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## In the Journals, April 2015 -- Part II

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By Aaron Seaman

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

#### [Felt stigma and obesity: Introducing the generalized other](#)

*Eva Barlösius and Axel Philipps*

People with a big body are tainted in western societies. Although most research on obesity occurs in the medical context, few studies investigate characteristics and effects of feelings and fears related to the fat stigma in the absence of overt discrimination. By linking Norbert Elias's and George H. Mead's theoretical frameworks, this paper offers a different approach to understanding and investigating felt stigma. The study is based on secondary data (25 semistructured interviews with children and adolescents). It explores internalized societal perspectives on overweight and obesity and inquires into the way in which interviewees handle the blame frame of personal responsibility during their interview. The preliminary findings suggest that specific forms of managing one's self-presentation in interviews indicate felt stigma. Consequently, the paper argues for an analytical approach that extends the focus on the content of interviews to include its dynamics.

#### [How family members manage risk around functional decline: The autonomy management process in households facing dementia](#)

*Brandon Berry, Ester Carolina Apesoa-Varano, and Yarin Gomez*

Most dementia research investigates the social context of declining ability through studies of decision-making around medical treatment and end-of-life care. This study seeks to fill an important gap in research about how family members manage the risks of functional decline at home. Drawing on three waves of in-depth interviewing in 2012–2014, it investigates how family members in US households manage decline in an affected individual's natural range of daily activities over time. The findings show that early on in the study period affected individuals were perceived to have awareness of their decline and routinely drew on family members

for support. Support transformed when family members detected that the individual's deficit awareness had diminished, creating a corresponding increase in risk of self-harm around everyday activities. With a loss of confidence in the individual's ability to regulate his or her own activities to avoid these risks, family members employed unilateral practices to manage the individual's autonomy around his or her activity involvements. These practices typically involved various deceits and ruses to discourage elders from engaging in activities perceived as potentially dangerous. The study concludes by discussing the implications that the social context of interpretive work around awareness and risk plays an important role in how families perceive an elder's functional ability and manage his or her activity involvements.

[Flexible positions, managed hopes: The promissory bioeconomy of a whole genome sequencing cancer study](#)

*Rachel Haase, Marsha Michie, and Debra Skinner*

Genomic research has rapidly expanded its scope and ambition over the past decade, promoted by both public and private sectors as having the potential to revolutionize clinical medicine. This promissory bioeconomy of genomic research and technology is generated by, and in turn generates, the hopes and expectations shared by investors, researchers and clinicians, patients, and the general public alike. Examinations of such bioeconomies have often focused on the public discourse, media representations, and capital investments that fuel these "regimes of hope," but also crucial are the more intimate contexts of small-scale medical research, and the private hopes, dreams, and disappointments of those involved. Here we examine one local site of production in a university-based clinical research project that sought to identify novel cancer predisposition genes through whole genome sequencing in individuals at high risk for cancer. In-depth interviews with 24 adults who donated samples to the study revealed an ability to shift flexibly between positioning themselves as research participants on the one hand, and as patients or as family members of patients, on the other. Similarly, interviews with members of the research team highlighted the dual nature of their positions as researchers and as clinicians. For both parties, this dual positioning shaped their investment in the project and valuing of its possible outcomes. In their narratives, all parties shifted between these different relational positions as they managed hopes and expectations for the research project. We suggest that this flexibility facilitated study implementation and participation in the face of potential and probable disappointment on one or more

fronts, and acted as a key element in the resilience of this local promissory bioeconomy. We conclude that these multiple dimensions of relationality and positionality are inherent and essential in the creation of any complex economy, “bio” or otherwise.

