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## In the Journals, September 2014 - Part I

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By Anna Zogas

Here's the first selection of articles published in September. Enjoy!

### [American Anthropologist](#)

#### [Resisting Commensurability: Against Informed Consent as an Anthropological Virtue](#)

*Kirsten Bell*

In this article, I examine anthropology's embrace of the informed consent doctrine at the end of the 1990s. Although acknowledging its utility in resolving the tensions between disciplinary ideals of openness in field research and the diverse array of contexts in which anthropologists now work, I argue that it has not been in our best interest to co-opt the concept. Bringing together the prior critiques of the informed consent doctrine's application to ethnography, I criticize the tendency of some ethnographers to characterize ethnographic practice as "insuperably flawed," pointing instead to the problems with the doctrine itself. I tease out underlying assumptions about the nature of research (and researchers and research subjects) that it presumes, and I conclude by suggesting the need for anthropology take a principled stance against the informed consent doctrine.

#### [The Demise of the Bumbler and the Crock: From Experience to Accountability in Medical Education and Ethnography](#)

*Janelle S. Taylor*

In this article, I consider Howard Becker's 1955 research among medical students in relation to my own late-2000s research on standardized patients, or SPs (i.e., people hired to portray patients in staged clinical encounters with medical students). Becker's mid-20th-century subjects used the term *crock* for patients who presented obstacles to their acquisition of valued kinds of clinical "experience." SP simulations, as one among many forms of simulation used to teach clinical skills today, exclude the possibility of crocks. While medical education has changed, so too has

ethnographic practice. Becker's account of his fieldwork, like many at midcentury, portrayed the ethnographer as a clueless "bumbler" who, through experience, gains understanding and expertise and is transformed into a professional anthropologist. Today, by contrast, the necessity to account in advance for the risks, rewards, and outcomes of ethnographic research has rendered stumbling inadmissible. I argue that the disappearance of the "bumbler" and the "crock" as regular figures in the discourses of anthropology and medicine points toward a reevaluation of "experience" in both fields and a shift toward new regimes of accountability, grounded in the changing political economy of knowledge production. At risk of being lost in the process are faith, surprise, and humor.

### [Social-Science Fiction: The Genesis and Legacy of Horace Miner's "Body Ritual among the Nacirema"](#)

*Mark Burde*

In this article, I present the first comprehensive examination and analysis of what remains, nearly sixty years after its initial publication, not only one of the most frequently read articles in the history of *American Anthropologist* but also one of the more widely circulated English-language pieces of 20th-century social science. Combining archival research at Horace Miner's home institution, interviews with family members and former colleagues, and examination of over 50 partial or full anthological reproductions of the piece spanning five decades, I examine the genesis and reception of the work with an eye to unpacking the reasons for its extraordinary longevity. My conclusions are, first, that the work has been read in a surprisingly atomized rather than holistic manner, resulting in a misunderstanding of Miner's likely intentions. Second, the work has accumulated diametrically opposed readings as either illustrative of or, since the late 1960s, radically skeptical of basic ethnographic method. Third, this and other paradoxes inherent in the composition and reception of the work, combined with its comic traits, qualify it as a latter-day example of the carnivalesque.

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

#### [Patient-Centered Development? Comparing Japanese and Other Gynecological Examination Tables and Practices](#)

*Kyoko Mimura, Minori Kokado, Hyunsoo Hong, Chiungfang Chang and Azumi Tsuge*

In Japan, gynecological examinations (GEs) are normally conducted on a specially designed examination table called *naishin-dai*. Recent *naishin-dai* are remarkably high-tech, equipped with mechanisms to automatically position the patient perfectly for the GE, so “all patients need to do is sit.” However, such high-tech machines are not commonly used in the West. To determine what sociocultural contexts legitimize and encourage such development, we conducted semistructured interviews with manufacturers of *naishin-dai* and gynecology practitioners in Japan, as well as gynecology practitioners in Taiwan, South Korea, Britain, France, and the United States. Comparative analysis of these data by employing the concept of genderscript revealed that multilayered and interrelated inscriptions of gendered norms and relations provided such legitimacy and encouragement. Furthermore, the genderscripts of *naishin-dai* are in fact East Asian genderscripts, which reveal how traditional East Asian stereotypes of women patients are framed in the practice of modern Western gynecology.

