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## In the Journals, January 2018

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By Anna Zogas

Here are some articles of interest published in January 2018. Enjoy!

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

#### [The consequence of “doing nothing”: Family caregiving for Alzheimer’s disease as non-action in the US](#)

*Aaron T. Seaman*

This article adopts a discursive approach in order to examine how dominant US discourses shape both public and personal understandings of the caregiving work that families do, specifically in the context of Alzheimer’s disease (AD). Family caregivers are an essential, increasingly recognized piece of the US health care system. Dominant discourses of AD and caregiving articulate family caregiving in contrast to biomedical intervention. The dichotomy privileges the ability to affect a biomedical outcome and, using that metric, minimizes caregiving’s potential value as meaningful action. Family caregiving comes to be seen as what I term non-action, action that, while voluminous, is not perceived as meaningful in terms of its outcome. Drawing on over 26 months of ethnographic fieldwork in the Midwestern US with families living with early-onset AD (2011–2013), I focus on spousal caregivers to trace how these discourses shape the possibilities for family caregiving. I show how advocacy rhetoric is taken up and reproduced by family members, who learn to see their own caregiving labor through a biomedical lens. However, I also demonstrate that, obscured by dominant discourses, caregivers engage in relational labor, the continual work of making and unmaking social relations. Recognition of caregiving as part of longer-term relational endeavors, I argue, offers the potential to reframe caregiving discourses and reimagine the value the labor of caregiving as meaningful in its own right.

#### [“Do-it-yourself”: Vaccine rejection and complementary and alternative medicine \(CAM\)](#)

*Katie Attwell, Paul R. Ward, Samantha B. Meyer, Philippa J. Rokkas, Julie Leask*

In this article, we elucidate a symbiotic relationship between

complementary and alternative medicine (CAM) and rejection of, or hesitancy towards, vaccination. In Fremantle, Western Australia, and Adelaide, South Australia, we conducted in-depth interviews from September 2013–December 2015 with 29 parents who had refused or delayed some or all of their children’s vaccines. Our qualitative analysis found that for many, their do-it-yourself ethic and personal agency was enhanced by self-directed CAM use, alongside (sometimes informal) CAM practitioner instruction. Reifying ‘the natural,’ these parents eschewed vaccines as toxic and adulterating, and embraced CAM as a protective strategy for immune systems before, during and after illness. Users saw CAM as harm-free, and when it came to experiences that non-users might interpret as demonstrating CAM’s ineffectiveness, they rationalised to the contrary. They also generally glossed over its profit motive. CAM emerged as part of an expert system countering Western medicine. CAM’s faces were trusted and familiar, and its cottage capitalism appeared largely free from the taint of “Big Pharma.” A few parents employed a scientific critique of CAM modalities – and a minority were dubious of its profit motive – but others rejected the epistemology underpinning biomedicine, framing CAM as a knowledge not poisoned by avarice; a wisdom whose very evidence-base (anecdote and history) was demeaned by an arrogant scientific process only permitting belief in that which could be quantified. However, all parents engaged with Western medicine for broken bones and, sometimes, medical diagnoses. Our analysis suggests that pro-vaccination health professionals, policymakers and information-providers seeking to address the role of CAM in vaccine rejection face significant challenges due to the epistemic basis of some parents’ decisions. However, we make some suggestions for professional practice and policy to enhance trust in vaccination.

[“One of the greatest medical success stories:” Physicians and nurses’ small stories about vaccine knowledge and anxieties](#)

*Terra Manca*

In recent years, the Canadian province of Alberta experienced outbreaks of measles, mumps, pertussis, and influenza. Even so, the dominant cultural narrative maintains that vaccines are safe, effective, and necessary to maintain population health. Many vaccine supporters have expressed anxieties that stories contradicting this narrative have lowered herd immunity levels because they frighten the public into avoiding vaccination. As such, vaccine policies often emphasize educating parents and the public about the importance and safety of vaccination. These policies rely on health professionals to encourage vaccine uptake and assume that all professionals support vaccination. Health professionals, however, are socially positioned between vaccine experts (such as immunologists) and non-experts (the wider public). In this article, I discuss health professionals’ anxieties about the potential risks associated with

