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## In The Journals, August 2019

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By Gabrielle Hanley-Mott

A short round up this month. This month's collection will be most valuable for those interested in topics such as: childbirth, immigration and health, disability and Disability Studies, and Public Health.

### **Health, Risk, and Society**

[Caesarean or vaginarean epidemics ? Techno-birth, risk and obstetric practice in Turkey](#) (*Open Access*)

*Sezin Topçu*

Caesarean sections (C-sections) have become a substitute for vaginal birth in a number of developing and emerging economies. Often in these contexts, the promotion of caesarean delivery as a safe or even zero-risk and zero-pain alternative to vaginal birth continues to serve as a powerful discursive tool in governing childbirth, despite growing international evidence on the iatrogenic effects of C-sections. These caesarean 'epidemics' are often explained in terms of obstetricians' individual preferences for C-sections. Drawing on ethnographic research conducted in one private and one public hospital in western Turkey, I argue that there are a wide range of factors influencing obstetricians' risk conceptualisations, discourses and practices. I also contend that the medical justifications for C-sections and their public popularity can best be understood by looking at the ways in which both caesarean and vaginal births are organised. In the settings examined, the processes around caesarean and vaginal births were blurred to such an extent that vaginal delivery was, in its technicised and closely monitored nature, transformed into what I propose to call 'vaginarean' birth. Recent state regulations in Turkey aiming to prevent 'caesarean abuse' had only had limited effects on obstetricians' practices. The notion of risk continued to operate as a major driving force in that an institutional risk colonisation came to compete with medical framings of risk, while deficiencies in the national obstetric care system were made invisible. I conclude that regulations aimed at eradicating a caesarean epidemic, such as those implemented in Turkey since 2012, are unlikely to be effective unless they also aim to combat

the vaginarean epidemic.

[Conceiving of risk in childbirth: obstetric discourses, medical management and cultural expectations in Switzerland and Jordan](#)

*Irene Maffi & Solène Gouilhers*

In highly industrialised societies, risk shapes representations and practices surrounding childbirth. However, few studies examine the impact of the transnational diffusion of risk in medium and low income societies, where, despite the adoption of biomedical protocols on an institutional level, women and birth attendants often seem to follow different rationales in their practices. In this article, we are interested in the various components of the notion of risk, which shall be understood and examined in relation to specific socio-economic, political and cultural configurations. Drawing on two ethnographic studies conducted, respectively, in a Swiss university hospital and in three Jordanian government hospitals, we investigate how surveillance and medical interventions are deployed in pregnancy and childbirth in unequally structured health systems and describe negotiations and appropriations surrounding this management. These two contrasting cultural, socio-economic and health 'system' contexts reveal important differences in the way birth attendants and women consider the notion of risk in childbirth in that it is seldom present in clinicians' and women's discourses and practices in Jordan, whereas it plays a pertinent role in Switzerland. We argue that the heterogeneous configurations of risk mobilised by the participants in these studies reveal that dissimilar histories in terms of medical institutions and health care service provisions, political regimes, economic conditions, and social configurations shape the cultural and techno-medical arrangements of the institutions we studied. Comparing our Jordanian and Swiss ethnographies, we show that the mobilisation of biomedical risk does not happen in a vacuum but rather intertwines with specific social arrangements, eliciting resistance and adaptation that fashion the discourses and behaviours of birth attendants and pregnant women.

[Social Studies of Science](#)

[Impossible, unknowable, accountable: Dramas and dilemmas of data law](#)

*Alison Cool*

On May 25, 2018, the European Union's General Data Protection Regulation (GDPR) came into force. EU citizens are granted more

control over personal data while companies and organizations are charged with increased responsibility enshrined in broad principles like transparency and accountability. Given the scope of the regulation, which aims to harmonize data practices across 28 member states with different concerns about data collection, the GDPR has significant consequences for individuals in the EU and globally. While the GDPR is primarily intended to regulate tech companies, it also has important implications for data use in scientific research. Drawing on ethnographic fieldwork with researchers, lawyers and legal scholars in Sweden, I argue that the GDPR's flexible accountability principle effectively encourages researchers to reflect on their ethical responsibility but can also become a source of anxiety and produce unexpected results. Many researchers I spoke with expressed profound uncertainty about 'impossible' legal requirements for research data use. Despite the availability of legal texts and interpretations, I suggest we should take researchers' concerns about 'unknowable' data law seriously. Many researchers' sense of legal ambiguity led them to rethink their data practices and themselves as ethical subjects through an orientation to what they imagined as the 'real people behind the data', variously formulated as a Swedish population desiring data use for social benefit or a transnational public eager for research results. The intentions attributed to people, populations and publics – whom researchers only encountered in the abstract form of data – lent ethical weight to various and sometimes conflicting decisions about data security and sharing. Ultimately, researchers' anxieties about their inability to discern the desires of the 'real people' lent new appeal to solutions, however flawed, that promised to alleviate the ethical burden of personal data.

