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## In the Journals, March 2020, Part 2

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By Megh Marathe

[Medical Anthropology Quarterly](#)

[Corporate Logic in Clinical Care: The Case of Diabetes Management](#)

*Linda M. Hunt, Hannah S. Bell, Anna C. Martinez-Hume, Funmi Odumosu, Heather A. Howard*

As large corporations come to dominate U.S. health care, clinical medicine is increasingly market-driven and governed by business principles. We examine ways in which health insurers and health care systems are transforming the goals and means of clinical practice. Based on ethnographic research of diabetes management in a large health care system, we argue that together these organizations redefine clinical care in terms that prioritize financial goals and managerial logics, above the needs of individual patients. We demonstrate how emphasis on quality metrics reduces clinical work to quantifiable outcomes, redefining diabetes management to be the pursuit of narrowly defined goal numbers, despite often serious health consequences of treatment. As corporate employees, clinicians are compelled to pursue goal numbers by the heavy emphasis payers and health systems place on quality metrics, and accessing the required medications becomes the central focus of clinical practice.

[Expanding Personhood beyond Remembered Selves: The Sociality of Memory at an Alzheimer's Center in Poland](#)

*Jessica C. Robbins*

Examining the social and processual dimensions of personhood can transform ethnographic and clinical understandings of “person-centered care” in dementia care specifically and in medicine more generally. Ethnographic research among people with early-stage Alzheimer’s disease in a day center in Poznań, Poland, shows that practices of remembering involving collective memory can sustain personhood and foster ties of relatedness among people with dementia, defying some expectations about the destructive effects of dementia on personhood. This apparent

paradox between people with dementia's loss of memory and their capacity to build social relations based on remembering can be resolved through expanding understandings of personhood to include practices of remembering involving collective pasts—in this case, through shared national frameworks and embodied practices of sociality. Attending to these two dimensions of collective memory reveals unexpected aspects of personhood among people with dementia.

### [Living with/out Dementia in Contemporary South Korea](#)

*Jieun Lee*

While the debate on diagnostic disclosure is often based on the premise that knowing about one's condition (the diagnosis and its prognosis) is essential in securing the patient's autonomy, many people with dementia in Korea are not told directly about their diagnosis. This article concerns the laborious and ethically contentious post-diagnostic living undertaken by the families of people with dementia, which I call "living with/out dementia." This is a paradoxical form of living that has emerged through the increasing biomedicalization of dementia, the socialization of elder care, and an enduring fear of dependency in old age. Attending to how living with/out dementia comes to be initiated and maintained through efforts of care, I argue that nondisclosure entails a kind of ethical process through which dementia is un/done in the caregivers' struggle to truthfully engage with the person with dementia while actively hiding the diagnostic truth from him or her.

### [Conjuring Biosecurity in the Post-Ebola Kissi Triangle: The Magic of Paperwork in a Frontier Clinic](#)

*Raphael Frankfurter*

This article considers the increasing centrality of biosecurity and epidemiological surveillance as key priorities for the Sierra Leonean health care system after the 2014–2016 Ebola outbreak. Amid this broad shift from conceiving of clinics as sites primarily for the provision of therapeutics to instead sites for disease surveillance and threat mitigation, paperwork regimes have proliferated within remote facilities that are out of stock of nearly all supplies and unable to address even the most basic of infectious diseases. Drawing on fieldwork in one such clinic in the region in which Ebola first emerged, I describe one nurse whose endless paperwork tasks seem to have transformed into a type of magical therapeutic practice, resonant with other forms of local text-based

healing. Thus, I reflect on the ways that the logics of the fetish—and the emergent ambiguities and perils therein—come to operate through paperwork for local healing practices and biosecuritization efforts alike.