vaccination and with the limitations of Alberta's immunisation program. Specifically, I address the question: If medical knowledge overwhelmingly supports vaccination, then why do some professionals continue to question certain vaccines? To investigate this topic, I interviewed twenty-seven physicians and seven nurses. With stock images and small stories that interviewees shared about their vaccine anxieties, I challenge the common assumption that all health professionals support vaccines uncritically. All interviewees provided generic statements that supported vaccination and Alberta's immunisation program, but they expressed anxieties when I asked for details. I found that their anxieties reflected nuances that the culturally dominant vaccine narrative overlooks. Particularly, they critiqued the influence that pharmaceutical companies, the perceived newness of specific vaccines, and the limitations of medical knowledge and vaccine schedules.

[The possible worlds of global health research: An ethics-focused discourse analysis](#)

*Ben Brisbois, Katrina Plamondon*

Representations of the world enable global health research (GHR), discursively constructing sites in which studies can legitimately take place. Depoliticized portrayals of the global South frequently obscure messy legacies of colonialism and motivate technical responses to health problems with political and economic root causes. Such problematic representations of the world have not yet been rigorously examined in relation to global health ethics, a major site of scholarly effort towards GHR that promotes justice and fairness. We carried out a discourse analysis of four guidance documents relevant to the ethical practice of GHR, purposively selecting texts covering different genres (UN documents and journal articles) and prominent GHR foci (HIV and clinical trials). In light of increasing acknowledgement of the lessons Indigenous health scholarship holds for global health ethics, the four analyzed texts also included a set of principles developed to support Indigenous nation-building. Three of four documents featured global disparities as reasons for ethical caution. These inequalities appeared without explanation or causes, with generation of new scientific knowledge following as a logical response to such disparities. The fourth – Indigenous health-focused – document clearly identified 'colonialism' as a reason for both inequities in society, and related harmful research practices. Solutions to disparities in this text did not necessarily involve cutting-edge research, but focused instead on empowerment and responsiveness to community priorities and needs. These contrasting representations of the world were accomplished in ways that depended on texts' 'participants', or the people they represented; specific vocabularies or language usages; intertextual relationships to prior texts; and overall objectives or intentions of the author(s). Our results illustrate how ethics and other guidance

documents serve as an important terrain for constructing, naturalizing or contesting problematic representations of the world of GHR.

[Therapeutic landscapes and longevity: Wellness tourism in Bama](#)

*Liyuan Huang, Honggang Xu*

Due to the rising demand for healthcare products and concern over environmental pollution, wellness tourism has been booming in China in recent years. The therapeutic landscape theory provides a multi-scale interpretation of wellness tourism to explore how wellness tourists achieve health in healing places. By presenting the results of 83 interviews conducted in Bama, China, this study reveals that the “longevity village” Bama, endorsed by centenarians, provides a retreat that combines natural beauty and a harmonious neighbourhood for wellness tourists. This article argues that although three themes—natural environment, social interaction and symbolic landscape—work together in the healing process of tourists, the symbolic landscape, which is significantly shaped by the longevity culture, plays a dominant role. Longevity in Chinese culture symbolizes the alignment of a strong body, graceful mind, and pleasant habitat. Furthermore, tourism reinforces the importance of symbols and imagination (of a place), the perception of longevity demonstrates the symbolic landscape and thus increases tourists’ attachment to the place, and the unusual environment leads to a different therapeutic landscape from that of daily life. Finally, since to date there has been very few works on therapeutic landscapes in China, it is expected that this study will fill the knowledge gap and broaden the scope of application as well as conceptualization of the therapeutic landscape.

