

<http://somatosphere.net/2020/in-the-journals-january-2020.html/>

In the Journals, January 2020

2020-01-30 16:50:35

By Anna Zogas

Here's our monthly digest of new journal articles! A special issue of **Medical Anthropology** on "[Aging, Chronicity, and Negotiations of Care](#)" is among the highlights. Happy reading!

[Medical Anthropology: Cross-Cultural Studies in Health and Illness](#)

[Neurodegeneration and the Intersubjectivities of Care](#) (open access)

Narelle Warren & Dikaïos Sakellariou

Caring for a family member or friend with a serious health condition is a common feature of social life. Often, such care is framed as a burden, an unwelcome rupture in the fabric of everyday life. We draw on research conducted in Australia and the UK to examine care in the everyday lives of people living with and caring for neurodegenerative diseases and to trouble care as a burden. Participants in our studies mobilized practices of care to collaboratively produce a "good life". We argue that above all, care is a relational, enacted practice requiring examination in its local context.

[The "Last Child": Lone Family Caregivers in St. Croix, US Virgin Islands](#)

Devin Flaherty

I investigate local explanations for a common family configuration of care for older relatives on the island of St. Croix, U.S. Virgin Islands: the "lone family caregiver." Through the examination of a paradigm case emerging from these explanations, I argue that local logics can divest some children of obligations to care for their older parents. I suggest that this case is an important addition to recent discussions within the anthropology of care that emphasize how families practice "care across distance," as it offers an alternative example of how families manage care in the context of migration.

["Like He's a Kid": Relationality, Family Caregiving, and Alzheimer's](#)

[Disease](#)*Aaron T. Seaman*

Spousal caregivers draw upon understandings of shifting relationality to maintain a familial understanding of their spouse with Alzheimer's disease. Working through what it means to think of an adult with Alzheimer's disease "like a child," I trace how spouses negotiate their shifting relationships across the course of Alzheimer's. While regarding adults as childlike can be perceived as dehumanizing infantilization, for families living with Alzheimer's disease, conceiving of one's spouse as like a child can actually enable processes of continued care, sustained recognition, and love to uphold personhood in the midst of often radical change.

[Precarity, Assemblages, and Indonesian Elder Care](#)*Peter van Eeuwijk*

The provision (or failure) of care reflects and produces vulnerability in old age. Reliable and appropriate care widely affects the imagination of "good care" of older Indonesians in North Sulawesi. Yet, their striving for better life goes with the growing chronification of conditions and processes with unpredictable endings. Three factors shape such uncertainty in elder care in North Sulawesi: (1) unsustainable, fragile care arrangements; (2) progressive-degenerative non-communicable diseases and aging impairments; and (3) structural insecurity in elder care and health-care institutions. Older persons mitigate the degree of chronifying care uncertainty by expanding social spaces, but often in normatively less accepted ways.

[Cancer Survivorship at the Intersections of Care and Personhood](#)*Michelle Ramirez, E. Amy Janke, Marcia Grant, Andrea Altschuler, Mark Hornbrook & Robert S. Krouse*

Surviving colorectal cancer following ostomy surgery with an intestinal stoma presents numerous challenges to the cultural category of full adult personhood. The foremost is managing unpredictable bowel activity. The technical management of the ostomy facilitated by biomedical specialists, is essential for personhood realignment. This article focuses on how some female long-term cancer survivors manage and adapt to this new fecal habitus by mobilizing various assemblages of care – receiving care, continuing to provide particular gendered forms of care, and returning to caregiving roles. These interdependent practices of

care realign personhood, or at the very least, minimize the assaults that having an ostomy presents to the cultural category of full adult personhood.

[Frequent Callers: “Good Care” with ICTs in Indian Transnational Families](#)

(open access)

Tanja Ahlin

In the context of transnational family life, everyday information and communication technologies (ICTs) are key members of transnational care collectives. Through the approach of material semiotics to care as a relational practice between people and nonhuman entities, I explore frequent calling as one aspect of these collectives. I analyze the practice of frequent calling on phone and webcam between elderly parents living in Kerala, South India, and their adult children who work abroad as nurses. When family members are scattered around the world, frequent calling becomes a way to enact “good care” at a distance.

[The Care of “Small Things”: Aging and Dignity in Rwanda](#)

Aalyia Feroz Ali Sadruddin

In Rwanda, disruptions to family and social life as a result of the 1994 genocide, and the economic transformations in its aftermath, have complicated the fabric of elder care across the country. In this article, I focus on how elderly Rwandans are reconfiguring their care networks – many of which were destroyed during the genocide – by acting as caregivers and care receivers for each other on a daily basis. Although emotionally and physically taxing, elderly Rwandans emphasize that the “small things” embedded in the giving and receiving of care are intricately connected to how personal and collective dignity is cultivated.

[Meaningful Deaths: Home Health Workers’ Mediation of Deaths at Home](#)

Cati Coe

After several generations in the United States in which medicalized deaths have become normal, more people are seeking to die at home. However, home deaths lead to emotional uncertainty and practical confusion, in which kin lack a cultural script. In this article I draw on interviews with patients’ kin and their African immigrant home health workers, and show that the care workers helped create a more meaningful death through their knowledge of death,

familiarity with the physical processes of death, and their presence, which they used to create pathways for their patients and their kin.

[Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine](#)

[Non-strategic ignorance: Considering the potential for a paradigm shift in evidence-based mental health](#)

Susan McPherson, Felicitas Rost, Sukhjit Sidhu, Maxine Dennis

Randomised controlled trials form a central building block within the prevailing evidence-based mental health paradigm. Both methodology and paradigm have been widely problematised since their emergence in the mid-late twentieth century. We draw on the concept of 'strategic ignorance' to understand why the paradigm still prevails. We present focus group data gathered from 37 participants (service users, public, carers, general practitioners, commissioners) concerning the way they made sense of a randomised controlled trial of psychotherapy for treatment-resistant depression. Thematic analysis of the findings revealed an overall critique of randomised controlled trial methods which we refer to as 'non-strategic ignorance'. Specifically, participants problematised the construct of depression, unseating the premise of the randomised controlled trial; they were sceptical about the purpose and highlighted its failure to show how therapy works or who might benefit; the randomised controlled trial was seen as inadequate for informing decisions about how to select a therapy. Participants assumed the treatment would be cost-effective given the client group and nature of the therapy, irrespective of any randomised controlled trial findings. Each area of lay ('non-strategic') critique has an analogous form within the methodological expert domain. We argue that 'expert' critiques have generally failed to have paradigmatic impact because they represent strategic ignorance. Yet parallel non-strategic critiques have common sense appeal, highlighting the potential power of lay voices. The discussion considers whether the evidence-based mental health paradigm is faced with epistemological problems of such complexity that the conditions exist for a new paradigm in which service user views are central and randomised controlled trials peripheral.

[Expertise, advocacy and activism: A qualitative study on the activities of prostate cancer peer support workers](#)

Marjaana Jones, Ilkka Pietilä

Peer support workers are now working with patients in a variety of settings, coming into close contact and even work alongside health professionals. Despite the potentially influential position peer support workers hold in relation to those engaged in support activities, their role, duties and their relationship to peers and health professionals lack clarity and is often defined by other actors. This study explores how peer support workers interpret and define the activities, responsibilities and knowledge associated with their work. Using methods of membership categorisation analysis, we analysed interview materials generated by conducting individual semi-structured interviews during the autumn of 2016 with prostate cancer peer support workers (n = 11) who currently volunteer as support workers in Finland. Although the peer support workers acknowledged the psychosocial aspects of the work, we argue that their interpretations extend far beyond this and encompass expertise, advocacy and activism as central features of their work. These can be used to strengthen their position as credible commentators and educators on issues relating to cancer and men's health; raise awareness and represent the 'patient's voice' and attempt to influence both policy and clinical practice. These findings suggest that by categorising their work activities in different ways, voluntary sector actors such as peer support workers can attempt to portray themselves as legitimate authorities on a range of issues and influence decision-making ranging from individual level treatment decisions all the way to health policy.

['Not a film about my slackness': Making sense of medically unexplained illness in youth using collaborative visual methods](#)

Silje Vagli Østbye, Maria Fredriksen Kvamme, Catharina Elisabeth Arfwedson Wang, Hanne Haavind, Trond Waage, Mette Bech Risør

Persistent medically unexplained symptoms have debilitating consequences for adolescents, dramatically altering their social world and future aspirations. Few studies have focused on social and moral aspects of illness experience relevant to adolescents. In this study, the aim is to explore these aspects in depth by focusing on a single case and to address how young people attempt to create social accountability in a search for meaning when facing illness and adversity. The study is based on a view of meaning as dialogically constituted during the research process, which calls for the use of collaborative film methodology and life-mode interviewing. With a dialogic–performative approach to a narrative emplotment of medically unexplained symptoms, we present Peter as intentional and purposive, and as a person who in a reflective process of meaning making claimed his own voice and developed

his own strategies of coping with his illness. The analysis brings forward a narrative of suffering, hope and intentionality that is configured by the immediate limited possibilities of agency due to Peter's medical condition. It is, however, configured to an even greater degree by aspirations, that is, to become an accountable person through social experiences and to meet sociocultural and moral expectations of being an adolescent. The study provides insight into relational and existential aspects of meaning making in dealing with contested illness in youth and points to the potential of visual and other experience-near methods for supporting adolescents in their coping attempts and in overcoming communication barriers in everyday life and clinical encounters.

