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In the Journals, June 2014 -- Part II

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By Aaron Seaman

And now, Part II of the journal roundup for June.

We begin with two special issues in the journals Cambridge Anthropology and Science in Context. The former, entitled “Epidemic Events and Processes,” is discussed [here](#), while a roundup of the latter, “Science, Technology, Medicine – and the State: The Science-State Nexus in Scandinavia, 1850–1980,” can be found [here](#).

As for the other journals with issues this month, see the listings below. (Open access articles, issues, and journals are marked as such.)

[Medical Anthropology Quarterly](#)

[Ethnography, Fidelity, and the Evidence that Anthropology Adds: Supplementing the Fidelity Process in a Clinical Trial of Supported Employment](#)

Carolyn Smith-Morris, Gilberto Lopez, Lisa Ottomanelli, Lance Goetz, and Kimberly Dixon-Lawson

This discussion considers the role and findings of ethnographic research within a clinical trial of supported employment for veterans with spinal cord injury. Contributing to qualitative evaluation research and to debates over anthropological evidence vis-à-vis clinical trials, we demonstrate how enactors of a randomized controlled trial can simultaneously attend to both the trial’s evidentiary and procedural requirements and to the lived experiences and needs of patients and clinicians. Three major findings are described: (1) contextual information essential to fidelity efforts within the trial; (2) the role of human interrelationships and idiosyncratic networks in the trial’s success; and (3) a mapping of the power and authority structures relevant to the staff’s ability to perform the protocol. We emphasize strengths of anthropological ethnography in clinical trials that include the provision of complementary, qualitative data, the capture of otherwise unmeasured parts of the trial, and the realization of important information for the translation of the clinical findings into new settings.

[First-Class Health: Amenity Wards, Health Insurance, and Normalizing Health Care Inequalities in Tanzania](#)

James Ellison

In 2008, a government hospital in southwest Tanzania added a “first-class ward,” which, unlike existing inpatient wards defined by sex, age, and ailment, would treat patients according to their wealth. A generation ago, Tanzanians viewed health care as a right of citizenship. In the 1980s and 1990s, structural adjustment programs and user fees reduced people’s access to biomedical attention. Tanzania currently promotes “amenity” wards and health insurance to increase health care availability, generate revenue from patients and potential patients, and better integrate for-profit care. In this article, I examine people’s discussions of these changes, drawing on ethnographic fieldwork in the 2000s and 1990s. I argue that Tanzanians criticize unequal access to care and health insurance, although the systemic structuring of inequalities is becoming normalized. People transform the language of socialism to frame individualized market-based care as mutual interdependence and moral necessity, articulating a new biomedical citizenship.

[ARVs and ARTs: Medicoscapes and the Unequal Place-making for Biomedical Treatments in sub-Saharan Africa](#)

Viola Hörbst and Angelika Wolf

Asking why some diseases gain global attention whereas others are neglected, we present two case studies that demonstrate the unequal treatment and financing options available for HIV/AIDS versus infertility treatments. We track three key phenomena central to understanding the unequal public attention given to certain ailments: peace and security, subordination of the social to the biological, and a “global” quality. Existing concepts such as global assemblages or therapeutic citizenship are quite limited when it comes to bodily conditions that result in social suffering and do not satisfy the conditions of advocacy. Since it is not enough to observe “flowing” and “moving,” we propose the concept of medicoscapes, to acknowledge that such activities simultaneously entail channeling and carving out. Medicoscapes enhance the analysis of linkages between different health conditions regardless of whether they are biological or social and how they interconnect places, sites, and people.

[“Lungisa”—Weaving Relationships and Social Space to Restore Health in Rural KwaZulu Natal](#)

Anette Wickström

Many Zulu people who live in big cities in South Africa return to their rural homestead when they fall ill. Although the health care offered in rural areas is not efficient, people wish to connect to their family and ancestors. My aim is to explore acts of lungisa (“to put in order”) and what they say about health, agency, and the circumstances under which people live. Returning home means weaving oneself firmly within a web of relationships that are located in material things and places. Healing involves imperfect strategies used to better connect bodies, relationships, and places. I theorize the acts of returning using Adriana Cavarero’s concept of weaving together and argue that people produce space and relationships over time to exert some control over a life lived under political and economic circumstances that have created separation. Six months of ethnographic fieldwork make up the material for my analysis.

[Everyday Narratives on Race and Health in Brazil](#)

Anna Pagano

In 2006, Brazil approved a groundbreaking policy aimed at reducing significant racial health inequalities among its citizens. Like health disparities programs in the United States, Brazil’s policy is based on the assumptions that racial identity and racism are important health determinants and that citizens who identify as “black” suffer disproportionately from a number of health problems. How do these assumptions compare to Brazilian citizens’ conceptions of racial identity and health inequalities? To address this question, I present ethnographic data from two years of fieldwork in Brazilian public clinics and low-income neighborhoods. I show that a majority of research participants made no connection between race and better or worse health. Of those who perceived health inequalities by race, most believed that white Brazilians had more health problems than black or brown Brazilians. Finally, I consider the implications of these ethnographic findings for Brazil’s health disparities campaign.

[“I Didn’t Feel Like I Was a Person Anymore”: Realigning Full Adult Personhood after Ostomy Surgery](#)

Michelle Ramirez, Andrea Altschuler, Carmit McMullen, Marcia Grant, Mark Hornbrook and Robert Krouse

Colorectal cancer (CRC) is the third most common cancer in the United States. For some CRC patients, cancer treatment involves creating a permanent or temporary intestinal ostomy. Having an ostomy often results in complex social and physical concerns—including unpredictable and at times publicly noticeable bowel output. In this article, we discuss findings from 30 in-depth interviews with female CRC survivors with ostomies in the western United States. We highlight how having an ostomy disrupts culturally sanctioned practices of continence that mark the attainment of full-adult personhood. We discuss how survivors reclaim a sense of full personhood after ostomy surgery through a process of realignment that entails both learning how to manage ostomy equipment to conceal bowel activity and reappraising their illness and suffering. We suggest that the anthropological categories of personhood and personhood realignment be incorporated into research and interventions aimed at increasing support among cancer survivors living with bodily impairments.