[The role of boundary maintenance and blurring in a UK collaborative research project: How researchers and health service managers made sense of new ways of working](#)

*Simon Smith and Vicky Ward*

The paper investigates whether, how and in what circumstances boundary blurring or boundary maintenance is productive or destructive of sense in collaborative research based on a case study involving researchers from two universities and two principal organisational stakeholders in a local healthcare system in England between 2009 and 2012. Adopting a narrative method, using meeting observation, document analysis and interviews, we describe two key sets of activities in the evolution of collaboration, which allows us to tackle the question at two levels. Studying the production of documents and their use as boundary objects in project management meetings, we show how these were used to enable cooperation by establishing a truce between worldviews, giving participants a better feel for the game and a clearer perception of its stakes. Studying how the partnership expanded to take in other organisations besides the two formal partners, we show how the project accommodated pre-existing organisational interests but thereby sacrificed its experimental ethos. In showing how actors needed to subvert their experimental script to enact collaborative partnership, we argue for understanding and evaluating the latter as the co-produced outcome of disputes and co-orientations towards a practical ideal, not as an organisational format for knowledge co-production.

[Civil Society Organizations and medicines policy change: A case study of registration, procurement, distribution and use of misoprostol in Uganda](#)

*Esther CathyIn Atukunda, Petra Brhlikova, Amon Ganafa Agaba, and Allyson M. Pollock*

Misoprostol use for postpartum haemorrhage (PPH) has been promoted by Civil Society Organizations (CSOs) since the early 2000s. Yet, CSOs' role in improving access to misoprostol and shaping health policy at global and national levels is not well understood. We document the introduction of misoprostol in

Uganda in 2008 from its registration, addition to treatment guidelines and national Essential Medicines List (EML), to its distribution and use. We then analyse the contribution of CSOs to this health policy change and service provision. Policy documents, procurement data and 82 key informant interviews with government officials, healthcare providers, and CSOs in four Ugandan districts of Kampala, Mbarara, Apac, Bundibugyo were collected between 2010 and 2013.

Five key CSOs promoted and accelerated the rollout of misoprostol in Uganda. They supported the registration of misoprostol with the National Drug Authority, the development of clinical guidelines, and the piloting and training of health care providers. CSOs and National Medical Stores were procuring and distributing misoprostol country-wide to health centres two years before it was added to the clinical guidelines and EML of Uganda and in the absence of good evidence. The evidence suggests an increasing trend of misoprostol procurement and availability over the medicine of choice, oxytocin. This shift in national priorities has serious ramifications for maternal health care that need urgent evaluation. The absence of clinical guidelines in health centres and the lack of training preclude rational use of misoprostol. CSOs shifted their focus from the public to the private sector, where some of them continue to promote its use for off-label indications including induction of labour and abortion. There is an urgent need to build capacity to improve the robustness of the national and local institutions in assessing the safety and effectiveness of all medicines and their indications in Uganda.

In addition, there was a special issue section in the second April issue, entitled "[Pharmaceuticalization: Problems and Prospects](#)." It was edited by Jonathan Gabe, Simon Williams, Paul Martin and Catherine Coveney, who write in the opening of their introduction:

This special issue stems from a symposium organised by the authors at the University of Warwick, UK, in December 2011. The event brought together a range of researchers in medical sociology, Science and Technology Studies (STS) and cognate fields in order to take stock and critically examine, from a variety of different perspectives, the role of pharmaceuticals in society. More specifically, the aim was to consider the empirical and theoretical questions arising from recent trends in the development, regulation, marketing and use of pharmaceutical products.

## [Social Studies of Science](#)

### [‘For men arousal is orientation’: Bodily truthing, technosexual scripts, and the materialization of sexualities through the phallometric test](#)

*Tom Waidzunus and Steven Epstein*

We trace the history of the phallometric test – which measures erections of men exposed to visual erotic stimuli to characterize sexualities – in order to account for its functioning as a ‘truthing technology’. On the basis of a content analysis of 410 key scientific journal article abstracts, we argue that since its invention in Czechoslovakia in the 1950s, phallometry has been employed within three distinct assemblages: as a test of predominance of sexual desire, as a test for therapeutic efficacy, and as a threshold test of sexual risk. Drawing on works of theorists of materialization and proponents of script theory, we argue that within each assemblage phallometric testing materializes male desire and renders it measurable via a ‘technosexual script’. We consider the performative effects of phallometry in establishing scientific conceptions of normal and abnormal sexualities. At the same time, through attention to debates among practitioners and broader controversies surrounding the employment of phallometry, we examine the limits of researchers’ abilities to establish the broader credibility of the test and capture the phenomenon of sexual desire. This analysis contributes to the study of truthing technologies (or ‘truth machines’) as a class, while also helping to build bridges between science and technology studies and sexuality studies.

