examining the diversity of interests and commitments that affect research practices in the life sciences. To illustrate these claims, we use three case studies that highlight the challenges surrounding decisions about how—and how best—to make things open. These cases, drawn from ethnographic engagement with Open Science debates and semistructured interviews carried out with UK-based biologists and bioinformaticians between 2013 and 2014, show how the enactment of openness reveals judgments about what constitutes a legitimate intellectual contribution, for whom, and with what implications.

[Social Science and Medicine](#)

[Trade liberalization and social determinants of health: A state of the literature review](#)

Courtney McNamara

The health impacts of trade liberalization are often described in relation to access to medicines, changing dietary patterns, tobacco use and alcohol consumption. The impacts of trade liberalization on the social determinants of health (SDH), are by contrast, less well known. Missing is an account of how liberalizing processes identified across different research areas relate to each other and how the association between trade liberalization and health is conceptualized within each of them, especially with reference to SDH. This paper presents a systematic review which provides a more complete picture of the pathways between trade liberalization and health, with special attention to SDH pathways. This picture captures the interrelationships between different areas of investigation, along with current limitations of our understanding and recommendations for future research.

[The mental health of Indigenous peoples in Canada: A critical review of research](#)

Sarah E. Nelson and Kathi Wilson

Many scholars assert that Indigenous peoples across the globe suffer a disproportionate burden of mental illness. Research indicates that

colonialism and its associated processes are important determinants of Indigenous peoples' health internationally. In Canada, despite an abundance of health research documenting inequalities in morbidity and mortality rates for Indigenous peoples, relatively little research has focused on mental health. This paper provides a critical scoping review of the literature related to Indigenous mental health in Canada. We searched eleven databases and two Indigenous health-focused journals for research related to mental health, Indigenous peoples, and Canada, for the years 2006–2016. Over two hundred papers are included in the review and coded according to research theme, population group, and geography. Results demonstrate that the literature is overwhelmingly concerned with issues related to colonialism in mental health services and the prevalence and causes of mental illness among Indigenous peoples in Canada, but with several significant gaps. Mental health research related to Indigenous peoples in Canada overemphasizes suicide and problematic substance use; a more critical use of the concepts of colonialism and historical trauma is advised; and several population groups are underrepresented in research, including Métis peoples and urban or off-reserve Indigenous peoples. The findings are useful in an international context by providing a starting point for discussions, dialogue, and further study regarding mental health research for Indigenous peoples around the world.

[Assessment of acculturation in minority health research](#)

Molly Fox, Zaneta Thayer, and Pathik D. Wadhwa

Acculturation represents an important construct in the context of health disparities. Although several studies have reported relationships between various aspects of acculturation and health in minority populations, crucial inconsistencies remain. One likely reason for these inconsistencies may relate to limitations in the conceptualization and operationalization of acculturation, particularly in the context of health research. The acculturation construct underwent major conceptual and operational change when it was adapted from anthropology to psychology, and we argue another major shift is now required for use of this construct in health research. Issues include determining whether acculturation measures should focus on an individual's internal attitudes or overt behaviors; whether they should characterize cultural orientation status at a given point in time or change over time; whether measures should be culture-specific or more global in nature; how the issue of multiculturalism should be addressed; how measures can optimally incorporate multiple dimensions of acculturation; and whether proxy measures should be used. These issues are important in the context of health research because of their implications for determining the direct and indirect effects of cultural change on health-related biological and behavioral processes. We elaborate on and address each of these issues from a perspective that

spans multiple disciplines across the biological and social sciences, and offer concrete recommendations with the ultimate goal of achieving a better understanding of the role of acculturation in minority health and health disparities.

[Guilt without fault: A qualitative study into the ethics of forgiveness after traumatic childbirth](#)

Katja Schrøder, Karen la Cour, Jan Stener Jørgensen, Ronald F. Lamont, and Niels Christian Hvidt

When a life is lost or severely impaired during childbirth, the midwife and obstetrician involved may experience feelings of guilt in the aftermath. Through three empirical cases, the paper examines the sense of guilt in the context of the current patient safety culture in healthcare where a blame-free approach is promoted in the aftermath of adverse events. The purpose is to illustrate how healthcare professionals may experience guilt without being at fault after adverse events, and Gamlund's theory on forgiveness without blame is used as the theoretical framework for this analysis. Philosophical insight has proven to be a useful resource in dealing with psychological issues of guilt and Gamlund's view on error and forgiveness elucidates an interesting dilemma in the field of traumatic events and medical harm in healthcare, where healthcare professionals experience that well-intended actions may cause injury, harm or even death to their patients. Failing to recognise and acknowledge guilt or guilty feelings may preclude self-forgiveness, which could have a negative impact on the recovery of midwives and obstetricians after adverse events. Developing and improving support systems for healthcare professionals is a multi-factorial task, and the authors suggest that the narrow focus on medico-legal and patient safety perspectives is complemented with moral philosophical perspectives to promote non-judgemental recognition and acknowledgement of guilt and of the fallible nature of medicine.