[“Playing the Numbers Game”: Evidence-based Advocacy and the Technocratic Narrowing of the Safe Motherhood Initiative](#) (Open Access)
Katerini T. Storeng and Dominique P. Béhague

Based on an ethnography of the international Safe Motherhood Initiative (SMI), this article charts the rise of evidence-based advocacy (EBA), a term global-level maternal health advocates have used to indicate the use of scientific evidence to bolster the SMI’s authority in the global health arena. EBA represents a shift in the SMI’s priorities and tactics over the past two decades, from a call to promote poor women’s health on the grounds of feminism and social justice (entailing broad-scale action) to the enumeration of much more narrowly defined practices to avert maternal deaths whose outcomes and cost effectiveness can be measured and evaluated. Though linked to the growth of an audit- and business-oriented ethos, we draw from anthropological theory of global forms to argue that EBA—or “playing the numbers game”—profoundly affects nearly every facet of evidence production, bringing about ambivalent reactions and a contested technocratic narrowing of the SMI’s policy agenda.

[Material Proximities and Hotspots: Toward an Anthropology of Viral Hemorrhagic Fevers](#) (Open Access)
Hannah Brown and Ann H. Kelly

This article outlines a research program for an anthropology of viral

hemorrhagic fevers (collectively known as VHFs). It begins by reviewing the social science literature on Ebola, Marburg, and Lassa fevers and charting areas for future ethnographic attention. We theoretically elaborate the hotspot as a way of integrating analysis of the two routes of VHF infection: from animal reservoirs to humans and between humans. Drawing together recent anthropological investigations of human–animal entanglements with an ethnographic interest in the social production of space, we seek to enrich conceptualizations of viral movement by elaborating the circumstances through which viruses, humans, objects, and animals come into contact. We suggest that attention to the material proximities—between animals, humans, and objects—that constitute the hotspot opens a frontier site for critical and methodological development in medical anthropology and for future collaborations in VHF management and control.

[Medical Humanities](#)

[Ideology and disease identity: the politics of rickets, 1929–1982](#) (Open Access)

Roberta Bivins

How can we assess the reciprocal impacts of politics and medicine in the contemporary period? Using the example of rickets in twentieth century Britain, I will explore the ways in which a preventable, curable non-infectious disease came to have enormous political significance, first as a symbol of socioeconomic inequality, then as evidence of racial and ethnic health disparities. Between the 1920s and 1980s, clinicians, researchers, health workers, members of Parliament and later Britain's growing South Asian ethnic communities repeatedly confronted the British state with evidence of persistent nutritional deficiency among the British poor and British Asians. Drawing on bitter memories of the 'Hungry Thirties', postwar rickets—so often described as a 'Victorian' disease—became a high-profile sign of what was variously constructed as a failure of the Welfare State; or of the political parties charged with its protection; or of ethnically Asian migrants and their descendants to adapt to British life and norms. Here I will argue that rickets prompted such consternation not because of its severity, the cost of its treatment, or even its prevalence; but because of the ease with which it was politicised. I will explore the ways in which this condition was envisioned, defined and addressed as Britain moved from the postwar consensus to Thatcherism, and as Britain's diverse South Asian communities developed from migrant enclaves to settled

multigenerational ethnic communities.

['Heavier the interval than the consummation': bronchial disease in Seán Ó Ríordáin's diaries](#)

Ciara Breathnach

Narratives of the experience of pulmonary tuberculosis (TB) are relatively rare in the Irish context. A scourge of the early twentieth century, TB was as much a social as a physically debilitating disease that rendered sufferers silent about their experience. Thus, the personal diaries and letters of Irish poet, Seán Ó Ríordáin, (1916–1977) are rare. This article presents translations of his personal papers in a historico-medical context to chronicle Ó Ríordáin's experience of a life marred by respiratory disease. Familiar to generations of schoolchildren are his imaginative poems, whose lively metre punctuated the Irish language curriculum from primary through to secondary schooling; for most they leave an indelible mark. Such buoyant poems however belie the reality of his existence, lived in the shadow of chronic illness, and punctuated with despair over his condition and anxiety about the periods of extended sick leave his illness necessitated. Although despair dominated his diaries and he routinely begged God, Mary, the Saints and the devil for death, they were also the locus where his creativity developed. In his diaries, caricatures of friends and sketches of everyday things nestle among the first lines of some of his most influential poems and quotes from distinguished philosophers and writers. Evocative and tragic, his diaries offer a unique prism to the experience of respiratory disease in Ireland.

[Accounting for personhood in palliative sedation: the Ring Theory of Personhood](#)

Lalit Kumar Radha Krishna

Application of sedation at the end of life has been fraught with ethical and clinical concerns, primarily focused on its potential to hasten death. However, in the face of clinical data that assuage most of these concerns, a new threat to this treatment of last resort has arisen. Concern now pivots on its effects on the personhood of the patient, underpinned by the manner in which personhood has been conceptualised. For many authors, it is consciousness that is seen to be the seat of personhood, thus its loss is seen to rob a patient of their moral and ethical worth, leaving them in a state that cannot ethically be differentiated from death. Here I proffer a

clinically based alternative to this view, the Ring Theory of Personhood, which dispels these concerns about sedation at the end of life. The Ring Theory envisages personhood as a coadunation of three domains of concern: the innate, the individual and the relational elements of personhood. The innate element of personhood is held to be present among all humans by virtue of their links with the Divine and or their human characteristics. The individual elements of personhood pivot on the presence of consciousness-dependent features such as self-awareness, self-determination and personality traits. The relational component of personhood envisages an individual as being 'socially embedded' replete with social and familial ties. It is these three equally important inter-related domains that define personhood.