### [Organizing for ontological change: The kernel of an AIDS research infrastructure](#) *(open access)*

*David Ribes and Jessica Beth Polk*

Is it possible to prepare and plan for emergent and changing objects of research? Members of the Multicenter AIDS Cohort Study have been investigating AIDS for over 30 years, and in that time, the disease has been repeatedly transformed. Over the years and across many changes, members have continued to study HIV disease while in the process regenerating an adaptable research organization. The key to sustaining this technoscientific flexibility has been what we call the kernel of a research infrastructure: ongoing efforts to maintain the availability of resources and services that may be brought to bear in the investigation of new objects. In the case of the Multicenter AIDS Cohort Study, these resources are as follows: specimens and data, calibrated

instruments, heterogeneous experts, and participating cohorts of gay and bisexual men. We track three ontological transformations, examining how members prepared for and responded to changes: the discovery of a novel retroviral agent (HIV), the ability to test for that agent, and the transition of the disease from fatal to chronic through pharmaceutical intervention. Respectively, we call the work, 'technologies', and techniques of adapting to these changes, 'repurposing', 'elaborating', and 'extending the kernel'.

## **Sociology of Health & Illness**

### **'I've used the word cancer but it's actually good news': discursive performativity of cancer and the identity of urological cancer services**

*Karolina Agata Kazimierczak and Zoe Skea*

Drawing on the ethnographic study of urological cancer services, this article explores how a set of particular discourses embedded in the everyday clinical work in a large teaching hospital in the UK helps materialise particular configurations of cancer and related professional identities. Emerging on the intersection of specific socio-material arrangements (cancer survival rates, treatment regimens, cancer staging classifications, metaphors, clinical specialities) and operating across a number of differential relations (curable/incurable, treatable/untreatable, aggressive/nonaggressive), these configurations help constitute the categories of 'good' and 'bad' cancers as separate and contrasting entities. These categories help materialise particular distributions of power and are thus implicated in the making of specific claims about the identity of urological cancer services as unique and privileged. Exploring these issues in view of feminist and material-semiotic approaches to studying science, technology and medicine, this article seeks to move away from the understanding of cancer discourses as primarily linguistic performances, proposing to see them instead as arrangements of practices and relations simultaneously material and semiotic through which particular categories, entities and phenomena acquire their determinate nature. In doing so, it seeks to contribute to sociology's broader concern with discursive performativity of cancer.

### **Inside 'bed management': ethnographic insights from the vantage point of UK hospital nurses**

*Davina Allen*

In the face of unprecedented financial and demographic challenges, optimising acute bed utilisation by the proactive management of patient flows is a pressing policy concern in high-income countries. Despite the growing literature on this topic, bed management has received scant sociological attention. Drawing on practice-based approaches, this article deploys ethnographic data to examine bed management from the perspective of UK hospital nurses. While the nursing contribution to bed management is recognised formally in their widespread employment in patient access and discharge liaison roles, nurses at all levels in the study site were enrolled in this organisational priority. Rather than the rational, centrally controlled processes promulgated by policymakers, bed management emerges as a predominantly distributed activity, described here as match-making. An example of micro-level rationing, for the most part, match-making was not informed by explicit criteria nor did it hinge on clearly identifiable decisions to grant or deny access. Rather it was embedded in the everyday practices and situated rationalities through which nurses accomplished the accommodations necessary to balance demand with resources.

[The politics of healthcare informatics: knowledge management using an electronic medical record system](#)

*Shirly Bar-Lev*

The design and implementation of an electronic medical record system pose significant epistemological and practical complexities. Despite optimistic assessments of their potential contribution to the quality of care, their implementation has been problematic, and their actual employment in various clinical settings remains controversial. Little is known about how their use actually mediates knowing. Employing a variety of qualitative research methods, this article attempts an answer by illustrating how omitting, editing and excessive reporting were employed as part of nurses' and physicians' political efforts to shape knowledge production and knowledge sharing in a technologically mediated healthcare setting.