[Conceptualisation of the 'good' self-manager: A qualitative investigation of stakeholder views on the self-management of long-term health conditions](#)

J. Ellis, E. Boger, S. Latter, A. Kennedy, F. Jones, C. Foster, and S. Demain

Healthcare policy in developed countries has, in recent years, promoted self-management among people with long-term conditions. Such policies are underpinned by neoliberal philosophy, as seen in the promotion of greater individual responsibility for health through increased support for self-management. Yet still little is known about how self-management is understood by commissioners of healthcare services, healthcare

professionals, people with long-term conditions and family care-givers. The evidence presented here is drawn from a two-year study, which investigated how self-management is conceptualised by these stakeholder groups. Conducted in the UK between 2013 and 2015, this study focused on three exemplar long-term conditions, stroke, diabetes and colorectal cancer, to explore the issue. Semi-structured interviews and focus groups were carried out with 174 participants (97 patients, 35 family care-givers, 20 healthcare professionals and 22 commissioners). The data is used to demonstrate how self-management is framed in terms of what it means to be a 'good' self-manager. The 'good' self-manager is an individual who is remoralised; thus taking responsibility for their health; is knowledgeable and uses this to manage risks; and, is 'active' in using information to make informed decisions regarding health and social wellbeing. This paper examines the conceptualisation of the 'good' self-manager. It demonstrates how the remoralised, knowledgeable and active elements are inextricably linked, that is, how action is knowledge applied and how morality underlies all action of the 'good' self-manager. Through unpicking the 'good' self-manager the problems of neoliberalism are also revealed and addressed here.

[The productive techniques and constitutive effects of 'evidence-based policy' and 'consumer participation' discourses in health policy processes](#)

K. Lancaster, K. Seear, C. Treloar, and A. Ritter

For over twenty years there have been calls for greater 'consumer' participation in health decision-making. While it is recognised by governments and other stakeholders that 'consumer' participation is desirable, barriers to meaningful involvement nonetheless remain. It has been suggested that the reifying of 'evidence-based policy' may be limiting opportunities for participation, through the way this discourse legitimates particular voices to the exclusion of others. Others have suggested that assumptions underpinning the very notion of the 'affected community' or 'consumers' as fixed and bounded 'policy publics' need to be problematised. In this paper, drawing on interviews (n = 41) with individuals closely involved in Australian drug policy discussions, we critically interrogate the productive techniques and constitutive effects of 'evidence-based policy' and 'consumer participation' discourses in the context of drug policy processes. To inform our analysis, we draw on and combine a number of critical perspectives including Foucault's concept of subjugated knowledges, the work of feminist theorists, as well as recent work regarding conceptualisations of emergent policy publics. First, we explore how the subject position of 'consumer' might be seen as enacted in the material-discursive practices of 'evidence-based policy' and 'consumer participation' in drug policy processes. Secondly, we consider

the centralising power-effects of the dominant ‘evidence-based policy’ paradigm, and how resistance may be thought about in this context. We suggest that such interrogation has potential to recast the call for ‘consumer’ participation in health policy decision-making and drug policy processes.

[From wanting to willing – controlled drug use as a treatment goal](#)

Margaretha Järvinen

This paper uses rational choice theory to analyse a new – and controversial – treatment approach to drug problems: services aimed at making clients capable of controlled use of illegal drugs. The paper highlights three mechanisms used in control-focused treatment: attempts to move drug use from the sphere of “wanting” to the sphere of “willing”; temporal framing of illegal drug use; and a therapeutic focus on clients’ resources rather than their problems. Furthermore, the paper identifies some of the main challenges associated with this kind of treatment. The paper is based on 30 qualitative interviews with young people (aged 18–25) enrolled in drug treatment in Copenhagen, Denmark.