[He drove forward with a yell: anger in medicine and Homer](#)

A. Bleakley, R. Marshall, and D. Levine

We use Homer and Sun Tzu as a background to better understand and reformulate confrontation, anger and violence in medicine, contrasting an unproductive 'love of war' with a productive 'art of war' or 'art of strategy'. At first glance, it is a paradox that the healing art is not pacific, but riddled with militaristic language and practices. On closer inspection, we find good reasons for this cultural paradox yet regret its presence. Drawing on insights from Homer's *The Iliad* and *The Odyssey*, we argue for better understanding of confrontation, anger, bullying, intimidation and violence in medicine in order to change the culture. For example, equating medicine with war is not a given condition of medicine but a convenient metaphor with historical origins and a historical trajectory. Other, non-martial metaphors, such as medicine as collaboration, may be more appropriate in an age of team-based care. Taking lessons from Homer, we suggest three key ways in which cold-hearted confrontation and anger in medicine can be transformed into productive, warm-hearted engagement: the transformation of angry impulse into (1) reflection, (2) moral courage and (3) empathy. Thinking with Homer can offer an aesthetically and morally charged alternative to the current body of literature on topics, such as anger in doctors, and how this may be 'managed', without recourse to an instrumental economy where emotions are viewed as commodities, and emotional responses can be 'trained' through communication skills courses.

[A short history of providing medical history within the British medical undergraduate curriculum](#)

N. H. Metcalfe and E. Stuart

This article aims to discuss the history of medical history in the British medical undergraduate curriculum and it reviews the main characters and organisations that have attempted to earn it a place in the curriculum. It also reviews the arguments for and against the study of the subject that have been used over the last 160 years.

[The madness of Gerard de Nerval](#)

Allan Beveridge

This paper examines the madness of Gerard de Nerval, the nineteenth-century French writer. It looks at his account of mental disturbance, how he responded to the psychiatric profession and how he reacted to being diagnosed as insane. It considers his autobiographical novella of madness, Aurelia, which he began at the suggestion of his alienist, Dr Emile Blanche, and while he was still an asylum inmate. Nerval's story raises important questions about the nature of madness. Is it, as he contended, a mystical experience revealing truths about spiritual worlds inaccessible to the 'sane'? Does psychiatry fail to understand it and inappropriately reduce it to the categories of scientific reason? Or are such notions of the spiritual value of madness guilty of the charge that they romanticise insanity? Do they make extravagant claims for an experience that is often disturbing and debilitating? What is the relationship between madness and recovery? Should an individual try to forget their experience of mental disturbance once they recover, or should they examine what the event reveals about themselves? Can the language of madness be decoded to unveil profound truths as Carl Jung and R.D. Laing have suggested, or is it, as the psychiatrist German Berrios maintains, merely a series of 'empty speech acts', signifying nothing? And finally, how does one avoid writing about madness, and instead write madness?

[The use of abstract paintings and narratives to foster reflective capacity in medical educators: a multinational faculty development workshop](#) (Open Access)

Khaled Karkabi, Hedy S. Wald, and Orit Cohen Castel

Reflective capacity is integral to core healthcare professional practice competencies. Reflection plays a central role in teacher education as reflecting on teaching behaviours with critical analysis can potentially improve teaching practice. The humanities including

narrative and the visual arts can serve as a valuable tool for fostering reflection. We conducted a multinational faculty development workshop aiming to enhance reflective capacity in medical educators by using a combination of abstract paintings and narratives. Twenty-three family physicians or physicians-in-training from 10 countries participated in the workshop. Qualitative assessment of the workshop showed that the combined use of art and narrative was well received and perceived as contributing to the reflective exercise. Participants generally felt that viewing abstract paintings had facilitated a valuable mood transformation and prepared them emotionally for the reflective writing. Our analysis found that the following themes emerged from participants' responses: (1) narratives from different countries are similar; (2) the use of art helped access feelings; (3) viewing abstract paintings facilitated next steps; (4) writing reflective narratives promoted examination of educational challenges, compassion for self and other, and building an action plan; and (5) sharing of narrative was helpful for fostering active listening and appreciating multiple perspectives. Future research might include comparing outcomes for a group participating in arts–narrative-based workshops with those of a control group using only reflective narrative or in combination with figurative art, and implementing a combination of qualitative and quantitative methods of assessment.

[Humanising illness: presenting health information in educational comics](#)

(Open Access)

Sarah McNicol

Research into the effectiveness of comic books as health education tools overwhelmingly consists of studies evaluating the information learnt as a result of reading the comic, for example using preintervention and postintervention questionnaires. In essence, these studies evaluate comics in the same way in which a patient information leaflet might be evaluated, but they fail to evaluate the narrative element of comics. Health information comics have the potential to do much more than simply convey facts about an illness; they can also support patients in dealing with the social and psychological aspects of a condition. This article discusses how some common elements of educational comics are handled in a selection of comics about diabetes, focusing on the more personal or social aspects of the condition as well as the presentation of factual information. The elements examined include: fears and anxieties; reactions of friends and family; interactions with medical professionals; self-management;

and prevention. In conclusion, the article argues that comics, potentially, have many advantages over patient information leaflets, particularly in the way in which they can offer 'companionship', helping patients to address fears and negative feelings. However, empirical studies are required to evaluate educational comics in a way which takes account of their potential role in supporting patients in coming to terms with their condition, as well as becoming better informed.