## **Health**

### **[Experiential knowledge of disability, impairment and illness: The reproductive decisions of families genetically at risk](#)**

*Felicity Boardman*

As the capacities of Reproductive Genetic Technologies expand, would-be parents face an increasing number of reproductive decisions regarding testing and screening for different conditions. Several studies have acknowledged the role that ‘experiential knowledge of disability’ plays in arriving at decisions around the use of these technologies; however, there is a lack of clarity within this literature as to what constitutes ‘experiential knowledge of disability’ and an over-reliance on medical diagnoses as a shorthand to describe different types of experience. Drawing on both social model of disability theory and the literature on chronic illness, this article presents an analysis of data from an in-depth qualitative interview study with 64 people with an inheritable condition in their family, Spinal Muscular Atrophy, and reports their views around reproduction and Reproductive Genetic Technologies. An experiential typology is presented which demonstrates the way in which experiences of ‘disability’, ‘embodied experiences of impairment’ or ‘embodied experiences of illness, death and bereavement’ are strategically privileged in accounts of reproductive decisions, in order to validate reproductive decisions taken, and, specifically, justify use (or

non-use) of Reproductive Genetic Technologies. By highlighting the experiential categories within which participants embedded their reproductive decisions, this article draws attention to the porous and collapsible nature of diagnostic categories in the context of reproductive decision-making and genetic risk, and suggests new ways of researching 'experiential knowledge of disability' within these contexts which are able to account for the various contours of the embodied lived reality of life with 'disability'.

## [Health & Place](#)

### [Mental health/illness and prisons as place: Frontline clinicians? perspectives of mental health work in a penal setting](#)

*Nicola Wright, Melanie Jordan, Eddie Kane*

This article takes mental health and prisons as its two foci. It explores the links between social and structural aspects of the penal setting, the provision of mental healthcare in prisons, and mental health work in this environment. This analysis utilises qualitative interview data from prison-based fieldwork undertaken in Her Majesty's Prison Service, England. Two themes are discussed: (1) the desire and practicalities of doing mental health work and (2) prison staff as mental health work allies. Concepts covered include equivalence, training, ownership, informal communication, mental health knowledge, service gatekeepers, case identification, and unmet need. Implications for practice are (1) the mental health knowledge and understanding of prison wing staff could be appraised and developed to improve mental healthcare and address unmet need. Their role as observers and gatekeepers could be considered. (2) The realities of frontline mental health work for clinicians in the penal environment should be embraced and used to produce and implement improved policy and practice guidance, which is in better accord with the actuality of the context – both socially and structurally.

## [International Journal of Social Psychiatry](#)

### [Beliefs, stigma and discrimination associated with mental health problems in Uganda: Implications for theory and practice](#)

*Neil Quinn and Lee Knifton*

Background: There are major gaps in knowledge about beliefs, stigma and discrimination in Uganda, including the relationship

between different cultural beliefs and stigmatising responses, how stigma and beliefs result in discrimination and the impact of social factors such as gender, poverty and ethnic conflict.

**Aim:** This exploratory study aims to understand beliefs, stigma and discrimination associated with mental health in Uganda in more depth from the perspectives of different stakeholders.

**Methods:** Focus groups and interviews were undertaken with mental health activists, policymakers, practitioners, non-governmental and human rights organisations, journalists and academics.

**Results:** Stigma was reported by individuals, families, communities and institutions, including health services. The study also found stigmatising beliefs linked to traditional, religious and medical explanatory frameworks, high levels of 'associated stigma', common mental health problems rarely medicalised and discrimination linked to poverty, gender and conflict.

**Conclusions:** The findings suggest the need to address stigma in their cultural and social context, alongside other human rights initiatives.