[Not talking about illness at meeting places in Norwegian community mental health care: A discourse analysis of silence concerning illness-talk](#)

Lill Susann Ynnesdal Haugen, Vegard Haugland, Andreas Envy, Marit Borg, Tor-Johan Ekeland, Norman Anderssen

Research on the topic of not talking about psychosocial hardships describes the presence of 'house rules' against illness-talk in common areas in 'meeting places' ('day centres') in community mental health care. The aim of this article was to explore the complexity of not talking about psychosocial hardships ('silence') in meeting places in Norwegian community mental health care. The research team consisted of first-hand and academic knowers of community mental health care (participatory research team). We performed two series of focus group discussions with service users and staff of meeting places. The focus group interviews were analysed within a discourse analytic framework, and five discursive constructions were identified: (1) biomedical colonization of illness-talk, (2) restricted access for biomedical psychiatry and problem-talk in the common spaces of meeting places, (3) censorship of service users' civil and human rights to freedom of speech, (4) protection from exploitation and burdens and (5) silent knowledge of the peer community. Based on the analysis, we suggest that not talking about illness (silence) entails a complexity ranging from under-privileging implications to promoting the interests of people who 'use' meeting places. For instance, restricting biomedical psychiatry may imply the unintended implication of further silencing service users, while silently shared understandings of hardships among peers may imply resistance against demands to speak to legitimize one's situation. The discussion illuminates dilemmas related to silence that require critical reflexive discussions and continuous negotiations among service users, staff and policymakers in community mental health

care.

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

[Science and Technology Studies in Policy: The UK Synthetic Biology Roadmap](#) (open access)

Claire Marris & Jane Calvert

In this paper, we reflect on our experience as science and technology studies (STS) researchers who were members of the working group that produced A Synthetic Biology Roadmap for the UK in 2012. We explore how this initiative sought to govern an uncertain future and describe how it was successfully used to mobilize public funds for synthetic biology from the UK government. We discuss our attempts to incorporate the insights and sensibilities of STS into the policy process and why we chose to use the concept of responsible research and innovation to do so. We analyze how the roadmapping process, and the final report, narrowed and transformed our contributions to the roadmap. We show how difficult it is for STS researchers to influence policy when our ideas challenge deeply entrenched pervasive assumptions, framings, and narratives about how technological innovation necessarily leads to economic progress, about public reticence as a roadblock to that progress, and about the supposed separation between science and society. We end by reflecting on the constraints under which we were operating from the outset and on the challenges for STS in policy.

[Witness and Silence in Neuromarketing: Managing the Gap between Science and Its Application](#) (open access)

Jonna Brenninkmeijer, Tanja Schneider, Steve Woolgar

Over the past decades commercial and academic market(ing) researchers have studied consumers through a range of different methods including surveys, focus groups, or interviews. More recently, some have turned to the growing field of neuroscience to understand consumers. Neuromarketing employs brain imaging, scanning, or other brain measurement technologies to capture consumers' (brain) responses to marketing stimuli and to circumvent the "problem" of relying on consumers' self-reports. This paper presents findings of an ethnographic study of neuromarketing research practices in one neuromarketing consultancy. Our access to the minutiae of commercial neuromarketing research provides important insights into how

neuromarketers silence the neuromarketing test subject in their experiments and presentations and how they introduce the brain as an unimpeachable witness. This enables us conceptually to reconsider the role of witnesses in the achievement of scientific credibility, as prominently discussed in science and technology studies (STS). Specifically, we probe the role witnesses and silences play in establishing and maintaining credibility in and for “commercial research laboratories.” We propose three themes that have wider relevance for STS researchers and require further attention when studying newly emerging research fields and practices that straddle science and its commercial application.

[Indigenous Knowledge in a Postgenomic Landscape: The Politics of Epigenetic Hope and Reparation in Australia](#)

Megan Warin, Emma Kowal, Maurizio Meloni

A history of colonization inflicts psychological, physical, and structural disadvantages that endure across generations. For an increasing number of Indigenous Australians, environmental epigenetics offers an important explanatory framework that links the social past with the biological present, providing a culturally relevant way of understanding the various intergenerational effects of historical trauma. In this paper, we critically examine the strategic uptake of environmental epigenetics by Indigenous researchers and policy advocates. We focus on the relationship between epigenetic processes and Indigenous views of Country and health—views that locate health not in individual bodies but within relational contexts of Indigenous ontologies that embody interconnected environments of kin/animals/matter/bodies across time and space. This drawing together of Indigenous experience and epigenetic knowledge has strengthened calls for action including state-supported calls for financial reparations. We examine the consequences of this reimagining of disease responsibility in the context of “strategic biological essentialism,” a distinct form of biopolitics that, in this case, incorporates environmental determinism. We conclude that the shaping of the right to protection from biosocial injury is potentially empowering but also has the capacity to conceal forms of governance through claimants’ identification as “damaged,” thus furthering State justification of biopolitical intervention in Indigenous lives.

[Malignant yet Benign: The Political Economy of a Skin Cancer Diagnosis in Colombia](#)

Camilo Sanz

This paper is about the ontology of a cancer diagnosis at high-end hospitals in Colombia. Drawing on a seventeen-month ethnographic fieldwork study in this country, it pays attention to how dermatologists, pathologists, and oncologists looked at my partner's skin during a routine medical checkup and enacted two seemingly contradictory diagnoses: a lethal melanoma and a benign dysplastic nevus—commonly known as mole. Because their differences under the microscope or through dermatology goggles may be subtle, physicians often disagree on what they see. When medical services are not unrelated to the economic possibilities of patients to pay for them, what emerges through a microscope might be different. With neoliberal medical reforms in Colombia as background, this paper focuses on the ontological indeterminacy of cancer and its relationship to high-end hospitals and a patient who could, albeit not without effort, pay for the treatment. Thus, I argue that how physicians saw was not unrelated to what they saw and therefore to their practices of medicine in neoliberal Colombia. How do medical practices and ways of seeing in Colombia enter into composition with the bodies they study? Could the same skin tissue simultaneously be cancerous and noncancerous?