[Into the Machine: Economic Tools, Sovereignty, and Joy in a Global Health Institution](#)

*Alexis Walker*

Since the early 1990s, the World Bank and Inter-American Development Bank have led efforts advocating the use of economic tools in setting priorities for health spending in poor countries. But while these powerful global health institutions present economic management as the key to improving health, they often fail to implement even their own policies requiring the use of economic tools for health project planning. In these institutions, economic tools operate beyond application for decision-making, becoming simultaneously a site of tensions regarding sovereignty and sites of enjoyment for economists at development bank headquarters. This article traces the ways that economic tools are both deployed and left aside across development bank networks, and in the process are productive of both affect and power. Attention to frictions in the use of economic tools ought to help motivate more just global health governance, taking into account political considerations that are built into expert practice.

[Liminal Living: Everyday Injury, Disability, and Instability among Migrant Mexican Women in Maryland's Seafood Industry](#) (*open access*)

*Thurka Sangaramoorthy*

Mexican women constitute an increasing proportion of labor migrants to the United States. They are segregated into a handful of low-wage occupations, disadvantaged by global economic forces and the social construction of gender within employment relations. Drawing on ethnographic research from Maryland's Eastern Shore, I explore experiences of everyday injury, disability, and instability among Mexican migrant women who work in the commercial crab processing industry, which is increasingly dependent on the H-2B visa program to fill seasonal, non-agricultural jobs. By focusing on the daily lives of Mexican migrant women who are part of this labor force, their health and social needs, and the gendered dimensions of labor migration, I document how temporary work programs institutionalize liminality

as permanent mode of being. I suggest that migrant women, amid the extraordinary uncertainty brought about by the processes of recurrent migration, reorient and recalibrate themselves through modes of conduct to make life more ordinary.

[Cancer and Conjuality in Contemporary Delhi: Mediating Life between Violence and Care](#)

*Dwaipayan Banerjee*

This article tracks the entanglement of cancer and patterns of conjuality in Delhi. Building on fieldwork with about 120 households in Delhi, it describes how the disease put pressure on already fraught marital biographies, revealing durable fissures in household relations. Often, these shifts in the distribution of conjugal vulnerability opened cracks that allowed long histories of domestic violence to seep through. In subtle ways, women could accrue a delicate agency through their practices of care. But at the same time, they continued to inhabit the vulnerable space of affinal homes. This article describes how in these arrangements, care and violence followed each other closely in their tracks. Building on these insights, the article deepens and shifts how anthropologists have understood the social life of the cancer. Specifically, anthropologists writing about the disease have demonstrated the ubiquity of a biotechnical imaginary of hope and survivorship in the Global North. This article develops an anthropology of cancer from the Global South that takes seriously the work of palliation and reconciliation, in the process provincializing Global North imaginaries of hope and survivorship.

[Social Science & Medicine](#)

[The mask of autism: Social camouflaging and impression management as coping/normalization from the perspectives of autistic adults](#)

*Iris Schneid, Aviad E.Raz*

Autism entails impression management, including social camouflaging, under conditions of conflict and stigma, with reduced ability to perform such social interaction as well as an increased toll that accompanies it. To examine the meanings of impression management and social camouflaging from the point-of-view of autistic people, we conducted a participatory study that included semi-structured interviews with 24 Israeli autistic adults in 2017–2018. We present views on the difference between camouflaging and impression management; impression

management as a social asset; the ambivalence of camouflaging; the limits of impression management; and autistic forms of social communication that provide an alternative to impression management and camouflaging. These perspectives are discussed as leading from prioritizing social integration to prioritizing autistic empowerment. We further explore how the stigma of autism is turned, through camouflaging, into the mask of autism, offering to deconstruct the neurotypical premises of academically-approved concepts of socialization and impression management. Emancipatory participative research thus provides a unique opportunity not only to sociologically explore the deeper contours of “social disability” but also the “disabilities of sociology”, offering directions for the neuro-diversification of sociology, in parallel with the recent thrust of building a “sociology of autism”.