[Social class, anxieties and mothers' foodwork](#)

*Jan Wright, JaneMaree Maher and Claire Tanner*

In the context of concerns about childhood obesity, mothers are placed at the forefront of responsibility for shaping the eating behaviour and consequently the health of their young children.

This is evident in a multitude of diverse sites such as government reports, health promotion materials, reality TV shows and the advice of childcare nurses and preschools. These sites produce a range of resources available to mothers to draw on to constitute themselves as mothers in terms of caring for their children's health. Drawing on a qualitative study of mothers recruited through three Australian preschool centres, this article examines how the working-class and middle-class mothers of preschool-aged children engage with knowledge about motherhood, children and health and how those engagements impact on their mothering, their foodwork and their children. We argue that, unlike the working-class mothers pathologised in some literature on obesity, these working-class mothers demonstrated a no-nonsense (but still responsabilised) approach to feeding their children. The middle-class mothers, on the other hand, were more likely to engage in practices of self-surveillance and to demonstrate considerable anxieties about the appropriateness of their practices for their children's current and future health.

Finally, the most recent issue of **Transcultural Psychiatry** is a special issue, entitled "[Evidence-Based Practice and Cultural Competence.](#)" Abstracts are below.

[Reconciling evidence-based practice and cultural competence in mental health services: Introduction to a special issue](#)

*Joseph P. Gone*

The calls for evidence-based practice (EBP) and cultural competence (CC) represent two increasingly influential mandates within the mental health professions. Advocates of EBP seek to standardize clinical practice by ensuring that only treatment techniques that have demonstrated therapeutic outcomes under scientifically controlled conditions would be adopted and promoted in mental health services. Advocates of CC seek to diversify clinical practice by ensuring that treatment approaches are designed and refined for a multicultural clientele that reflects a wide variety of psychological orientations and life experiences. As these two powerful mandates collide, the fundamental challenge becomes how to accommodate substantive cultural divergences in psychosocial experience using narrowly prescriptive clinical practices and approaches, without trivializing either professional knowledge or cultural difference. In this Introduction to a special issue of *Transcultural Psychiatry*, the virtue of an interdisciplinary conversation between and among anthropologists, psychologists, psychiatrists, and social work researchers in addressing these



tensions is extolled.

[Practitioner characteristics and organizational contexts as essential elements in the evidence-based practice versus cultural competence debate](#)

*Vivian Hopkins Jackson*

The different pathways chosen to efficiently and effectively provide relief to those struggling with mental health challenges reflect different assumptions about the human condition and have led to disagreements over which intervention strategies are best suited to particular individuals or populations. Evidence-based practice and culturally competent services, as discussed within the United States, have been characterized as opposites. However, neither approach captures all of the elements that embody the full treatment experience. This article offers a framework that includes the personal identity of the practitioner and the organizational context as two elements that serve as active agents in the helping relationship, although they have rarely been included in the discourse about evidence-based practice or cultural competence. Suggestions for practice, education, and research are included based on this analysis.

[An examination of the evidence in culturally adapted evidence-based or empirically supported interventions](#)

*Janet E. Helms*

Measurement yields perhaps the most critical evidence influencing whether culturally adapted evidence-based practice (EBP) and empirically supported treatments (EST) are deemed more effective for African Americans, Latino/a Americans, Asian/Pacific Islander Americans, Native Americans, and related immigrant groups than standard treatments, as well as for determining the validity of results of surveys of health conditions in nondominant populations internationally. However, little attention has been given to measuring the effects of race and ethnic culture, as experiential constructs rather than sociodemographic categories, on diagnosis, the treatment process, and outcomes. Three meta-analyses of culturally adapted treatments and three studies cited in them were analyzed to determine the ways in which researchers incorporated measurement of racial and ethnic cultural dynamics as explicit factors in any phase of their interventions. The analysis revealed that researchers did not report adapting standard measures to address cultural influences, nor did they define symptoms from

participants' cultural or racial experiences. The author concludes that although there are criteria for judging good research designs, which may or not be feasible for research on nondominant racial and ethnic groups, there are no paradigms for developing measures or for interpreting existing measures to incorporate ethnicity and racialized experiences. Some principles from cross-cultural assessment research (i.e., functional, conceptual, metric, and linguistic equivalence) are adapted to suggest how measures for investigating the effectiveness of culturally adapted interventions for nondominant ethnic and racialized groups might be developed and/or used more appropriately throughout the course of the intervention.