[The symbolic affordances of a video-mediated gaze in emergency psychiatry](#)

*Marianne V. Trondsen, Aksel Tjora, Alex Broom, Graham Scambler*

While mental illness is a significant health challenge worldwide, the availability of specialists is limited, especially in rural areas and for psychiatric emergencies. Although tele-psychiatry, via real-time videoconferencing (VC), is used to provide consultative services in areas that lack psychiatrists, there are a paucity of studies on the use of VC for psychiatric emergencies. We examine how VC matters for patient involvement and professional practice in the first Norwegian emergency tele-psychiatric service. Through a decentralised on-call system, psychiatrists are accessible 24/7 by telephone and VC for patients and nurses in regional psychiatry centres. Based on 29 interviews with patients, psychiatrists and nurses, this article addresses how participation is fostered by VC, and how it may change the social dynamics of therapeutic emergency encounters. We identified four contributions of the ‘video-mediated gaze’ in the therapeutic encounter including those of

the: (1) immediacy of assessment, (2) increased transparency, (3) sense of access to the 'real' expert, and (4) fostering of the patient's 'voice' in therapeutic decisions. These VC inflections of the therapeutic encounter are a mix of the pragmatic (1 and 2) and the symbolic (3 and 4), assembling in these contexts to foster patient-centeredness. With a sociological approach to video-conferenced emergency psychiatry, the identification of symbolic affordances adds necessary nuances to the application of new technologies into fragile therapeutic communication.

["I'm a normal autistic person, not an abnormal neurotypical": Autism Spectrum Disorder diagnosis as biographical illumination](#)

*Catherine D. Tan*

Building on Michael Bury's "biographical disruption" and Kathy Charmaz's "loss of self," which describe the deteriorative impacts of chronic illness on perceptions of selfhood, I propose "biographical illumination"—a transformed conceptualization of self and identity that is facilitated by but extends beyond medical meaning, enriching personal biography and social relationships. The concept is perhaps most applicable to experiences with neurological and neurodevelopmental conditions in which brain difference and personhood are perceived to be closely intertwined. In this study, biographical illumination is used to describe the experiences of autistic adults who learned of their Autism Spectrum Disorder (ASD) diagnosis during teen years or adulthood. Through an ASD lens, participants found explanation for their atypicality and developed a more valued self-concept. Learning of the condition did not disrupt their biography; rather, it became integral to and constitutive of it. With a new self-concept, participants re-gauged personal expectations for normalization and accessed communities of like others, forging relationships that affirmed identity.

[American Journal of Sociology](#)

[Emotions and Knowledge in Expert Work: A Comparison of Two Psychotherapies](#)

*Mariana Craciun*

Knowledge practices, expert and nonexpert alike, have received increased scholarly attention, but their affective underpinnings remain little understood. This article builds on the extant literature and on original ethnographic and interview data to elaborate a model of affective-relational knowledge that distinguishes between emotions' supportive, didactic, and inductive roles in expert work. The author compares psychoanalytic and cognitive behavioral psychotherapeutic practices and shows that all therapists rely on emotions' supportive role. However, while psychoanalytic therapists depend on their emotions'

inductive function to understand patients' internal states, their cognitive behavioral colleagues only rely on this strategy when their own tools fail to show results, emphasizing instead the didactic uses of their affective dispositions. Additionally, clinicians in these orientations adopt different strategies to legitimize their affective-relational work. Although psychotherapists are especially likely to rely on their emotions as epistemic tools, existing studies hint at this model's applicability in other expert domains.

## **Critical Public Health**

### **Cultural ontologies of cancer in India**

*Alex Broom, Katherine Kenny, Vanessa Bowden, Nagesh Muppavaram & Mahati Chittem*

India has undergone a considerable epidemiological transition in the past few decades. The rise of cancer and other chronic illnesses has, and will continue to have, a substantial impact on the overall burden of disease, as well as the lived experiences of illness in India. Little is known about the cultural inflection of cancer in the Indian medical, historical and religious/spiritual landscape, which is both highly varied and rapidly changing. Here, we explore some of the issues emergent from individuals' experiences of illness including their understandings of cancer, its 'origins', its meanings and subsequent everyday experiences. Drawing on interviews with 40 people with cancer in Hyderabad, we focus on the cultural ontologies of cancer in India, the social moralities and evolving individual responsabilisation around cancer, and some of the affective dimensions of these interpretations of illness.