### [Credibility work and moral evaluation at the ED](#)

*Marius Wamsiedel*

This paper contributes to the understanding of triage decision making by analyzing the credibility work jointly performed by patients and staff and its contribution to the non-clinical evaluation of clientele. I argue that the assessment of credibility occurs at the intersection between staff-devised typifications and patients' interactional performance, and is mediated by staff's experiential knowledge. In ordinary circumstances, patients can achieve credibility through three interactional strategies: embodying distress, limiting the voice of the lifeworld, and conveying narrative frankness. Patients belonging to groups associate by triage workers with disreputable characteristics, such as dishonesty, have the additional task of establishing themselves as trustworthy interlocutors by mobilizing worth claims. Embodying distress and limiting the voice of the lifeworld are instrumental to asserting legitimacy, whereas narrative frankness is an interactional prerequisite for manufacturing reasonableness.

### [Is healthy eating too expensive?: How low-income parents evaluate the cost of food](#)

*Caitlin Daniel*

Debates about whether a healthy diet is affordable often overlook how low-income consumers themselves evaluate food cost. This question is relevant to explaining food choices and measuring food prices. Drawing on interviews with 49 low-income primary caregivers and grocery-shopping observations with 34 of these

interviewees, I find that respondents judge food cost in two ways: 1) absolute judgments, or assessments of whether a food covers a family's needs with scarce resources and 2) relative judgments, or interpretations of price relative to another food that frames an item as affordable or pricey by contrast. Absolute judgments reflect actual expenditures, including not just the sticker price, but also four underappreciated monetary costs. These underappreciated costs stem from food waste; packages containing more than is needed; food that is consumed too quickly; and unsatiating foods. When monetary costs go unmeasured and when consumers interpret prices in relative terms, researchers' views of food cost diverge from the experiences of low-income people. Divergent views have two results: food-cost estimates overstate the affordability of a healthy diet and observers may misconstrue purchases as financially imprudent. These findings can inform policy, programming, and public discourse.

[Reassessing mental illness stigma in mental health care: Competing stigmas and risk containment](#)

*Kerry M. Dobransky*

Research on mental illness stigma tends to focus on the most severe diagnoses and settings, and it pays insufficient attention to how the treatment process itself relates to stigma. This study, calling on 28 interviews with providers treating a wide range of mental problems in varied settings, addresses these issues. Findings reveal that stigma is associated with treatment across settings and severity, although dynamics vary based on the intensity of setting. Mental illness stigma competes with other stigmas in presenting for treatment. Once in treatment, mental health care acts as a stigma-mitigating "stamp" of risk containment for other societal systems and institutions, signifying that risks posed by clients' problems are being officially contained.

[Race, death of a child, and mortality risk among aging parents in the United States](#)

*Rachel Donnelly, Debra Umberson, Robert A. Hummer, Michael A. Garcia*

The death of a child is a stressful and traumatic life event that has been linked to increased mortality risk among parents. Tragically, black parents are significantly more likely than white parents to lose a child in the United States; however, prior research has not addressed this racial disadvantage in relation to parents' mortality risk. In this study, we focus on the racial context of the United

States to suggest that black parents already face higher mortality rates compared to white parents, and the unequal burden of child death adds to their mortality risk. Using discrete-time event history models, we consider whether the death of a child by midlife is associated with increased mortality risk for black parents and for white parents in mid- to later-life using longitudinal data from the Health and Retirement Study (HRS; 1996–2016). Descriptive results show that by midlife, black parents, especially black mothers, experience substantially higher child mortality compared with white parents. At the same time, we find that losing a child prior to midlife is associated with heightened mortality risk for aging black mothers and white mothers. Controlling for educational attainment explains the association between child death and parental mortality risk among white mothers, whereas heightened biopsychosocial and behavioral risk factors explain the association for black mothers. Overall, the death of a child is associated with increased mortality risk for black mothers and for white mothers, but the processes linking child death to parental mortality seem to differ for black and white parents. These findings have implications for policies and interventions that address increased mortality risk for parents following the death of a child.