[Challenging Diversity: Steering Effects of Buzzwords in Projectified Health Care](#) (open access)

Michael Penkler, Kay Felder, Ulrike Felt

This article discusses the effects of two trends in contemporary biomedicine that have so far been largely addressed separately: the steering of fields through programmatic “buzzwords” and the projectified nature of contemporary health research, care, and promotion. Drawing on a case study of an Austrian diversity-sensitive health promotion project related to obesity prevention, we show how the articulation of these trends—governance by buzzwords and projectification—often leads to not unproblematic and often paradoxical outcomes. Buzzwords such as “diversity” become especially important in an innovation-driven environment encouraging a promissory rhetoric. At the same time, the project form shapes and restricts how buzzwords (as typically vague terms that need to be fleshed out) are articulated and translated into a specific project design. In our case study of an obesity prevention program, the need to translate diversity into a “doable” project encouraged the identification of seemingly clearly delineated target groups and thus promoted a rather narrow understanding of diversity, which stands in tension with much more fluid and context-sensitive ways of performing “diversity.” We show how actors grapple with these paradoxes.

This restricts the full power a buzzword such as diversity could achieve in terms of social justice.

[Data Performativity and Health: The Politics of Health Data Practices in Europe](#)

Gabriel G. Blouin

The European Commission produces the European Core Health Indicators (ECHI), a database containing different tools used to compare European Union (EU) countries and recommend policy changes. The ECHI feeds multiple reports and documents and finds its way into health policies. From this arises the main research question addressed in this paper: How is health in Europe influenced by ECHI data practices? Specifically, we look at how some health issues or populations are prioritized or dismissed, which ultimately shapes the meaning of and knowledge about health in Europe. To do so, we first develop the conceptual framework of “data performativity,” underlining how data practices shape their object/subject. We then explore the politics of evidence behind the ECHI health data that materialize into (1) the absence of some health issues and populations and (2) the hypervisibility of neoliberal health. In the end, we argue, the ECHI serves as a site of individual, collective, and political identity enunciation.

[Social Science & Medicine](#)

[A critical content analysis of media reporting on opioids: The social construction of an epidemic](#)

Fiona Webster, Kathleen Rice, Abhimanyu Sud

Background. The 2000s have seen a proliferation of media reporting about opioid use in North America. Given the significant role that popular media plays in shaping the public’s perceptions and understandings of the issues that it represents, analysing the content of this media coverage can help understand public discourse about opioid use.

Methods. We conducted a critical content analysis of Canadian newsprint media reporting on opioids using a sociological lens. We performed a qualitative thematic analysis of these texts, coding 826 articles and applying a critical discourse analysis in our interpretation of the findings.

Findings. Our analysis showed a slow transition from a

conversation primarily about clinical pain care towards a discussion of criminality, especially the increasingly fluidity of boundaries between prescription opioid use and the illegal drug trade. Patients tend to be dichotomized as either innocently following physician prescriptions or drug-seeking, as an aspect of lives characterized by addiction and street crime. These depictions map onto characterizations of physicians as naively following pharmaceutical industry advice or becoming irrelevant once criminality is introduced.

Discussion. The social construction of the opioid epidemic polarizes individuals as good or bad with little attention paid to underlying institutional interests both in the creation of the problem or in the solutions that are proposed. We show that as concerns about harms from opioids become more pronounced, the narrative shifts to home in on illicit street-use with a corresponding uptake of stigmatizing references to so-called addicts. Concurrently, most references to the pharmaceutical industry disappear from view. This framing of the problem defines the kinds of solutions that then seem natural. For example, increased criminalization is suggested for people who use drugs and stigmatizing those who suffer with chronic pain becomes a higher priority than implementing safer and more effective therapies for managing their pain.

[Diagnosing uncertainty: The challenges of implementing medical screening programs for minority sub-populations in Canada](#)

Mark Gaspar, Ron Rosenes, Ann N. Burchell, Troy Grennan, Irving Salit, Daniel Grace