### **Performing Black womanhood: a qualitative study of stereotypes and the healthcare encounter**

*Tina K. Sacks*

The US health system remains fraught with racial, gender, and class biases that lead to health care inequities. Although Black middle-class women are rarely studied in the context of health care disparities, they continue to face stereotyping and differential treatment. I argue that Black middle-class women are aware of pervasive stereotyping which leads them to emphasize specific class and cultural resources, i.e. cultural health capital, to mitigate discrimination. Based on in-depth interviews of 19 middle-class African-American women and two focus groups, the study explores stereotyping, bias and the use of cultural health capital as a strategy to mitigate them. Respondents overwhelmingly endorsed the importance of implementing these strategies, noting they were necessary to avoid differential treatment. The findings highlight pervasive stereotypes Black women face in health care settings and in general. Finally, the



findings refocus our attention to the durability of race and gender discrimination across socioeconomic status and point to fundamental social inequities as determinants of health care disparities.

[Popular television and public mental health: creating media entertainment from mental distress](#)

*Lesley Henderson*

This paper explores how tensions and power differentials within public mental health interact with the practices of media production in entertainment television. I present the findings of a qualitative study involving semi-structured interviews with story consultants from mental health organisations and Senior Executives, Producers and script-writers from UK television series (n = 14). Story advisors welcome the opportunity to reach larger and younger audiences in distinct ways and to share the 'lived experience' of mental distress through well-researched characters. They accept their relative lack of power to negotiate dramatic storylines which conflate mental distress with criminality and may undermine their anti-stigma ideals. The 'medical model' is prioritised in mainstream television drama and the causes of mental distress framed in biomedical terms. Storylines tend to emphasise the certain benefits of medication and marginalise self-management of conditions. Television industry professionals recognise their anti-stigma public service role and are receptive to working with programme consultants to help create authentic characters. Perceptions of the nature of drama as requiring resolution may help to explain the principal focus on biomedical conceptualisations of mental distress. Medication provides a relatively simple on-screen solution to resolve complex stories. Entertainment television operates within limited ideological frames. Mental distress and stigma are addressed at an individual, not collective level. Debates within the survivor movement and public mental health concerning medication, treatment and recovery tend to be obscured. These might provide a productive alternative vein of storytelling that could broaden our understanding of the social meaning of suffering and thus help challenge stigma.

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

[Practices of partnership: Negotiated safety among couples who inject drugs](#)

*Jake Rance, Tim Rhodes, Suzanne Fraser, Joanne Bryant, Carla Treloar*

Despite the majority of needle–syringe sharing occurring between sexual partners, the intimate partnerships of people who inject drugs have been largely overlooked as key sites of both hepatitis C virus prevention and transmission, and risk management more generally. Drawing on interviews

with 34 couples living in inner-city Australia, this article focuses on participants' accounts of 'sharing'. While health promotion discourses and conventional epidemiology have tended to interpret the practice of sharing (like the absence of condom use) in terms of 'noncompliance', we are interested in participants' socially and relationally situated 'rationalities'. Focussing on participants' lived experiences of partnership, we endeavour to make sense of risk and safety as the participants themselves do. How did these couples engage with biomedical knowledge around hepatitis C virus and incorporate it into their everyday lives and practices? Revisiting and refashioning the concept of 'negotiated safety' from its origins in gay men's HIV prevention practice, we explore participants' risk and safety practices in relation to multiple and alternative framings, including those which resist or challenge mainstream epidemiological or health promotion positions. Participant accounts revealed the extent to which negotiating safety was a complex and at times contradictory process, involving the balancing or prioritising of multifarious, often competing, risks. We argue that our positioning of participants' partnerships as the primary unit of analysis represents a novel and instructive way of thinking about not only hepatitis C virus transmission and prevention, but the complexities and contradictions of risk production and its negotiation more broadly.

[Social ecology of resilience and Sumud of Palestinians](#) (open access)  
*Mohammad Marie, Ben Hannigan, Aled Jones*