## **New Genetics and Society**

### **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.

[Social Science & Medicine](#)

[The psychiatric report as moral tool: A case study in a French district court](#)

*Fabrice Fernandez and Samuel Lézé*

Mental health evaluation within a legal setting is widely seen as a power to judge. The aim of this paper is to challenge this current thesis, which was popularised by Michel Foucault, who encapsulated the notion in a brief sentence: “The sordid business of punishing is thus converted into the fine profession of curing” (: 23). On the basis of an ethnography of a French district court (between September 2008 and May 2009, n = 60 trials) including interviews with judges (n = 10) and psychiatrists (n = 10), we study the everyday penal treatment of sexual offenders using psychiatric reports. Our findings show how (i.) the expectations of the judges select the psychiatrists’ skills (based on the following criteria for their reports: accessibility of knowledge, singularization and individualization of content) and (ii.) reframe the psychiatric report as a moral tool. The clinical reasoning of forensic psychiatrists in their reports offer moral affordances due to their clinical caution regarding the risk of recidivism (therapeutic and criminological reversal, moral prevention). Both the judges’ evaluation and the psychiatrists’ clinical authority are shaped by a moral economy of dangerousness, which eclipses the idea of lack of criminal responsibility. In conclusion, we show that these unintended effects are necessarily of interest to most clinical practitioners engaged in work as expert witnesses.

[The social life of health records: Understanding families’ experiences of autism](#)

*Amber M. Angell and Olga Solomon*

Outside of the epidemiological surveillance studies of autism prevalence, health records of children diagnosed with autism have not been sufficiently examined, yet they provide an important lens for showing how autism diagnosis, services and interventions are negotiated, coordinated and choreographed by families and practitioners across multiple settings. This article provides a multifaceted understanding of these processes from an ethnographic and discourse analytic perspective that reveals structural and interactional phenomena contributing to disparities in autism diagnosis and services. We consider health records as dualistic, material-discursive artifacts that are socio-interactionally co-constructed and variably interpreted, contested and utilized across home, school and clinic contexts. We chronicle several families’ experiences of their children’s autism diagnoses and interventions and describe ways in which health records are

socially constructed, curated and placed in the middle of clinical encounters. We show how the parents in our study draw upon health records' material-discursive properties to display epistemic authority, expertise and knowledge in interactions with healthcare and school professionals involved in authorizing and planning their children's care. We describe how the parents experience the health records' clinical portrayals of their children and themselves, and how the parents' portrayals of their children are tacitly ratified or negated in the health records. The data include health record reviews, narrative interviews with parents and practitioners, and clinical observations. These data were collected between October 2009 and August 2012 as part of a larger study on disparities in autism diagnosis, interventions and services experienced by African American children with autism and their families living in Los Angeles County, California. Our analysis reveals the central role of health records in maintaining continuity of an autism diagnosis, interventions and services. This article contributes to enhanced professional awareness, parent-professional partnerships, and equity in the provision of healthcare and human services related to autism.

[Social recovery and the move beyond deficit models of depression: A feminist analysis of mid-life women's self-care practices](#)

*Simone Fullagar and Wendy O'Brien*

In Australia, like other advanced liberal democracies, the adoption of a recovery orientation was hailed as a major leap forward in mental health policy and service provision. We argue that this shift in thinking about the meaning of recovery requires further analysis of the gendered dimension of self-identity and relationships with the social world. In this article we focus on how mid-life women constructed meaning about recovery through their everyday practices of self-care within the gendered context of depression. Findings from our qualitative research with 31 mid-life women identified how the recovery process was complicated by relapses into depression, with many women critically questioning the limitations of biomedical treatment options for a more relational understanding of recovery. Participant stories revealed important tacit knowledge about recovery that emphasised the process of realising and recognising capacities and self-knowledge. We identify two central themes through which women's tacit knowledge of this changing relation to self in recovery is made explicit: the disciplined self of normalised recovery, redefining recovery and depression. The findings point to the need to reconsider how both recovery discourses and gendered



expectations can complicate women's experiences of moving through depression. We argue for a different conceptualisation of recovery as a social practice through which women realise opportunities to embody different 'beings and doings'. A gendered understanding of what women themselves identify is important to their well-being, can contribute to more effective recovery oriented policies based on capability rather than deficit.