The social science literature on medical screening has documented a notable disjuncture between the promises of population-based screening programs and the complex realities of their rollout in everyday practice. We contribute to this scholarship by examining how healthcare providers confront numerous uncertainties associated with the implementation of anal cancer screening programs in Canada given the absence of standardized national evidence-based guidelines. The data was derived from in-depth interviews conducted with 13 physicians and 2 clinical researchers about anal cancer screening for gay, bisexual and other men who have sex with men living with HIV, the minority sub-population at the highest risk for HPV-associated anal cancer. Despite having unknown utility and low specificity, an initial anal Pap test was used to triage patients into anal dysplasia clinics for high-resolution anoscopy. This process led to technological scepticism toward the Pap's accuracy, diagnostic ambiguity

related to the interpretation of the cytology results and increased patient anxiety regarding abnormal results. Physicians navigated a tension between wanting to avoid exposing their patients to additional uncertainties caused by screening and pre-cancer treatment and wanting to ensure that their patients did not develop anal cancer under their care. A high number of abnormal anal Pap results paradoxically reintroduced some of the capacity issues that the Pap was meant to resolve, as the existing dysplasia clinics were incapable of seeing all patients with abnormal results. We define this sequence as the epistemic-capacity paradox, a dynamic whereby seeking evidence to improve healthcare capacity simultaneously produces evidence that introduces capacity challenges and generates additional uncertainty. The epistemic-capacity paradox demonstrates the limitations of evidence-based medicine frameworks at determining best practices in the context of rarer health conditions affecting minority sub-populations, where smaller population numbers and limited institutional support pose systemic challenges to the acquisition of sufficient evidence.

[Questions regarding 'epistemic injustice' in knowledge-intensive policymaking: Two examples from Dutch health insurance policy](#)
Floortje Moes, Eddy Houwaart, Diana Delnoij, Klasien Horstman

In contemporary healthcare policies the logic of Evidence-based Medicine (EBM) is typically proposed as a way of addressing a demand to explicitly justify policy decisions. Policymakers' use of 'evidence' is presumed to pertain to ideals of justice in decision-making. However, according to some, EBM is liable to generate 'epistemic injustice' because it prefers quantitative types of evidence and – as a result of that – potentially undervalues the qualitative testimonies of doctors and patients. Miranda Fricker's concept of 'epistemic injustice' refers to a wrong done to a person in their capacity as a knower. This paper explores the usefulness and limits of this concept in the context of public decision-making. How is evidence-based policymaking intertwined with questions of 'epistemic injustice'? Drawing from ethnographic research conducted at the National Health Care Institute, we analyze two cases of EBM-inspired policy practices in Dutch social health insurance: 1) the use of the principles of EBM in making a public reimbursement decision, and 2) private insurers' use of quantitative performance indicators for the practice of selective contracting on the Dutch healthcare market. While the concept of 'epistemic injustice' misses some key processes involved in understanding how 'knowing gets done' in

public policy, it does shed new light on priority-setting processes. Patients or medical professionals who are not duly recognized as credible and intelligible epistemic agents, subsequently, lack the social power to influence priority-setting practices. They are thus not merely frustrated in their capacity to be heard and make themselves understood, they are potentially deprived of a fair share in collective financial and medical resources. If we fail to recognize inequalities in credibility and intelligibility between diverse groups of knowers, there is a chance that these epistemic inequalities are being reproduced in our system of health insurance and our ways of distributing healthcare provisions.

[The changing landscape of abortion care: Embodied experiences of structural stigma in the Republic of Ireland and Northern Ireland](#)

Kathleen Broussard

The private use of abortion medication outside of the formal healthcare setting is an international phenomenon. Despite new and expanding pathways to abortion access, we know little about how women's perceptions and experiences of abortion may also be changing. This study examines the embodied experience of 68 women who sought abortion services in Northern Ireland and the Republic of Ireland. Social stigma and restrictive abortion laws were major barriers to care at the time of study, providing the opportunity to explore the ways biological, social, and structural factors shape embodiment. Those who obtained an abortion either traveled abroad for clinical care or self-managed a medication abortion at home. Participant's perceptions of pain, the fetus, the method (medication vs. surgical), and environment in which they sought abortion care (at home vs. in a clinic) were shaped by structural stigma. Women gained greater experiential knowledge through medication self-management, allowing them to relate abortion to other natural bodily processes and redefine their beliefs about pregnancy and the fetus. Preferences and attitudes about the environment of abortion care were informed by stigma and differential perceptions of risk. Those who traveled most often emphasized legal and medical risks of abortion at home, while those who self-managed emphasized social, financial, and emotional risks of pursuing clinical abortion care abroad. Given the increase in reproductive self-care alternatives, these findings situate self-managed abortion in the literature of (de)medicalization and reveal the ways technology and structural factors shape perceptions and beliefs about pain, the fetus, method, and environment. For some, self-managed medication abortion may be a preferred pathway to care. Policies that consider medication

self-management as part of a spectrum of legitimate options can improve abortion access for marginalized groups while also offering an improved abortion experience for those who prefer medication abortion and an out-of-clinic environment.