The aim of this article is to provide an overview of theoretical perspectives and practical research knowledge in relation to 'resilience', the resilience of Palestinians in particular and the related concept of 'Sumud'. 'Sumud' is a Palestinian idea that is interwoven with ideas of personal and collective resilience and steadfastness. It is also a socio-political concept and refers to ways of surviving in the context of occupation, chronic adversity, lack of resources and limited infrastructure. The concept of 'resilience' has deep roots, going back at least to the 10th century when Arabic scholars suggested strategies to cope with life adversity. In Europe, research into resilience extends back to the 1800s. The understanding of resilience has developed over four overlapping waves. These focus on individual traits, protective factors, ecological assets and (in the current wave) social ecological factors. The current wave of resilience research focuses on the contribution of cultural contextualisation and is an approach that is discussed in this article, which draws on Arabic and English language literature located through a search of multiple databases (CINAHL, British Nursing Index, ASSIA, MEDLINE, PsycINFO and EMBASE). Findings suggest that 'Sumud' is linked to the surrounding cultural context and can be thought of as an innovative, social ecological, approach to promoting resilience. We show that resilience is a prerequisite to 'Sumud', meaning that the individual has to be resilient in



order to stay and not to leave their place, position or community. We close by pressing the case for studies which investigate resilience especially in underdeveloped countries such as Palestine (occupied Palestinian territories), and which reveal how resilience is embedded in pre-existing cultural contexts.

[Delaying and seeking care for obstructive sleep apnea: The role of gender, family, and morality](#)

*Dana Zarhin*

Social scientists have proposed various theories as to when, why, and how people come to seek medical care for multiple conditions. Yet, there is still little empirical research to illustrate the pathways into and out of care, especially for chronic illness. This article contributes to this body of work by exploring individuals' reasons for delaying and seeking care for obstructive sleep apnea, which despite being the most diagnosed sleep disorder, has been largely neglected by social scientists. Drawing upon in-depth interviews with 65 Jewish-Israeli obstructive sleep apnea patients, this study shows how intersections of gender, family, and morality shape and are shaped by care-seeking behavior. The analysis reveals that married men claim they do not do health, thereby reaffirming their masculinity, but they maintain moral status because their wives do much of their illness work for them. Unmarried men, however, claim to be more vigilant in their pursuit of health and present it as one of their responsibilities. Women acknowledge they have the double burden of protecting their own health as well as that of their loved ones, and often feel that they are incapable of meeting these social expectations. However, men and women are able to maintain moral status by explaining their neglect of health as resulting from their attempts to care for significant others. Finally, married women differ from men and unmarried women in their motivations for seeking care. In keeping with their gender roles, married women emphasize disturbance to others whereas men stress disturbance to self.

[Tenacious assumptions of person-centred care? Exploring tensions and variations in practice](#)

*Öncel Naldemirci, Doris Lydahl, Nicky Britten, Mark Elam, Lucy Moore, Axel Wolf*

In recent decades, the 'tenacious assumptions' of biomedicine regarding the neutrality and universality of its knowledge claims have been significantly challenged by the growth of new collaborative and patient-focused models of Healthcare delivery. In this article, we discuss and critically reflect upon one such alternative Healthcare model developed at the University of Gothenburg Centre for Person-Centred Care in Sweden. This centre uses three clinical routines of narrative,

partnership and documentation to provide Healthcare to people recognized as unique individuals rather than patients. Person-centred care in Gothenburg and more broadly is based on the assumption that a person is independently capable of reasoning and verbal expression and willing to provide clear and genuine narratives and cooperate with Healthcare professionals. However, we argue that by emphasizing individual capabilities of reasoning and verbal expression, an unnecessarily limited conception of personhood risks being imposed on these routines. Drawing upon semi-structured interviews with researchers in three very different Gothenburg Centre for Person-Centred Care research projects – about healthy ageing in migrant communities, neurogenic communication disorders, and psychosis – we highlight that how persons are recognized as unique and capable varies significantly in practice across different Healthcare settings. Thus, we assert that person-centred care's own potentially tenacious assumptions about the attributes of personhood risk distracting attention away from the variety of creative ways that professionals and persons promisingly find for translating the ideal of person-centred care into practice.

[The lived experience of Huntington's disease: A phenomenological perspective on genes, the body and the lived experience of a genetic disease](#)

*Niclas Hagen*

The purpose of this article is to explore the intersections between genes, the body and the lived experience of a genetic disease. This article is based on empirical material from a study on how individuals affected by Huntington's disease experience their everyday life. This study identified two themes that represent and capture the experience of the affected individuals. The themes are (1) noticing symptoms in everyday life and (2) neither health nor disease. The analysis of the empirical material was performed by employing a theoretical framework based on phenomenology. The findings of this study showed that the lived experiences among individuals affected by Huntington's disease were both fluid and dynamic in their nature. Furthermore, the analysis of the empirical material suggests that this fluid and dynamic character can be linked to a dimension that revolves around the intersections between genetics and the body. Following phenomenologist Drew Leder's outline of the divergence between the invisible and the visible features of the body, the analysis of the empirical material suggests that the mutated gene that causes Huntington's disease can be seen as a phenomenological nullpoint. It is important that the healthcare system acknowledges and addresses the lived experiences that are discussed in this article, particularly, as the use of genetics and genetic testing becomes more widespread usage within medicine.