## **Sociology of Health & Illness**

### **[Do those over 80 years of age seek more or less medical help? A qualitative study of health and illness beliefs and behaviour of the oldest old](#)**

*Tania Elias and Karen Lowton*

Increasing longevity and prevalence of long-term conditions contribute to older adults being the greatest users of health services. However, relatively little is known about the health and illness beliefs of the oldest old or how they decide to seek help in response to symptoms. Through analysis of in-depth interviews with day centre attendees aged 80–93, we find that a moral, hierarchical approach to health problems and help-seeking exists; similar to Cornwell's (1984) findings among 50–60 year-olds of a similar social group 30 years ago. However, when acting independently, those in their eighties and nineties report modifying their health and illness beliefs and behaviour, in response to their own perceived old age. Some health problems are 'demedicalised', being increasingly attributed to age and by being self-managed. Others are perceived as potentially more serious, leading to increased consultation with medical services. When obliged to act outside their moral belief–behaviour framework by others, the participants expressed feelings of disempowerment, yet resisted modifying their moral beliefs. This may represent resistance to adopt the 'sick role', while seeking to maintain control over uncertain health as functional dependence and frailty increases. This study furthers theoretical understanding of the health and illness beliefs and behaviour of the oldest old, with important practical implications.

### **[Whistle-blowing and workplace culture in older peoples' care: qualitative insights from the healthcare and social care workforce](#)**

*Aled Jones and Daniel Kelly*

Inquiries in the UK into mistreatment of older people by healthcare

employees over the last 30 years have focused on introducing or supporting employee whistle-blowing. Although whistle-blowers have made an important contribution to patient safety it remains a controversial activity. The fate of whistle-blowers is bleak, often resulting in personal and professional sacrifices. Here we draw on the views of healthcare and social care employees working with older people to explore perceptions of whistle-blowing as well as alternative strategies that may be used to raise concerns about the mistreatment of patients by co-workers. Whistle-blowing was perceived as a negative term. Managers said they promoted open cultures underpinned by regular team meetings and an open-door ethos. Others described workplace norms that were somewhat at odds with these open culture ideals. Whistle-blowing was considered risky, and this led to staff creating informal channels through which to raise concerns. Those who witnessed wrongdoing were aware that support was available from external agencies but preferred local solutions and drew upon personal ethics rather than regulatory edicts to shape their responses. We argue that the importance of workplace relationships and informal channels for raising concerns should be better understood to help prevent the mistreatment of vulnerable groups.

### [Subjectivity](#)

### [Depression, performativity and the conflicted body: An auto-ethnography of self-medication](#)

*Elena Trivelli*

In this article, I discuss intimate practices of self-medication in relation to political preoccupations with the ethics of the pharmaceutical economy, and discursive constructions of illness. Partly self-ethnographic, the article draws from my personal experience of clinical depression, and the discomforts in thinking of myself as a 'depressed' subject who consumes medications. Intervening in debates on new materialism and affect studies, I offer an account of dynamics where the material and the discursive, the human and the non-human, the personal and the political converge. I suggest that the experience and performative effects of self-medication lie not only in the activation of chemical compounds, but in the conscious bodily animation of cognitive and affective relations with medications. In this analysis, I employ creative forms of writing, to find a language of distress that blurs the boundary between the material and the discursive.

Finally, in case you missed it, we've [already highlighted](#) a special issue of **BioSocieties** titled [New Modes of Understanding and Acting on Human Difference in Autism Research, Advocacy, and Care](#). The guest editors of the issue are *Gil Eyal, Des Fitzgerald, Eva Gillis-Buck, Brendan Hart, Martine D. Lappé, Daniel Navon* and *Sarah S. Richardson*.

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