[Health in the Tenderloin: A resident-guided study of substance use, treatment, and housing](#)

Jamie Suki Chang

Substance use researchers recognize that environments – our homes, streets, communities, and neighborhoods – set the stage for substance use and treatment experiences by framing interactions, health options, and decision-making. The role of environment is particularly salient in places deemed disadvantaged or risky, such as parts of the Tenderloin neighborhood of San Francisco. Since risk is historically, socially, and structurally situated, an individual’s social position in a neighborhood shapes how risk environments are experienced. The purpose of this study was to explore how the environment shapes substance use and treatment experiences, described from the perspective of Tenderloin residents. I conducted docent method interviews with formerly homeless women living in supportive housing in San Francisco (N = 20). The docent method is a three-stage, participant-led, audiotaped, and photographed walking interview. As they guided me through target “sites of interest” (homes, streets, treatment programs, and safe spaces), participants discussed their experiences with substance use and treatment in the environment. First, they described that the risks of a broader drug market are concentrated in the Tenderloin, exposing residents to elevated and disproportionate risk. Second, for structural, economic, social, and physical reasons, participants described a sense of geographic or neighborhood stratification. Third,

multiple levels of policing and surveillance were persistent, even in participants' homes. Fourth, despite all the challenges, participants found security and support in the Tenderloin, and considered it their home. In the discussion, I offer that the Tenderloin environment provided residents many advantages, but forms of structural and everyday violence largely defined their experiences in the neighborhood.

[Identity in a medicine cabinet: Discursive positions of Andean migrants towards their use of herbal remedies in the United Kingdom](#)

Melissa Ceuterick and Ina Vandebroek

This study explores different rationales for using herbal remedies among people from Andean descent in the United Kingdom, using positioning theory as a conceptual framework. By analysing processes of positioning in narratives about healthcare choices conducted with 40 Bolivian and Peruvian migrants in London (between 2005 and 2009), we examine in which ways talking about personal preferences for herbal medicine can be constitutive of one's health identity. The results reveal three distinct discursive repertoires that frame the use of herbal remedies either as a tradition, a health-conscious consumer choice, or as a coping strategy, each allowing specific health identity outcomes. An enhanced understanding of how people make sense of their use of traditional, plant-based medicines enables healthcare professionals to better assist patients in making meaningful decisions about their health. Through illustrating how treatment choices are discursively linked with identity, the present results debunk the tendency to perceive patients with a migration background as one homogenous group and thus urge for a patient centred approach.

[Finger Pricks and Blood Vials: How doctors medicalize 'cultural' solutions to demedicalize the 'broken' hymen in the Netherlands](#)

Sherria Ayuandini

This paper provides new perspectives on the scholarship on medicalization and demedicalization, building on an ethnography of hymenoplasty consultations in the Netherlands. By examining how doctors can play an active role in demedicalization, this paper presents novel insights into Dutch physicians' attempt to demedicalize the "broken" hymen. In their consultations, Dutch doctors persuade hymenoplasty patients to abandon the assumed medical definition of the "broken" hymen and offer nonmedical solutions to patients' problems. Drawing from unique ethnographical access from 2012 to 2015 to 70 hymenoplasty consultations in the Netherlands, this paper's original contribution comes from closely examining how demedicalization can be achieved through the

process of medicalization. It investigates how Dutch physicians go even further in their efforts to demedicalize by medicalizing “cultural” solutions as an alternative course of action to surgery.

[The “Western disease”: Autism and Somali parents’ embodied health movements](#)

Claire Laurier Decoteau

There is some statistical evidence indicating that Somali refugees and immigrants have high rates of autism spectrum disorder (ASD). Somalis in North America call autism the “Western disease” because there is no word for autism in the Somali language and because many believe it does not exist in Somalia. In Toronto, Somali parents have forged an “epistemic community,” united around a coherent theory of the development of autism, its defining features, and most successful therapies. They work together with researchers to support the theory that gut bacteria is a causal factor for the development of autism. They argue that it is the diet and medical environment in North America (including the use of preservatives, genetically-modified processing, and antibiotics in both health care and food production) that explains the high rates of autism within the Somali diaspora. The paper argues that race and nationality have been underexplored in theories of embodied health movements. I argue that Somali parents’ organizing pushes theories of health social movements in new directions, by suggesting that experiences of forced migration and racial exclusion, as well as non-Western cultural ontologies of health, are important for understanding embodied experiences of illness and the forging of “politicized collective illness identities” that challenge mainstream scientific understandings of autism. As such, Somalis’ race and nationality play key roles in their pathways to group construction, in their embodied experiences of illness, and in their resources for mobilization.