[Subjunctive medicine: Enacting efficacy in general practice](#)

Doug Hardman, Adam W.A. Geraghty, Mark Lown, Felicity L. Bishop

Modern general practice is complex. Issues such as multimorbidity, polypharmacy and chronic illness management can make applying myriad single condition evidence-based guidelines increasingly difficult. This is compounded because the problems presented in general practice often require both clinical and social solutions. In response to these issues, generalist clinicians are now expected to practise ‘person-centred care’: enabling and empowering patients by combining the technical rationality of medical science with individual values, needs and preferences. To explore this difficult undertaking we conducted an ethnography of a general practice surgery in England, including participant observation, interviews, and focus groups with patients, clinicians, and support staff, from February 2018 to March 2019. Our findings suggest that clinicians in our study faced considerable constraints, broadly conceived as the limits of biomedicine and the structural constraints of general practice. However, they mitigated these by getting into good habits, which we conceive in two categories: using expert judgement and taking patients seriously. We further propose that clinicians did not merely will themselves towards these good habits but developed and adapted them by intuitively adopting a second-order ‘meta’ habit of enaction – treating each consultation as collaboratively co-created anew. This suggests an important feature of the general practice consultation: it is conducted as much in the subjunctive as the indicative mood. Developing this proposition, we propose a more general form of medical practice – subjunctive medicine – extolling the value of the co-created social order of the general practice consultation itself. We suggest that practising subjunctive medicine may help clinicians sustainably and resiliently achieve the aims of person-centred care in modern general practice.

[‘Becoming-with’ a repeat healthy volunteer: Managing and negotiating trust among repeat healthy volunteers in commercial clinical drug trials](#)

Shadreck Mwale

Recent sociological research has raised important sociological and

ethical questions about the role of financial rewards in terms of healthy volunteer involvement in clinical trials. Research suggests that it would be parochial to assume financial rewards alone are sufficient to explain repeat healthy volunteering. This paper explores other factors that might explain repeat healthy volunteering behaviours in phase I clinical drug trials. Drawing on qualitative research with healthy volunteers, the paper argues that while healthy volunteers make rational decisions to take part in drug trials, understanding how they become repeat volunteers requires considering varied relationships and networks involved. Drawing on Deleuze's concept of 'event' and 'becoming-with', the paper illustrates the relational, processual and embodied nature of trust in repeat healthy volunteer involvement in clinical drug trials. The paper concludes that repeat healthy volunteering is a constant flux of negotiating trust and mistrust. The paper contributes to sociological debates about trust and public engagement with technological innovations to illustrate trust among healthy volunteers as processual and changeable.

[Quantifying fertility? Direct-to-consumer ovarian reserve testing and the new \(in\)fertility pipeline](#)

Moira A. Kyweluk

Frequently branded the "egg timer" or "biological clock test," anti-Müllerian hormone (AMH) testing for women is becoming widely available in the United States (US) through online, direct-to-consumer (DTC) testing services. The level of AMH in the blood reflects the remaining egg supply or "ovarian reserve"—a potential fertility indicator. AMH level is primarily used as a diagnostic tool prior to ovarian stimulation for in vitro fertilization (IVF) or oocyte cryopreservation (OC; i.e., egg freezing). This article describes the first ethnographic research on DTC ovarian reserve testing in the US, with a recruited sample of 21 participants interested in pursuing testing who consented to participant observation and semi-structured interviews. Fieldwork took place from January 2018 to July 2018 in Chicago, Illinois. Ethnographic cases explore how experiences with ovarian reserve testing are shaped by relationship status, sexual orientation, socioeconomic status, racial/ethnic identity, and medical insurance coverage. Thematic analysis suggests that DTC ovarian reserve testing is a unique means of investigating fertility; participants felt empowered by receiving testing outside of traditional medical contexts. It was an alternative tool for family planning, particularly for LGBTQ + individuals and single women. However, participants experienced varying degrees of certainty about test results and the appropriate

next steps to take to confirm fertility status, preserve fertility, or conceive, thus suggesting that DTC testing may confound reproductive decision-making. I argue that DTC ovarian reserve testing is a new tool in a larger medical and social project to mitigate anticipated future infertility and is an entry point into what I term the new (in)fertility pipeline encouraging entanglement with reproductive technologies across the lifespan. Due to its low cost and widespread availability, DTC ovarian reserve testing reaches a broader demographic, encourages testing across diverse identities and backgrounds, and increases awareness of more advanced assisted reproductive technology (ART), including egg freezing.

[Collective strategies to cope with work related stress among nurses in resource constrained settings: An ethnography of neonatal nursing in Kenya](#)

Jacob McKnight, Jacinta Nzinga, Joyline Jepkosgei, Mike English

Kenyan neonatal nurses are asked to do the impossible: to bridge the gap between international standards of nursing and the circumstances they face each day. They work long hours with little supervision in ill-designed wards, staffed by far too few nurses given the pressing need. Despite these conditions, a single neonatal nurse can be tasked with looking after forty sick babies for whom very close care is a necessity. Our 18-month ethnography explores this uniquely stressful environment in order to understand how nurses operate under such pressures and what techniques they use to organise work and cope. Beginning in January 2015, we conducted 250 h of non-participant observation and 32 semi-structured interviews in three newborn units in Nairobi to describe how nurses categorise babies, balance work across shifts, use routinised care, and demonstrate pragmatism and flexibility in their dealings with each other in order to reduce stress. In so doing, we present an empirically based model of the ways in which nurses cope in a lower-middle income setting and develop early work in nursing studies that highlighted collective strategies for reducing anxiety. This allows us to address the gap left by prevalent theories of nursing stress that have focused on the personal characteristics of individual nurses. Finally, we extend outwards from our ethnographic findings to consider how a deeper understanding of these collective strategies to reduce stress might inform policy, and why, even when the forces that create stress are alleviated, the underlying model of nursing work may prevail.