[Data as promise: Reconfiguring Danish public health through personalized medicine](#) *Klaus Hoeyer*

'Personalized medicine' might sound like the very antithesis of population science and public health, with the individual taking the place of the population. However, in practice, personalized medicine generates heavy investments in the population sciences – particularly in data-sourcing initiatives. Intensified data sourcing implies new roles and responsibilities for patients and health professionals, who become responsible not only for data contributions, but also for responding to new uses of data in personalized prevention, drawing upon detailed mapping of risk distribution in the population. Although this population-based 'personalization' of prevention and treatment is said to be about

making the health services 'data-driven', the policies and plans themselves use existing data and evidence in a very selective manner. It is as if data-driven decision-making is a promise for an unspecified future, not a demand on its planning in the present. I therefore suggest interrogating how 'promissory data' interact with ideas about accountability in public health policies, and also with the data initiatives that the promises bring about. Intensified data collection might not just be interesting for what it allows authorities to do and know, but also for how its promises of future evidence can be used to postpone action and sidestep uncomfortable knowledge in the present.

[Accounting for accountable care: Value-based population health management](#) *Linda F Hogle*

Accountable Care Organizations (ACOs) are exemplars of so-called value-based care in the US. In this model, healthcare providers bear the financial risk of their patients' health outcomes: ACOs are rewarded for meeting specific quality and cost-efficiency benchmarks, or penalized if improvements are not demonstrated. While the aim is to make providers more accountable to payers and patients, this is a sea-change in payment and delivery systems, requiring new infrastructures and practices. To manage risk, ACOs employ data-intensive sourcing and big data analytics to identify individuals within their populations and sort them using novel categories, which are then utilized to tailor interventions. The article uses an STS lens to analyze the assemblage involved in the enactment of population health management through practices of data collection, the creation of new metrics and tools for analysis, and novel ways of sorting individuals within populations. The processes and practices of implementing accountability technologies thus produce particular kinds of knowledge and reshape concepts of accountability and care. In the process, account-giving becomes as much a procedural ritual of verification as an accounting for health outcomes.

[Social Science and Medicine](#)

[First do No harm: Medical legal violence and immigrant health in Coral County, USA](#)

*Meredith Van Natta*

Contemporary U.S. health and immigration policies exclude millions of noncitizens from healthcare coverage. Growing scholarship emphasizes legal status as a technology of social exclusion and determinant of health, but few studies capture the effects of recent policy uncertainty on noncitizen health. By examining the case of Coral County (a pseudonym), I highlight the challenges facing safety-net clinics and their noncitizen patients making life and death decisions amidst uncertainty before and after the 2016 presidential election. Observational and interview data with patients, clinic workers, and community partners (n = 27) revealed that growing anxiety over federal immigration policies altered clinical risk calculations through a process I refer to as “medical legal violence” (MLV). Whereas previous risk negotiation strategies leveraged bureaucratic routines to elevate imminent threats of illness and/or injury in health decisions, heightened immigration enforcement under the Trump administration shifted the balance in clinical risk calculations toward social risks of detention, deportation, and family separation. This transformed clinical care in Coral County by turning trusted medical-legal bureaucracies into potential tools for federal biopolitical surveillance of immigrant patients, blocking healthcare pathways and increasing patients’ fear and anxiety.

## **Social Theory and Health**

### **[The thing-power of the human-app health assemblage: thinking with vital materialism](#)**

*Deborah Lupton*

Hundreds of thousands of apps are now available that have been designed to monitor, manage or improve users’ health. In this article, I draw on feminist new materialist perspectives, and particularly the vital materialism offered by Jane Bennett, to consider the affordances, relational connections, affective forces and agential capacities that contribute to the thing-power of the human-app health assemblage. The discussion is underpinned by the assumption that digital technologies such as health apps are part of a more-than-human world, in which they generate forces and capacities only with and through their associations and relations with the humans who create and use them—or in some cases, relinquish or resist their use. To demonstrate how this approach can be applied to the analysis of empirical material, I discuss the findings of several of my recent projects involving people talking about their use of health apps. Drawing on these materials, I show that the vibrancy of the thing-power of the

human-app assemblage is a complex admixture of affective forces, personal biographies and life trajectories, human and nonhuman affordances and cultural imaginaries. All of these elements contribute to a greater or lesser degree to the agential capacities generated by this assemblage.