[Personal and political histories in the designing of health reform policy in Bolivia](#) Alissa Bernstein

While health policies are a major focus in disciplines such as public health and public policy, there is a dearth of work on the histories, social contexts, and personalities behind the development of these policies. This article takes an anthropological approach to the study of a health policy’s origins, based on ethnographic research conducted in Bolivia between 2010 and 2012. Bolivia began a process of health care reform in 2006, following the election of Evo Morales Ayma, the country’s first indigenous president, and leader of the Movement Toward Socialism (*Movimiento al Socialismo*). Brought into power through the momentum of indigenous social movements, the MAS government platform addressed racism,

colonialism, and human rights in a number of major reforms, with a focus on cultural identity and indigeneity. One of the MAS's projects was the design of a new national health policy in 2008 called The Family Community Intercultural Health Policy (*Salud Familiar Comunitaria Intercultural*). This policy aimed to address major health inequities through primary care in a country that is over 60% indigenous. Methods used were interviews with Bolivian policymakers and other stakeholders, participant observation at health policy conferences and in rural community health programs that served as models for aspects of the policy, and document analysis to identify core premises and ideological areas. I argue that health policies are historical both in their relationship to national contexts and events on a timeline, but also because of the ways they intertwine with participants' personal histories, theoretical frameworks, and reflections on national historical events. By studying the Bolivian policymaking process, and particularly those who helped design the policy, it is possible to understand how and why particular progressive ideas were able to translate into policy. More broadly, this work also suggests how a uniquely anthropological approach to the study of health policy can contribute to other disciplines that focus on policy analysis and policy processes.

[Sociology of Health and Illness](#)

[‘Sometimes, it’s easier to write the prescription’: physician and patient accounts of the reluctant medicalisation of sleeplessness](#)

Maired Eastin Moloney

The medicalisation of sleep is a rich and growing area of sociological interest. Previous research suggests that medicalisation is occurring within the context of physician office visits, but the inner workings remain unclear. This study is the first to provide perspectives on the office visit interaction from both sleepless patients ($n = 27$) and the physicians ($n = 8$) who treat them. Analyses of semi-structured qualitative interviews reveal that sleep-related conversations are typically patient-initiated in routine office visits. Physicians and patients conceptualised insomnia as a symptom of another issue (depression), an everyday problem of living (stress) or the result of a natural life process (aging). Lack of sleep was not necessarily linked to daytime impairment. Even though sleep aids were routinely requested and prescribed, patients and physicians consistently expressed attitudes of reluctance toward the use of sedative hypnotics. I call this a case of ‘reluctant medicalisation’ and highlight the liminal space between pathology and normalcy inhabited by patients and physicians. I also build on recent work acknowledging the dynamics between macro and micro levels of medicalisation and illustrate the influence of multilevel ‘engines’ (consumerism, biotechnology, managed

care and physicians) in patients' and physicians' accounts.

[The articulation of neoliberalism: narratives of experience of chronic illness management in Bulgaria and the UK](#)

Ivaylo Vassilev, Anne Rogers, Elka Todorova, Anne Kennedy, and Poli Roukova

The shift from social democratic to a neoliberal consensus in modern welfare capitalist states is characterised by an emphasis on individual responsibility, consumer choice, market rationality and growing social inequalities. There has been little exploration of how neoliberalism has shaped the environment within which chronic illness is experienced and managed. This article explores the different articulations of neoliberalism manifest in the arena of personal illness management in Bulgaria and the UK. People with type 2 diabetes discussed their experiences in terms of struggling with diet, diabetes as a personal failure, integrating illness management and valued activities, and the trustworthiness of the healthcare system. The UK narratives were framed within an individual responsibility discourse while in Bulgaria lack of resources dominated discussions, which were framed as structurally generated and unrelated to individual capabilities and choices. Respondents faced personal management challenges related to consumer and healthcare market failures in both countries. Differences in market regulation and emerging stakeholder and interest coalitions influenced users' expectations and their navigation and adaptation to market failures in managing their everyday illnesses. The UK and Bulgarian articulations of neoliberalism can be described differently: the first as a logic of managed choice and the second as a logic of unmanaged consumerism.