[Provisionally pregnant: uncertainty and interpretive work in accounts of home pregnancy testing](#)

*Emily Ross*

Upon their availability for purchase in the 1970s, home pregnancy testing devices were hailed as a 'revolution' for women's reproductive rights. Some authors, however, have described these technologies as further enabling the medicalisation of pregnancy and as contributing to the devaluing of women's embodied knowledge. The home pregnancy test is one of many technological devices encountered by women experiencing pregnancy in the United Kingdom today. Existing literature has described how engagement with medical technologies during pregnancy might address uncertainties experienced at this time, providing women with reassurance and alleviating anxieties. Drawing on interviews with women living in Scotland, this article explores accounts of testing for a first pregnancy, and women's descriptions of the impacts of home pregnancy testing upon experiences of early gestation. Participants engaged with pregnancy tests in varying ways, with uses shaping and shaped by their experiences of early pregnancy more broadly. Particular technical characteristics of the home pregnancy test led many participants to question their interpretation of a positive result, as well as the accuracy of the test itself. Rather than addressing the unknowns of early gestation by confirming a suspected pregnancy, a positive result could thus exacerbate uncertainty. Through participants' accounts, this article shows how uncertainty is lived out by users of mundane techno-medical artefacts and sheds new light on women's experiences of the first trimester of pregnancy.

[Health and Place](#)

["There is not a safe space where they can find themselves to be free": \(Un\)safe spaces and the promotion of queer visibilities among township males who have sex with males \(MSM\) in Cape Town, South Africa](#)

*N.R.Hassan, L. Swartz, A.Kagee, A.De Wet, A.Lesch, Z.Kafaar, P.A. Newman*

Males who have sex with males (MSM) are prioritised in the global fight against HIV/AIDS, as a key affected population to receive HIV prevention, treatment, and HIV-related care and support (WHO, 2016). There is, however, limited empirical research conducted on how to engage communities of South African MSM in clinical HIV prevention research programs. The development of LGBTIQ safe spaces may potentially be a viable option to promote community-based engagement by bridging the divides between HIV-prevention researchers, marginalised queer populations, and other HIV-prevention stakeholders located in heteronormative spaces (Molyneux et al., 2016). We conducted ten

in-depth, qualitative interviews with MSM safe space members who have been involved in HIV prevention research programs. Data were analysed using a thematic analytic strategy (Braun and Clarke, 2006). Our results indicate that the “safe spaces” currently operational in Cape Town are not stable spaces nor are they always safe, but they form part of a broader and much more long-term political and geographical strategy of inclusion and emancipation.

### **[Sociology of Health and Illness](#)**

#### **[The concept of chronicity in action: everyday classification practices and the shaping of mental health care](#)**

*Milena D. Bister*

For almost half a century social scientists have explored the phenomenon of chronic illness. In this paper, I examine how the concept of chronicity participates in present-day mental health care settings. Using ethnomethodology and material-semiotic theory within science and technology studies, I investigate how the classification ‘chronically mentally ill’ interacts with the everyday socio-material shaping of public mental health care in the context of professional institutions. Drawing on ethnographic fieldwork in a psychiatric day hospital and in a community day care centre in Berlin, Germany, I demonstrate how the classification of chronicity acts as a tool of description (of people or their conditions), regulation (of therapy, health care or administration), and connection to infrastructures of care (practised technologies or standards of various kinds). In these ways, I argue, the classification engages in actions of producing treatability, arranging resources, demarcating responsibilities, practicing accountability, and doing presence. Notably, community mental health care has developed into a designated territory of the concept: explicitly arranged for ‘the chronically mentally ill’ as a human kind, we can take everyday life in these institutions as instructive of how chronicity is defined in daily practice.