[Mental health, subjectivities and forms of neuroscience: a critical realist examination](#)

*David Pilgrim*

The examination of personal experience in human science has been highly variegated. At one end of a spectrum, strong subjectivists prioritise and privilege personal experience as an authentic marker of being human and as a window into our embedding social contexts. At the other end are neuro-reductionists, who explain (or even explain away) personal experience as merely an epiphenomenon of brain activity. With a focus on mental health and psychiatry, critical realism is used to explore this spectrum and it endorses a view that the brain affords our capacity to think, feel and act as human agents in contingent contexts but cannot ultimately explain any of these.

[Navigating the uncertainties of screening: the contribution of social theory](#)

*Natalie Armstrong*

Screening programmes are social interventions as much as they are medical, and as such they benefit from scrutiny informed by social theory. Screening gives rise to a range of uncertainties and the debates and controversies that result are rarely confined to policy makers and health professionals. Contestations about the science underlying screening are common, and frequently enter the public sphere, engaging with wider societal themes and normative questions. The uncertainties of screening and the need to balance potential benefits against possible harms are often underestimated and underrepresented within these. In this paper, I consider the contribution of social theory to navigating the uncertainties of screening. In doing so, I focus in particular on two relatively recent developments: first, the marked shift, at least in policy terms, towards screening based on an individual's informed consent, having weighed up the possible harms and benefits; and second, the emerging focus on overdiagnosis and overtreatment. I highlight some important ways in which social theory can add value by helping us gain analytical purchase on these issues.

## [South Atlantic Quarterly](#)

### [Introduction: Disorienting Disability](#) (Open Access)

*Michele Friedner; Karen Weingarten*

### [A Theory of Microactivist Affordances: Disability, Disorientations, and Improvisations](#)

*Arseli Dokumac?*

This article proposes a new theory of affordances that is developed through a critical disability and performance lens. Through parallels to be drawn between the creative space of aesthetic performance and the performance of everyday life lived with disability, this new theory situates affordances in the improvisatory space of performance, and introduces the notion of “micro-activist affordances” as a way to understand mundane acts of world-building that could emerge from encounters with a world of “disorienting affordances.” Experiencing disability is inherently disorienting. The environment, as years of disability activism have shown us, is built with a very limited conception of the human being in mind. But the environment can also be disorienting when experiencing bodily pain and chronic disease. I argue that disability, in all of its various manifestations, is experienced as the shrinking of the environment, and its readily available affordances. But, as I shall also argue, precisely at such moments of shrinking, something else happens. When the environment is narrowed down in its offerings, I propose that it is the creative space of performance (on or offstage) that opens up to make it afford otherwise. This very potential to invent affordances is precisely how I conceptualize everyday lives lived with disability as being analogous to the reimagined space of aesthetic performance and its reorientations.

### [Care Communities: Ethics, Fictions, Temporalities](#)

*Talia Schaffer*

The feminist philosophy of “ethics of care” has been important for disability studies inasmuch as it helps us see caregiving as widespread and admirable, rather than as a failure of autonomy. Care ethicists usually imagine care as either an institutional situation or an intimate dyad. However, in “Critical Care,” I add a third case in a midrange scale: the care community. The care community is a voluntary social formation, composed of friends, family, and neighbors, that coalesces around someone in need. It is my contention that by exploring the care community, we can



make important aspects of care visible and rethink care relationships. What we see in care communities is a process, rather than a preset care structure, and that fluidity allows us to interrogate the conditions under which care can develop and the dynamics of extended care. I use Victorian fiction to showcase care communities, since novels of this period are marked by ubiquitous spontaneous small groups forming around people who are ill or hurt, but I also make a case that care communities continue to exist today, particularly among queer communities and people of color, performing a vital function in our ordinary lives. Finally, I argue that care communities can help us fundamentally rethink disability as a need like any other need rather than an inherent identity. Eva Feder Kittay has argued that care relations are the foundation of civic society; in that case, disability and the care community that arises in response to it are not marginalized cases but are what, profoundly, makes social life possible.