[Nurses and electronic health records in a Canadian hospital: examining the social organisation and programmed use of digitised nursing knowledge](#)

Marie L. Campbell and Janet M. Rankin

Institutional ethnography (IE) is used to examine transformations in a professional nurse's work associated with her engagement with a hospital's electronic health record (EHR) which is being updated to integrate professional caregiving and produce more efficient and effective health care. We review in the technical and scholarly literature the practices and promises of information technology and, especially of its applications in health care, finding useful the more critical and analytic perspectives. Among the latter, scholarship on the activities of economising is important to our inquiry into the actual activities that transform 'things' (in our case, nursing knowledge and action) into

calculable information for objective and financially relevant decision-making. Beginning with an excerpt of observational data, we explicate observed nurse-patient interactions, discovering in them traces of institutional ruling relations that the nurse's activation of the EHR carries into the nursing setting. The EHR, we argue, materialises and generalises the ruling relations across institutionally located caregivers; its authorised information stabilises their knowing and acting, shaping health care towards a calculated effective and efficient form. Participating in the EHR's ruling practices, nurses adopt its ruling standpoint; a transformation that we conclude needs more careful analysis and debate.

[Unmasking the enterprising nurse: migrant care workers and the discursive mobilisation of productive professionals](#)

Antero Olakivi

Public care work organisations in Northern Europe often seek to increase their economic efficiency in ways that care workers criticise for reducing both their professional autonomy and the quality of care. Recently, the ideal of 'enterprising nursing' has emerged as a political belief according to which economic efficiency, care workers' autonomy and the quality of care can be improved in tandem by cultivating care workers' agential abilities. This article examines the reception of this belief among migrant care workers in Finland. Drawing on research interviews, the analysis demonstrates how migrant care workers may have difficulties in aligning themselves with the enterprising ideals but also in protesting them. Ethnicity, and the status of a migrant, can offer resources for both constructing enterprising subjectivities and reframing care workers' agency, and their organisational environment, in more critical terms.

[Enabling and controlling parenthood in publicly provided maternity healthcare: becoming a parent in Finland](#)

Riikka Homanen

This article discusses practices of parental support in the maternity healthcare provided by the welfare state. Drawing on ethnographic material from clinics in Finland, I discuss maternity healthcare practices and processes as the specific contexts of subjectification to parenthood in the Nordic welfare state. The analysis shows that in both nurses' (work) experience-based knowledge and population-statistical knowledge, parental competence is achieved largely through the 'natural' process of experiencing pregnant life. Care practices can be seen as enabling parenthood through respect for this process. Clinics encourage parents-to-be to self-reflect and be self-reliant. Emphasis on self-reflection and self-reliance has previously been interpreted as the state adoption of

therapy culture, and as a response to market demands for the welfare state to offer to and require of its citizens more autonomy and choice. I argue, however, that the parental subject emerging from the practices of this welfare service cannot be reduced to a neoliberal reflexive individual for whom parenthood is an individual project and who is to blame for individual shortcomings. Equally, they are no mere disciplined product of governmentality being pushed to conform to an idealised parent figure derived from collective ideas of good parenthood.

[Between stigma and pink positivity: women's perceptions of social interactions during and after breast cancer treatment](#)

Diane Trusson and Alison Pilnick

This study explores women's perceptions of social interaction during and after their treatment for early stage breast cancer. An analysis of interviews with 24 women between 6 months and 29 years post-diagnosis reveals that interactions can be influenced by conflicting public discourses surrounding breast cancer. For example, there is the continuing association of cancer with death and the resulting potential for a stigmatised identity. In contrast is the ultra-positive discourse around cancer survivorship, with breast cancer in particular being associated with pink campaigning and a push towards positive thinking. Participants described managing conversations during treatment; sometimes playing down their private suffering and presenting a positive (public) image rather than risk alienating support. After treatment they were encouraged to move on and get back to 'normal'. While other breast cancer patients and survivors were often good sources of support, there was also a danger of assuming that all experiences would be the same. We present data to illustrate that women often present public accounts that are driven by an expectation of positivity and fear of stigmatisation at all stages of breast cancer treatment and beyond.