[Fight like a ferret: a novel approach of using art therapy to reduce anxiety in stroke patients undergoing hospital rehabilitation](#)

Khalid Ali, Tony Gammidge, and Diane Waller

Rationale The holistic aspect of stroke rehabilitation to include psychological well-being is currently neglected, with more emphasis placed on physical recovery despite anxiety and depression being common poststroke. From the limited amount of current literature, it seems that creative strategies such as art therapy (AT) can be beneficial in reducing isolation and anxiety among stroke patients. / **Methods** Stroke patients (able to consent) in a hospital rehabilitation unit were invited to participate in two weekly AT sessions for 6 weeks, facilitated by an art psychotherapist using paints, crayons, clay, a camera and an iPad. Hospital anxiety and depression scales (HAD) and therapy outcome measures (TOM) were measured at the beginning and end of the study. / **Results** Six male patients were recruited, average age 69 years (38–85). Group discussions allowed patients to express openly feelings of frustration as well as hope for physical and emotional recovery: 'fight like a ferret', an expression used by a group member. The group produced several art objects and photographic images that were collated using stop-frame animation to produce a 10 min film. Median HAD score for the group was eight points upon entering the study and six points on finishing the study. **Key conclusions** There is little attention to the emotional needs of stroke patients in rehabilitation. Properly designed research studies exploring the role of AT in addressing anxiety and depression poststroke are needed. Our study showed that AT was a feasible intervention that helped patients explore the sequel of stroke in an open supportive environment.

Student Original Article

[The relationship between heart and 'inner self' from Aristotle to current clinical practice](#)

Anna Goodhart

Modern songs, films, novels and daily speech often use heart imagery to illustrate ‘inner self’ experiences, such as deeply felt emotions. Where do these ideas come from and what relevance (if any) do they have for medicine today? This article explores some of the key origins and periods of development of heart/‘inner self’ ideas before considering the significance of heart/‘inner self’ interactions in modern clinical practice: from Aristotelian anatomy and the translated Hebrew Scriptures; through Shakespeare, William Harvey and the Protestant Reformation; to theories of emotion and modern-day cardiology. I conclude that heart/‘inner self’ interactions exist in clinically significant ways, but are poorly understood and under-recognised in healthcare settings. Greater integration of cardiovascular and psychosocial medicine would improve patient care.

New Genetics and Society

[Managing expectational language: translational genetic professionals consider the clinical potential of next-generation sequencing technologies](#)

Pei P. Koay and Richard R. Sharp

Clinical genetic professionals are used to being flooded by claims about the seemingly endless potential and promise of next-generation sequencing (NGS) in medicine today. This paper is about managing expectations in translational medicine. From 2009 to 2011, we conducted focus groups with genetic and allied professionals concerned with genomics in the clinic to examine their attitudes and perspectives of genetic and genomic tools in this environment. In this paper, we examine and explore some of their discussions, specifically related to NGS and whole genome sequencing tests and their introduction as normal clinical tools. Informed by sociology of expectations (SE), we discuss expectational language in the arena of translational medicine. Through SE, illuminated are some barriers and strategies used by professionals to manage expectations. Further, our work suggests the importance of SE and more nuanced study to understand the discursive realm of translational genomic medicine.

[Negotiating blame and responsibility in the context of a “de novo” mutation](#)

Rebecca Dimond

This article examines the implications for parents and family members when a child is diagnosed with a genetic syndrome. In particular, it describes how practices of understanding are shaped when the syndrome occurs “de novo,” that is, when it has not been inherited from either parent and where there is no family history. Despite a significant body of research exploring the social implications of genetic disease and diagnostic technologies, sociological understandings of the implications of a de novo mutation are considerably limited. This article draws on semi-structured interviews conducted with 23 parents of children diagnosed with 22q11 deletion syndrome, a syndrome associated with high rates of de novo cases. Three themes were identified: “lay” understandings of genetics, making genetic connections and genetic gatekeeping. Overall, this article articulates and confirms the enduring significance of family for contextualizing health and illness.

[Social, ethical and legal considerations raised by the discovery and patenting of the BRCA1 and BRCA2 genes](#)

Yann Jolya and Patricia N. Tonin

The discovery of the BRCA1 gene had an immediate and profound impact on medical practice by providing a means to assess and manage breast and ovarian cancer risk in individuals and their families carrying a mutation in the gene. The patenting of BRCA1 and then BRCA2 (another cancer-predisposing gene) by Myriad Genetics Inc. raised controversial ethical and legal issues relating to access and research, and its enforcement caused growing discontent. In the USA, the validity of the patents on the isolated BRCA1 and BRCA2 genes was challenged in court. After a four-year legal battle, the US Supreme Court invalidated both patents. This commentary reviews the discovery of these cancer-predisposing genes from the perspective of one of the co-discoverers of BRCA1. It also discusses the socio-ethical impact of the patenting of BRCA1 and BRCA2 and the legal implications of the US Supreme Court’s decision.

[Making sense of the story – the dialogues between the police and forensic laboratories in the construction of DNA evidence](#)

Filipe Santos

The use of DNA technologies for criminal investigation purposes illuminates an interplay of knowledge and expertise where meaning and relevance of biological traces are negotiated.

Through the analysis of five criminal cases that took place in Portugal between 1995 and 2010, and where DNA technologies were used, this article will focus on the dialogues established between the police and the forensic laboratories. I will argue that, on the one hand, the police investigators' uses of DNA technologies seek to legitimate and provide an external source of neutrality and objectivity to the constructed narratives surrounding the commission of a crime. On the other hand, laboratories and forensic experts engage in the delimitation and preservation of their professional autonomy by developing boundary work around their scientific expertise through the translation and conversion of criminal traces into scientific artifacts.