[Exploring the geography of suicide threats and suicide attempts: An application of Risk Terrain Modeling](#)

*Kim M. Lersch*

The purpose of this research is twofold: first, the spatial distribution of 911 emergency calls for service to the police for suicides in progress and threats of suicide in the City of Detroit, Michigan will be explored to determine whether these events exhibit different patterns of spatial clustering. Second, this research will explore the utility of Risk Terrain Modeling (RTM) to assist in our understanding of the locations of calls for service to the police related to suicide threats and suicides in progress. The results suggest that these events are different social phenomenon, both with respect to the spatial clustering of these events as well as qualitative differences in the environmental factors that may contribute to their occurrence.

[How organizations shape medical technology allocation: Insulin pumps and pediatric patients with type 1 diabetes](#)

*Cassidy Puckett, Jenise C. Wong, Tanicia C. Daley, Kristina Cossen*

Although guidelines for prescribing insulin pumps to patients with

type 1 diabetes (T1D) focus on patient assessment, sociological research shows decision-making is influenced by the organizations within which actors are embedded. However, how organizational context shapes unequal resource allocation by race and class is less well understood. To investigate this, we compare two pediatric endocrinology centers differing in racial and socio-economic equity in pump use. Using over 400 h of observations and 16 provider interviews, we find allocation is shaped by how organizations use patient cultural health capital to determine pump eligibility, frame technology use, and structure decision-making processes. Overall, findings extend health inequalities research by describing how organizations shape technology resource allocation by race and class.

### [Sociology of Health & Illness](#)

#### [Doing care work on the fly – exploring the unnoticed socio?emotional skills of male ambulance staff](#)

*Morten Kyed*

Prehospital ambulance work is a healthcare arena hitherto neglected by sociologists of health and illness. This is unfortunate because it is an interesting and dynamic area, and in contrast to most healthcare sectors, it is male dominated. Via ethnographic fieldwork, this article examines the particular caring practices and socio?emotional skills that ambulance staff use in practising prehospital care work. The empirical analysis outlines six recurring prehospital practices: medicine work, machine work, scene management, becalming work, communication work and bodywork. Each practice represents a different element of prehospital care practice and is best understood as a repertoire, as many different assemblages of these care practices can work effectively in prehospital situations. The article concludes that despite institutionalised blue?collar masculinity, numeric dominance and scarce formal education in ambulance psychology, male ambulance staff are generally proud and reflexive care practitioners.

#### [Restraint minimisation in mental health care: legitimate or illegitimate force? An ethnographic study](#)

*Mick McKeown, Gill Thomson, Amy Scholes, Fiona Jones, Soo Downe, Owen Price, John Baker, Paul Greenwood, Richard Whittington, Joy Duxbury*

Coercive practices, such as physical restraint, are used globally to respond to violent, aggressive and other behaviours displayed by mental health service users.<sup>1</sup> A number of approaches have been designed to aid staff working within services to minimise the use of restraint and other restrictive practices. One such approach, the 'REsTRAIN Yourself' (RYS) initiative, has been evaluated in the UK. Rapid ethnography was used to explore the aspects of organisational culture and staff behaviour exhibited by teams of staff working within 14 acute admission mental health wards in the North West region of the English NHS. Findings comprise four core themes of space and place; legitimation; meaningful activity; and, therapeutic engagement that represent characteristics of daily life on the wards before and after implementation of the RYS intervention. Tensions between staff commitments to therapeutic relations and constraining factors were revealed in demarcations of ward space and limitations on availability of meaningful activities. The physical, relational and discursive means by which ward spaces are segregated prompts attention to the observed materialities of routine care. Legitimation was identified as a crucial discursive practice in the context of staff reliance upon coercion. Trauma-informed care represents a potentially alternative legitimacy.

['Well, I knew this already' – explaining personal genetic risk information through narrative meaning-making](#)

*Karoliina Snell, Ilpo Helén*

This article presents results from a Finnish focus group's study conducted among participants of a project called GeneRISK, in which the participants received a personal risk score for having a cardiovascular event based on genetic analysis, lifestyle and laboratory results. In the discussions, interpretations of the genetic risk score and its meaning were incorporated into personal narratives of health and illness. We argue that instead of serving as an explanation for health and illness, which can help guide people's lives and choices, the genetic risk information became an object of explanation. Therefore, the risk information did not create new conceptions of personal risk, nor did it generate enough power to push people to change their lifestyles. Instead, the risk information was used to strengthen the existing impression of personal risk and the narrative of personal health and illness.