[Changing tastes: learning hunger and fullness after gastric bypass surgery](#)

Line Hillersdal, Bodil J. Christensen, and Lotte Holm

Gastric bypass surgery is a specific medical technology that alters the body in ways that force patients to fundamentally change their eating habits. When patients enrol for surgery, they enter a learning process, encountering new and at times contested ways of sensing their bodies, tasting, and experiencing hunger and fullness. In this paper, we explore how patients begin to eat again after gastric bypass surgery. The empirical data used here are drawn from a Danish fieldwork study of individuals undergoing obesity surgery. The material presented shows how the patients used instructions on how to eat. We explore the ways in which

diverse new experiences and practices of hunger and fullness are part of the process of undergoing surgery for severe obesity. New sensory experiences lead to uncertainty; as a result, patients practice what we term mimetic eating, which reflects a 'sensory displacement' and hence a rupture in the person's sense of self and social relations. We suggest that eating should be conceptualised as a practice that extends beyond the boundaries of our bodies and into diverse realms of relations and practices, and that changing the way we eat also changes the fundamentally embodied experience of who we are.

[Theory, Culture and Society](#)

[Biopolitics, Thanatopolitics and the Right to Life](#)

Muhammad Ali Nasir

This article focuses on the interrelationship of law and life in human rights. It does this in order to theorize the normative status of contemporary biopower. To do this, the case law of Article 2 on the right to life of the European Convention on Human Rights is analysed. It argues that the juridical interpretation and application of the right to life produces a differentiated governmental management of life. It is established that: 1) Article 2 orients governmental techniques to lives in order to ensure that both deprivation and protection of lives is lawful; 2) A proper application of Article 2 grounds itself on a proper discrimination of lives which causes Article 2 to be applied universally but not uniformly to all juridical subjects; 3) The jurisprudence of Article 2 is theoretically appreciable only in a 'politics of life'. Finally, the article ends with a plea to analyse other fundamental human rights in the context of 'biopolitical governmentality'.

[Anthropology and Medicine](#)

[mHealth and the management of chronic conditions in rural areas: a note of caution from southern India](#)

Papreen Nahar, Nanda Kishore Kannuri, Sitamma Mikkilineni, G.V.S. Murthy and Peter Phillimore

This article examines challenges facing implementation of likely mHealth programmes in rural India. Based on fieldwork in Andhra Pradesh in 2014, and taking as exemplars two chronic medical 'conditions' – type 2 diabetes and depression – we look at ways in which people in one rural area currently access medical treatment; we also explore how adults there currently use mobile phones in daily life, to gauge the realistic likelihood of uptake for possible mHealth initiatives. We identify the very different pathways to care for these two medical conditions, and we highlight the

importance to the rural population of healthcare outside the formal health system provided by those known as registered medical practitioners (RMP), who despite their title are neither registered nor trained. We also show how limited is the use currently made of very basic mobile phones by the majority of the older adult population in this rural context. Not only may this inhibit mHealth potential in the near future; just as importantly, our data suggest how difficult it may be to identify a clinical partner for patients or their carers for any mHealth application designed to assist the management of chronic ill-health in rural India. Finally, we examine how the promotion of patient 'self-management' may not be as readily translated to a country like India as proponents of mHealth might assume.

[Herbal medicines for diabetes control among Indian and Pakistani migrants with diabetes](#)

Tania Porqueddu

Drawing on data collected during a 16-month ethnographic investigation, this paper explores practices around Indians' and Pakistanis' use of herbal medications for diabetes control. The ethnographic study was conducted among Indian and Pakistani migrants in Edinburgh, Scotland and included extended participant observation, six group discussions and 21 semi-structured interviews. Respondents showed great resistance in adhering to medication prescriptions for diabetes control due to their various side effects, especially within the stomach. In order to avoid such side effects, respondents decreased medication dosage and turned to non-allopathic remedies that usually consisted of herbal medications that, according to Indians and Pakistanis, did not cause side effects as medications did and tackled the cause of the disease rather than its symptoms. Such remedies however, were not only combined with allopathic ones but also eventually replaced without the doctor's consultation.