[Technocratic precautionary principle: Korean risk governance of genetically modified organisms](#)

Eun-Sung Kim

Regulations for genetically modified organisms (GMOs) in Korea fluctuate between technocracy and the precautionary principle (PP). Technocratic PP denotes the coexistence, or coproduction, of technocracy with PP – a complex ensemble of technocratic, precautionary policies, and hybrids of the two. This paper analyzes four types of PP-based policies linked to Korean GMO regulations: foresight and monitoring of risk; reverse burden of proof; public participation; and the public's right to know. Korean GMO regulations are consistent with the Cartagena Protocol on Biosafety, a type of PP, but lack long-term risk assessment as well as public participation. Technocracy is embedded both in advance informed agreements as a reverse burden of proof and in proof-based GMO labeling as a right-to-know policy. Technocratic PP results in inconsistencies between PP and technocratic epistemology and the gap between PP-based institutions and technocratic practices. Technocratic PP is therefore a typical phenomenon that occurs in the “glocalization” of risk regulation.

[Philosophy, Ethics, and Humanities in Medicine](#) (Open Access)

[A four-part working bibliography of neuroethics: part 1: overview and reviews – defining and describing the field and its practices](#)

Liana Buniak, Martina Darragh, and James Giordano

Background Neuroethics entails investigations of neurocognitive mechanisms of morality and ethics; and studies and address of the ethical issues spawned by the use of neuroscience and its

technologies to investigate cognition, emotion and actions. These two principal emphases, or what have been called “traditions” of neuroethics both mirror traditional bioethical discussions (such as debates about the safety of technological and pharmaceutical advances and ethical implications of new scientific and technological discoveries), and engage discourse about neuroscientific investigations of (proto-moral and moral) cognition, emotions and behaviors, and what such findings may mean for human beliefs and conduct – from the individual to the political levels. Given the growth, range, and rapid maturation of the field of neuroethics we provide an iterative, four-part document that affords a repository of international papers, books, and chapters that address the field in overview, and present discussion(s) of more particular aspects and topics of neuroethics. This first installment lists reviews and overviews of the discipline, and broad summaries of basic developments and issues of the field. **Methods** To systematically survey the neuroethics literature, searches were performed by accessing 11 databases, 8 additional literature depositories, and 4 individual journal searches using indexing language for National Library of Medicine (NLM) Medical Subject Heading databases. Searches and assurance against overlapping coverage were conducted using the RefWorks citation management program. **Results** Overview, review and reflections upon the history and multicultural perspectives of neuroethics were obtained and relevant listings from international journals, books, and book chapters are provided. Part I will be followed by three installments that will address a): the neuroscience of morality and ethics, including discussions of free will, and personal autonomy; b) “second tradition neuroethics”, to include specific ethical issues in neuroscience; clinical neuroethics; and c) neuroethics education/training; neuroethics and society; neuroethics and law; neuroethics and policy; and international neuroethics.

[Retrospective diagnosis of a famous historical figure: ontological, epistemic, and ethical considerations](#)

Osamu Muramoto

The aim of this essay is to elaborate philosophical and ethical underpinnings of posthumous diagnosis of famous historical figures based on literary and artistic products, or commonly called retrospective diagnosis. It discusses ontological and epistemic challenges raised in the humanities and social sciences, and attempts to systematically reply to their criticisms from the viewpoint of clinical medicine, philosophy of medicine, particularly the ontology of disease and the epistemology of diagnosis, and

medical ethics. The ontological challenge focuses on the doubt about the persistence of a disease over historical time, whereas the epistemic challenge disputes the inaccessibility of scientific verification of a diagnosis in the past. I argue that the critics are in error in conflating the taxonomy of disease (nosology) and the act of diagnosing a patient. Medical diagnosis is fundamentally a hypothesis-construction and an explanatory device that can be generated under various degrees of uncertainty and limited amount of information. It is not an apodictic judgment (true or false) as the critics presuppose, but a probabilistic (Bayesian) judgment with varying degrees of plausibility under uncertainty. In order to avoid this confusion, I propose that retrospective diagnosis of a historical figure be syndromic without identifying underlying disease, unless there is justifiable reason for such specification. Moreover it should be evaluated not only from the viewpoint of medical science but also in a larger context of the scholarship of the humanities and social sciences by its overall plausibility and consistency. On the other hand, I will endorse their concerns regarding the ethics and professionalism of retrospective diagnosis, and call for the need for situating such a diagnosis in an interdisciplinary scope and the context of the scholarship of the historical figure. I will then enumerate several important caveats for interdisciplinary retrospective diagnosis using an example of the retrospective diagnosis of Socrates for his life-long intermittent neurologic symptoms. Finally, I will situate the present argument in a larger context of the major debate among the historians of medicine and paleopathologists, and discuss the similarities and differences.

[The moral code in Islam and organ donation in Western countries: reinterpreting religious scriptures to meet utilitarian medical objectives](#)

Mohamed Y. Rady and Joseph L. Verheijde

End-of-life organ donation is controversial in Islam. The controversy stems from: (1) scientifically flawed medical criteria of death determination; (2) invasive perimortem procedures for preserving transplantable organs; and (3) incomplete disclosure of information to consenting donors and families. Data from a survey of Muslims residing in Western countries have shown that the interpretation of religious scriptures and advice of faith leaders were major barriers to willingness for organ donation. Transplant advocates have proposed corrective interventions: (1) reinterpreting religious scriptures, (2) reeducating faith leaders, and (3) utilizing media campaigns to overcome religious barriers in Muslim communities. This proposal disregards the intensifying

scientific, legal, and ethical controversies in Western societies about the medical criteria of death determination in donors. It would also violate the dignity and inviolability of human life which are pertinent values incorporated in the Islamic moral code. Reinterpreting religious scriptures to serve the utilitarian objectives of a controversial end-of-life practice, perceived to be socially desirable, transgresses the Islamic moral code. It may also have deleterious practical consequences, as donors can suffer harm before death. The negative normative consequences of utilitarian secular moral reasoning reset the Islamic moral code upholding the sanctity and dignity of human life.