["Shattering culture": perspectives on cultural competence and evidence-based practice in mental health services](#)

*Mary-Jo DelVecchio Good and Seth Donal Hannah*

The concept of culture as an analytic concept has increasingly been questioned by social scientists, just as health care institutions and clinicians have increasingly routinized concepts and uses of culture as means for improving the quality of care for racial and ethnic minorities. This paper examines this tension, asking whether it is possible to use cultural categories to develop evidenced-based practice guidelines in mental health services when these categories are challenged by the increasing hyperdiversity of patient populations and newer theories of culture that question direct connection between group-based social identities and cultural characteristics. Anthropologists have grown concerned about essentializing societies, yet unequal treatment on the basis of cultural, racial, or ethnic group membership is present in medicine and mental health care today. We argue that discussions of culture—patients' culture and the "culture of medicine"—should be sensitive to the risk of improper stereotypes, but should also be sensitive to the continuing significance of group-based discrimination and the myriad ways culture shapes clinical presentation, doctor–patient interactions, the illness experience, and the communication of symptoms. We recommend that mental health professionals consider the local contexts, with greater appreciation for the diversity of lived experience found among individual patients. This suggests a nuanced reliance on broad cultural categories of racial, ethnic, and national identities in evidence-based practice guidelines.

[Practice to research: Integrating evidence-based practices with culture and](#)

[context](#)

*Thomas S. Weisner and M. Cameron Hay*

There are ways to integrate culturally competent services (CCS) and evidence-based practices (EBP) which can improve the experiences of patients and their families and communities when faced with health problems, as well as the effectiveness and positive experiences of practitioners. CCS and EBP evidence should be jointly deployed for helping patients and clinicians. Partnership research models are useful for achieving the integration of CCS and EBP, since they involve close observation of and participation by clinicians and practitioners in the research process, and often use integrated qualitative and quantitative mixed methods. We illustrate this with 3 examples of work that can help integrate CCS and EBP: ongoing collection of information from patients, clinicians and staff, or “evidence farming”; close study and continuous improvement of activities and accommodations; and use of evidence of tacit, implicit cultural scripts and norms, such as being “productive,” as well as explicit scripts. From a research practice point of view, collaborative partnerships will likely produce research with culture and context bracketed in, and will contribute stronger research models, methods, and units of analysis.

[Toward a cultural adaptation of pharmacotherapy: Latino views of depression and antidepressant therapy](#)

*Sylvanna M. Vargas, Leopoldo J. Cabassa, Andel Nicasio, Ana Alicia De La Cruz, Elizabeth Jackson, Melissa Rosario, Peter J. Guarnaccia, and Roberto Lewis-Fernández*

Relative to non-Latino Whites, Latinos in the United States with major depressive disorder (MDD) show low engagement in antidepressant therapy, whether engagement is defined as pharmacotherapy access, medication initiation, pill-taking, or treatment retention. One potential reason for this disparity in depression care is the low cultural congruence of pharmacotherapy for this population. To examine Latinos' views of depression and antidepressant therapy, we conducted qualitative interviews with 30 Latino outpatients initiating antidepressants prior to their first treatment visit using the semistructured Treatment Adherence and Retention Questionnaire. These baseline interviews were randomly selected from data collected for a randomized controlled trial testing a novel intervention to enhance engagement by depressed Latino outpatients. Participant narratives were analyzed using open coding and the iterative

analytical approach derived from grounded theory. Patient views about depression addressed stigmatizing views held by others in their social circle. Most participants directly refuted these views by providing alternate explanations to depression experiences. Antidepressant therapy narratives also revealed marked stigmatization, but participants tended not to refute these views. Instead, patients expressed concerns about antidepressants and showed marked ambivalence about seeking psychiatric care. Participants, however, did suggest ways in which clinicians and patients might collaborate to address their concerns about antidepressants. Some cultural views, such as concerns about addiction to or dependence on medication, may be negotiable barriers to treatment. Prescribing clinicians should address cultural views and concerns in order to improve Latino engagement in antidepressant therapy.

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