#### **[From loss to repair. A study of body narratives in patient claims for medical injury](#)** (open access)

*Myriam Winance, Janine Barbot, Isabelle Parizot*

In this article we examine the body’s status in the complaints that patients filed with a compensation agency. Taking a corpus of letters, we analyse the way in which the patients mobilise their bodily experience from the angle of the damage for which they demand compensation. To this end, we articulate an approach in terms of the sociology of complaint with an approach rooted in the sociology of medicine, health and illness. To analyse the body narratives, we use the notion of loss. We highlight the manner in which patients approach their losses as ‘losses in practice’.

These losses are defined by the patients putting forward the concrete experience of a body harmed by the treatment received, and by their formulation of expectations in terms of compensation. We therefore identify four ways in which the reality of the damaged body is given a form in terms of expectations of repair: the 'body-producer', the 'body-ecological', the 'body-help' and the 'body-self-image'. Our analysis adds to studies on the status of the body in care and in complaint by showing: the specific influence of the enunciative situation, the plurality of patient evaluations and their temporal dynamic.

[Putting public health infrastructures to the test: introducing HPV vaccination in Austria and the Netherlands](#) (open access)

*Katharina T. Paul, Iris Wallenburg, Roland Bal*

This article presents two cases of policymaking concerning the vaccine against Human Papilloma Virus (HPV), which is sexually transmitted and carcinogenic. Our analysis focuses on its introduction in Austria and the Netherlands. In both contexts, we find prevention and screening to be at once complementary and competing public health logics and we draw on the concept of 'infrastructure' to understand their roles in shaping the reception of the vaccine. We reveal how the HPV vaccine had to be made 'good enough', much like the Pap smear (Casper and Clarke 1998), by means of diverse tinkering practices that transformed both the technology and the infrastructures in which they emerged. At the same time, it was important that the vaccine would not come to problematise Pap smear-based screening. The article points to the contextually contingent nature of policymaking around new medical technologies, and the skillful care with which public health infrastructures such as immunisation and screening programmes are handled and tinkered with.

[Disciplinary power and the process of training informal carers on stroke units](#)

*Euan Sadler, Rebecca Hawkins, David J Clarke, Mary Godfrey, Josie Dickerson, Christopher McKeivitt*

This article examines the process of training informal carers on stroke units using the lens of power. Care is usually assumed as a kinship obligation but the state has long had an interest in framing the carer and caring work. Training carers in healthcare settings raises questions about the power of the state and healthcare professionals as its agents to shape expectations and practices related to the caring role. Drawing on Foucault's notion of disciplinary power, we show how disciplinary forms of power exercised in interactions between healthcare professionals and carers shape the engagement and resistance of carers in the process of training. Interview and observational field note extracts are drawn from a multi-sited study of a training programme on stroke units targeting family

carers of people with stroke to consider the consequences of subjecting caring to this intervention. We found that the process of training informal carers on stroke units was not simply a matter of transferring skills from professional to lay person, but entailed disciplinary forms of power intended to shape the conduct of the carer. We interrogate the extent to which a specific kind of carer is produced through such an approach, and the wider implications for the participation of carers in training in healthcare settings and the empowerment of carers.

[Understanding lay perspectives on socioeconomic health inequalities in Britain: a meta-ethnography](#) (open access)

*Katherine E. Smith, Rosemary Anderson*

The links between socioeconomic circumstances and health have been extensively studied in Britain but surprisingly few studies consider lay perspectives. This is problematic given popular efforts to reduce health inequalities appear to be based on assumption that public understanding is limited (this is evident in efforts to raise awareness of both 'upstream' causes of health inequalities and health-damaging behaviours). The results of this meta-ethnography, involving 17 qualitative studies, fundamentally challenge this assumption. We show, first, that people who are living with socioeconomic disadvantage already have a good understanding of the links between socioeconomic hardship and ill-health. Indeed, participants' accounts closely mirror the research consensus that material-structural factors represent 'upstream' determinants of health, while 'psychosocial' factors provide important explanatory pathways connecting material circumstances to health outcomes. Despite this, people living in disadvantaged circumstances are often reluctant to explicitly acknowledge health inequalities, a finding that we suggest can be understood as an attempt to resist the stigma and shame of poverty and poor health and to (re)assert individual agency and control. This suggests that work to increase public awareness of health inequalities may unintentionally exacerbate experiences of stigma and shame, meaning alternative approaches to engaging communities in health inequalities discussions are required.