[Schizophrenia Bulletin](#) (Open Access)

[Culture and Hallucinations: Overview and Future Directions](#)

Frank Larøi, Tanya Marie Luhrmann, Vaughan Bell, William A. Christian Jr., Smita Deshpande, Charles Fernyhough, Janis Jenkins, and Angela Woods

A number of studies have explored hallucinations as complex experiences involving interactions between psychological, biological, and environmental factors and mechanisms. Nevertheless, relatively little attention has focused on the role of culture in shaping hallucinations. This article reviews the published research, drawing on the expertise of both anthropologists and psychologists. We argue that the extant body of work suggests that culture does indeed have a significant impact on the experience, understanding, and labeling of hallucinations and that there may be important theoretical and clinical consequences of that observation. We find that culture can affect what is identified as a hallucination, that there are different patterns of hallucination among the clinical and nonclinical populations, that hallucinations are often culturally meaningful, that hallucinations occur at different rates in different settings; that culture affects the meaning and characteristics of hallucinations associated with psychosis, and that the cultural variations of psychotic hallucinations may have implications for the clinical outcome of those who struggle with psychosis. We conclude that a clinician should never assume that the mere report of what seems to be a hallucination is necessarily a symptom of pathology and that the patient's cultural background needs to be taken into account when assessing and treating hallucinations.

[Interdisciplinary Approaches to the Phenomenology of Auditory Verbal](#)

[Hallucinations](#)

Angela Woods, Nev Jones, Marco Bernini, Felicity Callard, Ben Alderson-Day, Johanna C. Badcock, Vaughan Bell, Chris C. H. Cook, Thomas Csordas, Clara Humpston, Joel Krueger, Frank Larøi, Simon McCarthy-Jones, Peter Moseley, Hilary Powell, Andrea Raballo, David Smailes, and Charles Fernyhough

Despite the recent proliferation of scientific, clinical, and narrative accounts of auditory verbal hallucinations (AVHs), the phenomenology of voice hearing remains opaque and undertheorized. In this article, we outline an interdisciplinary approach to understanding hallucinatory experiences which seeks to demonstrate the value of the humanities and social sciences to advancing knowledge in clinical research and practice. We argue that an interdisciplinary approach to the phenomenology of AVH utilizes rigorous and context-appropriate methodologies to analyze a wider range of first-person accounts of AVH at 3 contextual levels: (1) cultural, social, and historical; (2) experiential; and (3) biographical. We go on to show that there are significant potential benefits for voice hearers, clinicians, and researchers. These include (1) informing the development and refinement of subtypes of hallucinations within and across diagnostic categories; (2) “front-loading” research in cognitive neuroscience; and (3) suggesting new possibilities for therapeutic intervention. In conclusion, we argue that an interdisciplinary approach to the phenomenology of AVH can nourish the ethical core of scientific enquiry by challenging its interpretive paradigms, and offer voice hearers richer, potentially more empowering ways to make sense of their experiences.

[Emerging Perspectives From the Hearing Voices Movement: Implications for Research and Practice](#)

Dirk Corstens, Eleanor Longden, Simon McCarthy-Jones, Rachel Waddingham, and Neil Thomas

The international Hearing Voices Movement (HVM) is a prominent mental health service-user/survivor movement that promotes the needs and perspectives of experts by experience in the phenomenon of hearing voices (auditory verbal hallucinations). The main tenet of the HVM is the notion that hearing voices is a meaningful human experience, and in this article, we discuss the historical growth and influence of the HVM before considering the implications of its values for research and practice in relation to voice-hearing. Among other recommendations, we suggest that the involvement of voice-hearers in research and a greater use of

narrative and qualitative approaches are essential. Challenges for implementing user-led research are identified, and avenues for future developments are discussed.

Science as Culture

'Who Were the Experts?' The Science of Love vs. Women's Knowledge of Love During the Spanish Dictatorship

Rosa M^a Medina-Doménech

During the most oppressive decades of National-Catholicism imposed by the Franco regime, scientific and medical expertise and knowledge were used to promote a particular form of heterosexual love that supported patriarchal normativity and notions of femininity. This 'science of love' represents two dispositifs of feminization that circulated through a range of scientific and medical knowledges (e.g. eugenics, ethology, physiology, neurosciences and psychiatry). It not only supported the internal coherence of science and medicine, but also supported particular forms of knowledge within the cultural context of National-Catholicism. Although the science of love was inspired by particular notions of romantic love, it was also contested by the daily and practical experiences of women. Different women in Franco's Spain deployed marginalized and subaltern knowledges as they orchestrated an emotional knowledge that was more emancipatory and useful for everyday amorous preoccupations and well-being than the one in medical and psychiatric texts. Women's discussions of love represented a key site and source of knowledge, an authentic repository of imaginative ideas that are also useful for the present to challenge patriarchal norms.