[Borderline well-being: Mental health in a development zone](#)

Chris Lyttleton

Mental illness contributes hugely to global disease burden. Inadequate resources, limited access to services and pervasive stigma jointly foster its increasing severity, especially in resource-poor countries. Despite recognition that social determinants such as poverty, inequality and marginalization aggravate mental distress, minimal scrutiny has focused on the negative impact of targeted development schemes creating social and economic change that exacerbates mental health risks for poor people. This article examines the rise of mental disorders as an unwanted consequence of a new special economic zone being built in a border district in Northwest Thailand. Ethnographic data from villages surrounding the intended industrial hub was collected during six-months fieldwork in 2017 and 2018. Informants included public health staff in the community and district hospitals, villagers who had lost farming land, health volunteers and spirit healers. Using local narratives and hospital data to show an emergent vulnerability to anxiety, depression and suicide, I argue that global public health approaches seeking to decentralise mental health services and donor-driven mitigation guidelines fail to alleviate stressors for locals caught up in development's slipstream. In turn, distressed by land reclamation, debt, gambling and substance abuse, villagers turn to reinvigorated forms of spirit-healing for assistance in regaining a sense of well-being. In this context, I demonstrate that development schemes potential to affect the epidemiology of behavioral pathologies remains significantly under-addressed within rubrics of 'border-health'.

[Spontaneity and serendipity: Space and time in the lives of people with diabetes](#)

Mark Lucherini

This article considers the relevance of non-representational theory to understanding the lived experience of diabetes. While non-representational theory has gained traction in the social sciences, especially Human Geography, its usefulness in extending our understanding of experiences of health and illness is often restricted to an idea of wellbeing that assumes an able and healthy body. This article draws on qualitative research on the everyday experiences of living with diabetes, to consider how non-representational theory can be applied to understanding the everyday experience of ill bodies. The analysis moves through ideas of mobility, routine, anticipation and adjustment to highlight the challenges of spontaneity and serendipity in the everyday lives

of people with diabetes. The article concludes by considering some of the advantages of a non-representational approach for healthcare practice.

[Sociology of Health and Illness](#)

[Female family carers' experiences of violent, abusive or harmful behaviour by the older person for whom they care: a case of epistemic injustice?](#)

Louise Isham, Caroline Bradbury-Jones, Alistair Hewison

Family carers affected by violent, abusive or harmful behaviour by the older person for whom they care face social and epistemic challenges in developing and sharing knowledge about their experiences. These difficulties have contributed to a situation in which there is a paucity of evidence and public discourse about how we understand violence and harm instigated by people who have care needs or are 'vulnerable'. This paper reports the findings of a qualitative study that involved 12 in-depth interviews with female carers affected by violence, abuse or harm. The study was informed theoretically by Miranda Fricker's concept of epistemic injustice which was used as a framework for analysis. There were two principal findings: (1) Carers were sensitive to anticipatory stigma and loss of moral autonomy. As a result, they self-censured what they shared and, at times, were met with subtle but powerful processes of silencing. (2) Carers had limited linguistic and conceptual resources to explain the emotional and social aspects of the harm they experienced, exacerbated by implicit social norms about the 'private' and gendered nature of familial care. To conclude, we discuss the implications of these findings for sociological research and health and social care practice.

[Getting the Sergeants on your side: the importance of interpersonal relationships and cultural interoperability for generating interagency collaboration between nurses and the police in custody suites](#)

Gethin Rees

In this article, I contribute to the literature around interagency collaboration, especially between law enforcement and health care, by reconciling the previous work of Sarah Charman (2014) with the interprofessional teamwork literature. Drawing upon a semi-structured interview-based study with 20 custody nurses working in English police custody suites (analysed using

Framework Analysis), I explore the ways they are able to achieve interagency collaboration with a particular police officer, the Desk Sergeant. I argue that nurses accomplish interagency interoperability by interacting regularly with the Desk Sergeant, anticipating their needs and limiting their own goals to those that are commensurate with the Desk Sergeant's, notably providing information and avoiding deaths in custody. Such practices are similar to the strategies of 'Cultural Interoperability' noted by Charman (2014); however, this study also identifies that such strategies are only available once a successful working relationship has formed between Desk Sergeant and nurse, and as a result, similarly to the findings of interprofessional teamwork studies, the success or failure of attempts to collaborate across agencies is underpinned by interpersonal relations. The paper concludes by commenting on the importance of analysing both the interpersonal and organisation levels when studying collaboration.