[Trail Blazing or Jam Session? Towards a New Concept of Clinical Decision-making](#)

Torsten Risør

Clinical decision-making (CDM) is key in learning to be a doctor as the defining activity in their clinical work. CDM is often portrayed in the literature as similar to 'trail blazing'; the doctor as the core agent, clearing away obstacles on the path towards diagnosis and treatment. However, in a fieldwork of young doctors in Denmark, it was difficult connect their practice to this image. This paper presents the exploration of this discrepancy in the heart of medical practice and how an alternative image emerged; that of a 'jam session'. The exploration is represented as a

case-based hypothesis-testing: first, a theoretically and empirically informed hypothesis (H0) of how doctors perform CDM is developed. In H0, CDM is a stepwise process of reasoning about clinical data, often influenced by outside contextual factors. Then, H0 is tested against a case from ethnographic fieldwork with doctors going through internship. Although the case is chosen for characteristics that make it 'most likely' to verify the hypothesis, verification proves difficult. The case challenges preconceptions in CDM literature about chronology, context, objectivity, cognition, agency, and practice. The young doctor is found not to make decisions, but rather to participate in CDM; an activity akin to the dynamics found in a jam session. Their participation circles in and through four concurrent interrelated constructions that suggest a new conceptualization of CDM; a starting point for a deeper understanding of actual practice in a changing clinical environment.

[Adherence and Recursive Perception Among Young Adults with Cystic Fibrosis](#)

August Oddleifson and Gregory S. Sawicki

Adherence to prescribed treatment is a pressing issue for adolescents and young adults with cystic fibrosis (CF). This paper presents two narratives from the thematic analysis of unstructured interviews with 14 adolescents, young adults, and older adults living with CF. Through a new identity-based framework termed *recursive perception* that draws focus on *how an individual perceives how others view them*, it explores the social context of adherence and self-care among young adults with CF. It demonstrates that an individual's understanding of self and desire to maintain a certain image for peers can be deeply embedded in adherence and self-care patterns, leading individuals to feel they need to choose between tending to their health needs and living their lives. This suggests that current biomedical innovation in CF care must be complemented with renewed efforts to find effective means to empower young adults with CF to successfully navigate the social challenges of their illness and avoid the pitfalls of nonadherence that can lead to a permanent worsening of their health condition.

[Unsettling the fistula narrative: cultural pathology, biomedical redemption, and inequities of health access in Niger and Ethiopia](#)

Alison Heller and Anita Hannig

Obstetric fistula, a maternal childbirth injury that results in chronic incontinence, affects an estimated one million women in the global south. In the course of media and donor coverage on this condition, fistula sufferers have been branded as 'child brides' who, following the onset of

their incontinence, become social pariahs and eventually find physical and social redemption through surgical repair. This narrative framing pits the violence of 'culture' against the potency of biomedical salvation. Based on over two years of ethnographic research at fistula repair centres in Niger and Ethiopia, this paper challenges this narrative and argues that most women with obstetric fistula remain embedded in social relations, receive continued familial support, and, unexpectedly, experience ambiguous surgical outcomes. This paper interrogates the existing logics of the fistula narrative that have had the unintended effects of obscuring global structural inequalities and diverting attention away from systemic health access reforms.

[Not 'Taking the Easy Way Out': Reframing Bariatric Surgery from Low-effort Weight Loss to Hard Work](#)

Sarah Trainer, Alexandra Brewis and Amber Wutich

Cultural notions equating greater morality and virtue with hard work and productive output are deeply embedded in American value systems. This is exemplified in how people understand and execute personal body projects, including efforts to become slim. Bariatric surgery is commonly viewed as a 'low-effort' means of losing weight, and individuals who opt for this surgery are often perceived to be 'cheating.' This extended ethnographic study within one bariatric program in the Southwestern United States shows how patients conscientiously perform this productivity. By prioritizing discourses that focus on their own hard work and the inherent value and necessity of their surgery, patients and practitioners alike contest the dominant public views of surgically-induced weight loss.

[Guardians of 'the gift': the emotional challenges of heart and lung transplant professionals in Denmark](#)

Anja M. B. Jensen

This paper deals with the emotional challenges encountered by doctors and nurses caring for heart and lung transplant patients. Organ transplantation enables body parts from the dead to become usable in patients with no other life-saving option. These exchanges are not possible without transplant professionals carefully selecting, guiding and interacting with organ recipients before, during and after the transplant. Based on anthropological fieldwork at a Danish heart and lung transplant unit, the paper explores how doctors and nurses experience and handle the emotional challenges of their working life. By focusing on the everyday life of the transplant unit which, contrary to public understanding of transplant miracles, is sometimes characterised by sad cases and

devastation, this paper argues that transplant professionals operate in the presence of death. Medically and emotionally they are at risk. They must take the difficult decisions of whether to admit critically ill patients onto the organ waiting list; face the distress of post-transplant sufferings and deaths; and deal with organ recipients who do not behave according to post-transplant recommendations. Drawing on a familiar metaphor for donated organs, it is suggested that transplant doctors and nurses are 'guardians of the gift'. Attention to the emotional burdens and rewards of this particular position enables new understandings of the practices of transplant medicine, of gift exchange theory, and of the role of emotion in medical practice.