Situating Standards in Practices: Multi Drug-Resistant Tuberculosis Treatment in India

Nora Engel and Ragna Zeiss

Public health care needs to cope with a basic dilemma between providing standardized care within public programmes across entire and at times resource-constrained countries and adapting this care locally when responding to individual needs. This tension between standardization and local adaptation becomes particularly obvious for the prolonged and complicated treatment of multidrug-resistant tuberculosis (MDR-TB). Situated standardization, as introduced by Zuiderent-Jerak [2007a, 2007b] offers a way out of this dilemma. It helps to focus on how

standards need to be situated in practice rather than viewing standardization and local adaptation as mutually exclusive practices. How do actors relate standardization and individual care in their practices of treating MDR-TB? Results from qualitative fieldwork at the first MDR-TB treatment sites of the Indian TB programme show that actors situate standards in a particular way. They assess the role of guidelines in a particular situation and on that basis recognize the core recommendations of guidelines or go beyond the guidelines. This allows actors to negotiate how standards should be situated and reconciles the dilemma between local adaptation and standardization. Having guidelines internalized, as is common for Indian TB control, bears both promises and pitfalls for engaging in standardization processes in a situated manner. The results contribute to science and technology study scholarship on guideline development. They highlight how actors coordinate the situating of standards and how this depends upon cultures of control. This illustrates the potential of qualitative studies on local adaptation for guideline developers by revealing existing practices of relating and negotiating local adaptation and standardization.

['We Are All the Same, We All Are Mestizos': Imagined Populations and Nations in Genetics Research in Colombia](#)

María Fernanda Olarte Sierra and Adriana Díaz Del Castillo Hernández

In Colombia, as in other Latin American countries, current population genetics research is based on the understanding that Colombians constitute a mestizo nation, given the admixture process that took place between Africans, Amerindians, and Europeans during colonial times. The mestizo is a pervasive category used by geneticists to conduct, organise, and publish research studies that deal with the continent's peopling process and the genetic makeup of its contemporary population(s). It is also the dominant imaginary for the Colombian population and a key nation-building ideology. By tracing how this category moves and is used across four Colombian genetics laboratories, it is possible to discern that despite its apparently clear-cut boundaries, the mestizo is contingent, contested, and flexible, allowing for multiple understandings and usages. This flexibility and multiplicity are visible in the quantification of genetic ancestry, the divisions of geographical location, and the understanding of gender. Such understandings allow one to think about a homogeneous nation (inclusive) that is simultaneously heterogeneous (exclusive); they provide multiple but not necessarily contradictory possibilities of being mestizo, allowing the coexistence of images of the nation

that could otherwise seem contradictory; and they permit navigation around contested terms such as race, while simultaneously thinking of mixed races or racialised individuals. Finally, these flexible and multiple constructions of the mestizo (re)produce various subjects as 'other', whether they are women, the Indigenous, the black/dark, or the poor.

Social Science & Medicine

[A qualitative exploration of access to urban migrant healthcare in Nairobi, Kenya](#)

Christine Arnold, Jason Theede, and Anita Gagnon

In recent years, Kenya's capital city Nairobi has experienced an influx of international economic migrants, as well as migrants forced to flee their neighboring countries of origin, or coming from UNHCR-managed refugee camps into the city. Urban migrants regularly face challenges integrating with host communities and consequently face health vulnerabilities. The International Organization for Migration in Kenya was concerned about the potential marginalization of urban migrants from mainstream health programming and a lack of data upon which to base their activities. The purpose of this project was to gain a greater understanding of urban migrants' barriers to accessing healthcare in Nairobi compared with barriers faced by Kenyans living in the same locations. Guiding our work was a conceptual framework for assessing access to healthcare, which defines availability, geographic accessibility, financial accessibility and acceptability as the four dimensions of access. We identified key informants in collaboration with The National Organisation for Peer Educators, and these individuals assisted in identifying communities within Nairobi where large proportions of migrants reside. Four communities were selected for further study. In each, interviews with government officials and service providers were conducted, and focus group discussions were held with both migrants and Kenyans. Verbatim transcripts were content-analyzed using an open coding technique. Common barriers to accessing care that were shared by migrants and Kenyans included waiting times, drug availability, transportation and cost. Barriers unique to migrants were: threat of harassment; cost discrepancies between migrant and Kenyan clients; real or perceived discrimination; documentation requirements and language barriers. Despite articles from the 2010 Constitution of Kenya that assert the right to health for every person in Kenya, migrants continue to experience unique barriers in accessing healthcare. Efforts to eliminate these

barriers should address policy-level interventions, strengthened networks and partnerships, improved migrant-sensitive services and especially continued research in migrant health.

[The multiple truths about crystal meth among young people entrenched in an urban drug scene: A longitudinal ethnographic investigation](#)

Danya Fast, Thomas Kerr, Evan Wood, and Will Small

Transitions into more harmful forms of illicit drug use among youth have been identified as important foci for research and intervention. In settings around the world, the transition to crystal methamphetamine (meth) use among youth is considered a particularly dangerous and growing problem. Epidemiological evidence suggests that, particularly among young, street-involved populations, meth use is associated with numerous sex- and drug-related “risks behaviors” and negative health outcomes. Relatively few studies, however, have documented how youth themselves understand, experience and script meth use over time. From 2008 to 2012, we conducted over 100 in-depth interviews with 75 street-entrenched youth in Vancouver, Canada, as well as ongoing ethnographic fieldwork, in order to examine youth’s understandings and experiences of meth use in the context of an urban drug scene. Our findings revealed positive understandings and experiences of meth in relation to other forms of drug addiction and unaddressed mental health issues. Youth were simultaneously aware of the numerous health-related harms and social costs associated with heavy meth use. Over time, positive understandings of meth may become entirely contradictory to a lived reality in which escalating meth use is a factor in further marginalizing youth, although this may not lead to cessation of use. Recognition of these multiple truths about meth, and the social structural contexts that shape the scripting of meth use among youth in particular settings, may help us to move beyond moralizing debates about how to best educate youth on the “risks” associated with meth, and towards interventions that are congruent with youth’s lived experiences and needs across the lifecourse.