[Hybrid bodies and the materiality of everyday life: how people living with pacemakers and defibrillators reinvent everyday routines and intimate relations](#)

*Nelly Oudshoorn*

Technologies inside bodies pose new challenges in a technological culture. For people with pacemakers and defibrillators, activities such as passing security controls at airports, using electromagnetic machines, electrical domestic appliances and electronic devices, and even intimate contacts with their loved ones can turn into events where the proper



functioning of their device may be at risk. Anticipation of potentially harmful events and situations thus becomes an important part of the choreography of everyday life. Technologies inside bodies not only pose a challenge for patients living with these devices but also to theorising body-technology relations. Whereas researchers usually address the merging of bodies and technologies, implants ask us to do the opposite as well. How are we to understand human-technology relations in which technologies should not entangle with bodies because they serve other purposes? Based on a study of the daily life practices of people with pacemakers and defibrillators in the Netherlands and the US, I argue that disentanglement work, i.e. work involved to prevent entanglements with objects and people that may inflict harm upon implanted devices, is key to understanding how hybrid bodies can survive in today's densely populated technological landscape.

### [Theory, Culture & Society](#)

#### [Merleau-Ponty and the Measuring Body](#)

*Aud Sissel Hoel, Annamaria Carusi*

In recent years a growing number of scholars in science studies and related fields are developing new ontologies to displace entrenched dualisms. These efforts often go together with a renewed interest in the roles played by symbolisms and tools in knowledge and being. This article brings Maurice Merleau-Ponty into these conversations, positioning him as a precursor of today's innovative recastings of technoscience. While Merleau-Ponty is often invoked in relation to his early work on the body and embodiment, this article focuses on his later work, where the investigation of perception is integrated with an ontological exploration. The resulting approach revolves around the highly original idea of the body as a standard of measurement. We further develop this idea by coining the term 'the measuring body', which to a greater extent than did Merleau-Ponty accentuates the relative autonomy of symbolisms and tools and their capacity to decentre the perceiving body.

#### [Biopolitics Meets Biosemiotics: The Semiotic Thresholds of Anti-Aging Interventions](#)

*Ott Puumeister, Andreas Ventsel*

Biosemiotics and the analysis of biopower have not yet been explicitly brought together. This article attempts to find their connecting points from the perspective of biosemiotics. It uses the biosemiotic understanding of the different types of semiosis in order to approach the practices of biopower and biopolitics. The central concept of the paper is that of the 'semiotic threshold'. We can speak of (1) the lower semiotic threshold, signifying the dividing line between non-semiosis and semiosis; and (2) the

secondary semiotic thresholds, signifying the borders between different types (iconic, indexical, symbolic) of semiosis. Speaking in terms of types of semiosis means speaking in terms of different capabilities for normativity, which is why the article uses the approaches of Michel Foucault on normalization in biopower and of Georges Canguilhem on organismic normativity. As an example on which biopolitics and biosemiotics could connect, the discourse of regenerative and anti-aging medicine is used.

### [Earworms, Daydreams and Cognitive Capitalism](#)

*Eldritch Priest*

Although the cognitive neurosciences are currently conducting research to determine the brain networks that are implicated in the production of 'earworms', my project seeks to address the technical nature of these abstract parasites that hears their spontaneous irruption in thought as both a product and source of contemporary capitalism's aim to draw value from involuntary nervous activities. In this respect, I approach the earworm from a deliberately speculative perspective in order to conceptualize its appearance as a technical matter expressive of the way historically 'useless thinking' (daydreaming, mind-wandering) is being imaginatively recuperated as a passive technology of the self. However, the earworm is a peculiar case of useless thinking, for its redundancy not only implicates it in the broader process of recuperation, but seems to realize a fatal tendency in sonic technics in ways that at once rely on, advance and disturb contemporary capitalism's encroachment on human cognitive capacities.

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