[After Marginalization: Pixelization, Disability, and Social Difference in Digital Russia](#)

*Cassandra Hartblay*

Contemporary social thought frequently posits sociopolitical exclusion as marginalization. This article argues that marginalization relies on a spatial metaphor that conceptualizes social exclusion as always already configured in relation to center and periphery. Suggesting that this reliance on marginalization as a way of understanding sociopolitical exclusion limits political thought, this article calls for a renewed attention to actual material configurations of social exclusion. Considering ethnographic research with adults with mobility and speech disabilities in Petrozavodsk, Russia, and representation of disability in contemporary Russian film, the concept of marginalization is demonstrated to be insufficient to analyze the actual spatial segregation of people with disabilities in contemporary Russia in the digital era. The spatial metaphor of marginalization fails to describe the way that interlocutors with mobility impairments are at once segregated and included in sociopolitical life in the digital era, when civic life unfolds in cyberspace. Drawing on ethnographic interviews and observation, this article proposes pixelization as a descriptor of the specific spatial pattern of sociopolitical exclusion of people with mobility and speech impairments in Petrozavodsk, characterized by material segregation in family apartments combined with intricate enabling connection to various publics via digital networks. Spatial metaphors for social difference matter for the kinds of alternate presents and futures that might be



envisioned, challenging the presumption that ableism's power comes from limiting political participation in public space defined by a liberal democratic agora.

### [Neoliberalism and Embodied Precarity: Some Crip Responses](#)

*Margrit Shildrick*

The term neoliberalism has appeared in the policies of the Global North for several decades, with the concept of precarity in employment practices coming from the same period. In the last few years, however, precarity has been embodied and personalized, coming to signify not only an epistemological category but something more akin to an ontological state that raises complex questions of identity. My contribution uses it in that latter sense and will take the links between precarity, debility, and more specifically disability as central concerns. In feminist thought in particular, precarity mobilizes both a critical perspective on neoliberalism and a transformative prospective. It allows us to both acknowledge and go beyond a concern with inequities of power, which so strongly signal an expectation of negativity and lack of social justice, to ask how the notion of precarious bodies might already signal a potential for communality and promote the strength of relationality. Rather than following the familiar path of putting the globalization of inequality center stage and calling for new social and political rights for disabled people that take account of their asymmetric specificities, I want to disturb some of the issues—and not least the unproblematized resort to identity categories—through thinking the phenomenological implications of global intercorporeality. As one highly significant aspect of contemporary globalization, neoliberalism pursues a policy of putative self-dependency and rational self-management that seem at odds with the widely recognized capacity of globalization to undermine the certainties of spatial and temporal orientations. While the latter clearly has its own risks, it would be a mistake, I think, to equate the two movements as though both were equally damaging. Instead we should ask how new configurations of time and space are operationalized, and new flows of energy enhanced. What can be gained from the apparent precarity of disorientation, and the entry into what Gilles Deleuze and Félix Guattari call zones of proximity? For feminist and disability scholars, the task is surely to think new horizons by considering how we might multiply possibilities of revitalization.

### [Faithful to the Contemplation of Bones: Disability and Irremediable Grief](#)

Christina Crosby

Just after I turned fifty, I broke my neck in a cycling accident. In the rehab hospital and for months afterwards, as my body tried to recover from the shock to my central nervous system, I suffered terrible neurological pain that lingers to this day. Drawing on theories of melancholia, on literary readings, disability studies, and understandings of loss, in this article I make an argument for exploring feelings of chronic pain and the temporal dislocations of grief as a way forward, remembering what has irretrievably happened in the hopes of making a transformative future. I consider the ways in which disability studies has understandably been hesitant to consider pain, especially the psychic pain of grief, in relation to disabled bodyminds, and turn to the work of Eli Clare and Alison Kafer, both of whom are now “grappling” (Clare’s verb) with phenomenological experiences of pain. To theorize these events and remain true to suffering and grief, I consider psychoanalytic understandings of melancholy, then turn to Walter Benjamin. In his theses on the philosophy of history, he writes against the forgetting that is required by a belief in history-as-progress, and warns that “not even the dead will be safe from the enemy, if he is victorious.” Analyzing sixteenth-century German “mourning plays,” he studies the allegorical poetics of the form to explore how a human world that seems inescapably mournful, is, in the end, transformed through a narrative and poetics of redemption. Benjamin considers this redemptive turn a “betrayal,” and I agree. I consider how that betrayal matters to my own account of living on after a major spinal cord injury and significant paralysis transformed my life.

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