[Hidden harms: Women’s narratives of intimate partner violence in a microbicide trial, South Africa](#)

Jonathan Stadler, Sinead Delany-Moretlwe, Thesla Palanee, and Helen Rees

In a context of high rates of intimate partner violence (IPV), trials of female-controlled technologies for HIV prevention such as

microbicides may increase the possibility of social harms. Seeking to explore the relationship between IPV and microbicide use further, this paper documents women's narratives of participating in the Microbicide Development Program (MDP) trial in Johannesburg, South Africa, and experiences of partner violence and conflict. A social science sub-study, nested within the trial, was conducted between September 2005 and August 2009, and 401 serial in-depth-interviews were undertaken with 150 women. Using coded interview transcripts, we describe the distribution of IPV and the possible association thereof with microbicide gel use and trial participation. More than a third of these 150 women reported IPV, of which half the cases were related to involvement in the trial. In their narratives, those women reporting IPV cast their partners as authoritarian, controlling and suspicious and reported verbal abuse, abandonment, and in some cases, beatings. Shared experiences of everyday violence shaped women's feelings of unease about revealing their participation in the trial to intimate partners and attempted concealment further contributed to strains and conflict within relationships. Our findings point to the role of social scientific enquiry in identifying the less obvious, hidden negative impacts of participation in a clinical trial therefore exposing limitations in the biomedical construction of 'social harms', as well as the implications thereof for potential future use outside the clinical trial setting.

[The breast-cancer-ization of cancer survivorship: Implications for experiences of the disease](#)

Kirsten Bell

Numerous observers have commented on the cultural prominence of breast cancer in North America. However, although popular and biomedical conceptions of cancer survivorship have been influenced to an inordinate degree by breast cancer, few researchers have examined the impact of dominant discourses on people diagnosed with other forms of cancer. Drawing on interviews with 32 Canadian men and women with a history of cancer conducted between 2010 and 2013, I demonstrate that breast cancer became central to their own experiences of cancer, providing an important lens through which to understand the effects of the disease. The effects of these comparisons were diverse, leading some participants to want to differentiate themselves from this implicit norm, leading others to downplay the seriousness of their own forms of suffering, and amplifying a sense of shame and stigma in yet others.

[Cultures of resistance? A Bourdieusian analysis of doctors' antibiotic prescribing](#)

Alex Broom, Jennifer Broom, and Emma Kirby

The prospect of an 'antimicrobial perfect storm' in the coming decades through the emergence and proliferation of multi-resistant organisms has become an urgent public health concern. With limited drug discovery solutions foreseeable in the immediate future, and with evidence that resistance can be ameliorated by optimisation of prescribing, focus currently centres on antibiotic use. In hospitals, this is manifest in the development of stewardship programs that aim to alter doctors' prescribing behaviour. Yet, in many clinical contexts, doctors' antibiotic prescribing continues to elude best practice. In this paper, drawing on qualitative interviews with 30 Australian hospital-based doctors in mid-2013, we draw on Bourdieu's theory of practice to illustrate that 'sub-optimal' antibiotic prescribing is a logical choice within the habitus of the social world of the hospital. That is, the rules of the game within the field are heavily weighted in favour of the management of immediate clinical risks, reputation and concordance with peer practice vis-à-vis longer-term population consequences. Antimicrobial resistance is thus a principal of limited significance in the hospital. We conclude that understanding the habitus of the hospital and the logics underpinning practice is a critical step toward developing governance practices that can respond to clinically 'sub-optimal' antibiotic use.

[Social Studies of Science](#)

[Robot visions](#)

Claudia Castañeda and Lucy Suchman

This article explores the resonating figures of primate, child, and robot in contemporary technoscientific corporealizations of the 'almost human'. We take as our model (in)organism 'Lucy the Robot Orangutan', roboticist Steve Grand's project to create an artificial life form with a mind of its own. One aspect of Lucy's figuration by Grand, we argue, which ties her to Haraway's analysis of the primate, is of the robot as a model for animal, and more specifically (or aspirationally) human, cognition. We follow the trope of 'model organism' as it is under discussion within science and technology studies and as an ironic descriptor for our own interest in Lucy as an entity/project through which to illuminate figurations within robotics more widely. Primate and robot together

are forms of natureculture that help to clarify how the categories of animal and machine are entangled, while making explicit investments in their differences from one another, and from the third category of the human. We conclude, again following Haraway, by imagining what other possibilities there might be for figuring humans, robots, and their relations if we escape the reiterative imaginary of the robot as proxy for becoming human.

[Body dirt or liquid gold? How the 'safety' of donated breastmilk is constructed for use in neonatal intensive care](#)

Katherine Carroll

When mothers of preterm infants are unable to produce sufficient volumes of breastmilk, neonatologists in many Western countries prescribe pasteurized donor breastmilk. Breastmilk has a paradoxical presence in the neonatal intensive care unit: while it has therapeutic properties, it also has the potential to transmit disease. National health authorities and local neonatal intensive care unit policies each delimit the safety of donor milk by focusing on the presence or absence of pathogens. It is in this light that breastmilk from the human milk bank is both sought and legitimated to minimize safety concerns. This research uses data arising from an ethnographic study of two human milk banks and two neonatal intensive care units in the United States, and 73 interviews with milk donors, neonatal intensive care unit parents and clinicians. The primary research question framing the study was 'What are the underlying processes and practices that have enabled donor milk to be endorsed as a safe and legitimate feeding option in neonatal intensive care units?' This study is framed using three key principles of Latour's 'new critique', namely, adding to reality rather than debunking it, getting closer to data rather than turning away from fact and creating arenas in which to assemble. As a result, conceptions of donor milk's safety are expanded. This case study of donor milk demonstrates how Latour's new critique can inform science and technology studies approaches to the study of safety in health care.

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