[Health, Risk and Society](#)

[Pregnancy and birth in the global South: a review of critical approaches to sociocultural risk illustrated with fieldwork data from northern Uganda](#)

Sarah Rudrum

In this article, I examine whether a critical approach to risk is relevant to pregnancy and maternity care in global South settings and I illustrate my review of current literature with examples from fieldwork I conducted in northern Uganda in 2012. Coxon, in a *Health, Risk & Society* editorial entitled 'Risk in pregnancy and birth: are we talking to ourselves?' (2014, *Health, Risk & Society*, 16(6), 481–493), noted that the analysis of risk in pregnancy has tended to focus on 'relatively privileged women in high-income countries' (p. 490), a narrow lens that in her view not only led to an account that was 'highly partial' but also contributed to theory in this area being overly focused on individual accounts, rather than structural inequalities. In this article, I draw on my experiences researching and writing about maternity care in Uganda, to consider whether and how a critical approach to sociocultural risk is relevant in low-income global South countries, as well as how a shift in lens to include less privileged women in low-income countries also shifts the theoretical contribution of a critical risk approach. I examine screening and surveillance as well as risk subjectivity, areas central to the discussion of risk and pregnancy, and find that a critical approach to risk offers insight into new forms of control and new discourses of responsibility. At the same time, I note that the social, political and medical contexts shaping both clinical and critical sociocultural approaches to risk have not occurred universally, and the critiques developed by scholars in and of the global North are not directly transferable to global South settings. Overall, I find that a critical approach to risk is indeed relevant and points to specific cases and discourses where such a lens is particularly valuable.

['Because I've been extremely careful': HIV seroconversion.](#)

[responsibility, citizenship and the neo-liberal drug-using subject](#)

Andrea Krüsi, Ryan McNeil, David Moore and Will Small

In this article, we examine how injection drug users who do not attribute their HIV infection to engaging in HIV risk behaviours take up and critique discourses of individual responsibility and citizenship relating to HIV risk and HIV prevention. We draw on data from a study in Vancouver, Canada (2006–2009) in which we interviewed individuals living with HIV who had a history of injection drug use. In this paper, we focus on six cases studies of participants who *did not* attribute their HIV infection to engaging in HIV risk behaviours. We found that in striving to present themselves as responsible HIV citizens who did not engage in HIV risk behaviours, these participants drew on individually focused HIV prevention discourses. By identifying themselves in these ways, they were able to present themselves as ‘deserving’ HIV citizens and avoid the blame associated with being HIV positive. However, in rejecting the view that they and their risk behaviours were to blame for their HIV infection and by developing an explanation that drew on broader social, structural and historical factors, these individuals were developing a tentative critique of focus on individual responsibility in HIV transmission as opposed to dangers of infection arising from the socio-economic environment. By framing the risk of infection in environmental rather than individual risk-behaviour terms, these individuals redistributed responsibility to reflect the social-structural realities of their lives. In this article, we reflect on the implications of these findings for public health measures such as risk prevention messages. We argue that it is important that such messages are not restricted to individual risk prevention but also include a focus of broader shared responsibilities of HIV.

AMA citation

Kowalski J. In the Journals--March 2017, Part II. *Somatosphere*. 2017. Available at: <http://somatosphere.net/?p=13471>. Accessed April 1, 2017.

APA citation

Kowalski, Julia. (2017). *In the Journals--March 2017, Part II*. Retrieved April 1, 2017, from Somatosphere Web site: <http://somatosphere.net/?p=13471>

Chicago citation

Kowalski, Julia. 2017. In the Journals--March 2017, Part II. *Somatosphere*. <http://somatosphere.net/?p=13471> (accessed April 1, 2017).

Harvard citation

Kowalski, J 2017, *In the Journals--March 2017, Part II*, Somatosphere.

Retrieved April 1, 2017, from <<http://somatosphere.net/?p=13471>>

MLA citation

Kowalski, Julia. "In the Journals--March 2017, Part II." 3 Apr. 2017.
Somatosphere. Accessed 1 Apr.
2017.<<http://somatosphere.net/?p=13471>>