[\(In\)visible materialities in the context of dementia care](#) (open access)

Helena Cleeve, Lena Borell, Lena Rosenberg

Seemingly mundane materialities are intertwined with important, but often neglected, care interactions. It has been argued that if healthcare professionals paid more attention to the roles materialities can have, everyday routines could become important occasions for care. In response to such proposals, we argue that it is relevant to examine how materialities are currently understood. In this article, we explore materialities as part of work in a dementia unit. Using abstracted illustrations of everyday materialities to elicit reflections, we conducted 11 individual interviews with certified nursing assistants. Through phenomenographic analysis we explain our findings as three different categories conceptualising understandings of materialities as: 'tools for care', 'a set of principles for care' and 'caring relationships'. Our analysis indicates that understanding materialities as instruments was reinforced and made visible through the healthcare organisation while understanding materialities as part of specific relationships with residents appeared informal and less visible. How materialities were understood seemed to have several implications for residents. While care practices could benefit from nursing assistants' abilities to alternate between ways of understanding materialities, such competence seemed dependent on how professional care was organised, structured and materialised.

[Intersex, infertility and the future: early diagnoses and the imagined life](#)

[course](#)*Charlotte Jones*

Infertility is often recognised as a status that is medically identified in adulthood after unsuccessful attempts to conceive. This paper develops existing literature by illustrating how current conceptualisations of infertility do not incorporate a full range of experiences. Drawing on detailed, reflective diaries and in-depth interviews with five participants, I explore how infertility is experienced and understood by women with variations of sex characteristics (VSCs) or intersex traits. I argue that greater consideration needs to be applied to intersex people and the circumstances of an infertility status that may be received in infancy, childhood or adolescence, before or outside of attempts to conceive, and without undergoing fertility treatment. Through discussions of time and futurity, this paper seeks to explore how visions of the future coalesce with an infertile status that is received in combination with an atypical sex status early in life. The paper indicates that early infertility can hinder some intersex children and young people's ambitions. However, infertility is not understood to be pathological or consistently prohibitive throughout the lives of everyone affected. Intersex women's conceptions of a potentially childless future are varied, complex, ambivalent and, in some cases, transitional throughout the life course.

[Health States of Exception: unsafe non-care and the \(inadvertent\) production of 'bare life' in complex care transitions](#)*Justin Waring, Simon Bishop*

This paper draws on the work of Giorgio Agamben to understand how the social organisation of care transitions can reduce people to their 'bare' life thereby making harmful and degrading treatment seemingly legitimate. The findings of a 2-year ethnographic study show how some people experience hospital discharge as undignified, inhumane and unsafe process, expressed through their lack of involvement in care planning, delayed discharge from hospital and poorly coordinated care. Our analysis explores how these experiences stem from the way patients are constituted as 'unknown' and 'ineligible' subjects and, in turn, how professionals become 'not responsible' for their care. The result being that the person is reduced to their 'bare' life with limited value within the care system. We suggest that the social production of 'bare life' is an inadvertent consequence of reconciling and aligning multiple disciplines within a complex care system.

[Performance management: a qualitative study of relational boundaries in personal assistance](#) (open access)

Tom Porter, Tom Shakespeare, Andrea Stöckl

Personal assistance (PA) is a model of support where disabled people take control of recruiting, training and managing the people that support them. Personal assistance differs from other forms of care, such as domiciliary or informal care, because the disabled person is in control of how, when and by whom they are supported. With the advent of personal health budgets, PA is no longer limited to social care but is also central to future NHS services and funding arrangements. The aims of this study were to gain a deeper understanding of PA relationships, and to explore how both parties manage interpersonal challenges. We report on data from 58 qualitative interviews with disabled employers and personal assistants. Applying concepts from Goffman's (1959) scheme of impression management, we present an analysis of the relational dynamics that occur when two people cooperate in shared endeavours. Goffman's concepts of team members and non-persons, in addition to the themes of regions and information control, aid a more fundamental understanding of the relational dynamics that occur between disabled employers and their PAs.

Share this:

- [Share](#)
-

Similar Posts

- [Special issues!](#)
- [Georges Canguilhem's essay on "Health" in new issue of Public Culture](#)
- [Miscellany](#)
- [Ethnographies of addiction in Cultural Anthropology](#)
- [Web Gleanings for the New Year](#)

AMA citation

Zogas A. In the Journals, January 2020. *Somatosphere*. 2020. Available at: <http://somatosphere.net/2020/in-the-journals-january-2020.html/>. Accessed January 31, 2020.

APA citation

Zogas, Anna. (2020). *In the Journals, January 2020*. Retrieved January 31, 2020, from Somatosphere Web site: <http://somatosphere.net/2020/in-the-journals-january-2020.html/>

Chicago citation

Zogas, Anna. 2020. In the Journals, January 2020. Somatosphere. <http://somatosphere.net/2020/in-the-journals-january-2020.html/> (accessed January 31, 2020).

Harvard citation

Zogas, A 2020, *In the Journals, January 2020*, Somatosphere. Retrieved January 31, 2020, from [<http://somatosphere.net/2020/in-the-journals-january-2020.html/>](http://somatosphere.net/2020/in-the-journals-january-2020.html/)

MLA citation

Zogas, Anna. "In the Journals, January 2020." 30 Jan. 2020. Somatosphere. Accessed 31 Jan. 2020. [<http://somatosphere.net/2020/in-the-journals-january-2020.html/>](http://somatosphere.net/2020/in-the-journals-january-2020.html/)