[Stigma, trauma and sexuality: the experiences of women hospitalised with serious mental illness](#)

*Emma C. Frieh*

Women with serious mental illness (SMI) occupy a social position in which their experiences are simultaneously influenced by stigmatisation, institutionalisation and gendered dimensions of trauma and power. Women with SMI are stigmatised in society, pushed to the margins and left vulnerable to victimisation and rejection, particularly if hospitalised in psychiatric institutions. Using modified labelling theory, I investigate how women hospitalised with SMI, especially those who have histories of sexual abuse and trauma, experience sexuality and perceive men and masculinity. I extend modified labelling theory by empirically analysing the role of social status and power in the labelling process. Specifically, I focus on gender, and analyse interviews with 55 women in US psychiatric hospitals, focusing on gendered experiences of trauma, stigma and attitudes about sexuality. I show how trauma increases the salience of stigma and potential for retraumatisation, both of which are amplified by the institutional setting. I find meaningful differences in the narratives of women who have experienced trauma and those who have not. Modified labelling theory helps explain how labelling can perpetuate self-stigma, which threatens women's self-esteem, safety and trust in others. The intersection of these experiences extends modified labelling theory and may have profound implications for recovery.

[Parents' constructions of normality and pathology in child mental health assessments](#)

*Michelle O'Reilly, Tom Muskett, Khalid Karim, Jessica N. Lester*

Central to a contemporary understanding of childhood is the developmental and clinical/medical construct of the 'normal' child. When judged to fall outside of culturally, socially and historically situated parameters of 'normality', children become labelled as 'deviant from the norm'; for instance, in mental health contexts where this may provide the basis for psychiatric diagnosis. However, judgements of a child's 'normality' are further complicated by the range of individuals who may have a stake in that construction, including parents/carers, professionals and the child themselves. Using discursive psychology, we analysed 28 video-recorded UK child mental health assessments, to examine ways that parents presented concerns about their children's development. They did this by drawing on notions of 'ab/normal', in ways that functioned to legitimise their need for services and built a rhetorical case to demonstrate clinical need; often by contrasting the child with other 'typical' children and/or

contrasting the same child's behaviour in different settings or contexts. We concluded that given the growing crisis in child mental health, initial assessments play a crucial clinical role in determining diagnosis and labelling, and therefore, a critical discussion of these concepts and processes is essential.

[Explaining the social gradient in smoking and cessation: the peril and promise of social mobility](#)

*Frances Thirlway*

Smoking in high-income countries is now concentrated in poor communities whose relatively high smoking prevalence is explained by greater uptake but above all by lower quit rates. Whilst a number of barriers to smoking cessation have been identified, this is the first paper to situate cessation itself as a classed and cultural practice. Drawing on ethnographic research carried out in a working-class community in the North of England between 2012 and 2015, I theorise smoking cessation as a symbolic practice in relation to the affective experience of class and social mobility. I show that ambivalence about upward mobility as separation and loss translated into ambivalence about smoking cessation. The reason for this was that the social gradient in smoking operated dynamically at the level of the individual life course, i.e. smoking cessation followed upward mobility. A serious health problem was an appropriate reason to quit but older women continued to smoke despite serious health problems. This was linked to historical gender roles leading to women placing a low priority on their own health as well as the intergenerational reproduction of smoking through close affective links with smoking parents.

[Therapy without a prescription: buprenorphine/naloxone diversion and the therapeutic assemblage in Taiwan \(open access\)](#)

*Jia-shin Chen*

Buprenorphine/naloxone (B/N) therapy is a prescription pharmacotherapy for opioid dependence. For certain health service providers, when B/N escapes supervision and diverts into the hands of people for whom it is unintended, it can pose serious risks even if it may still have therapeutic benefits. The line between therapy and diversion is thus a problematic one. By qualitatively analysing archival review and in-depth interviews, this study uses the concept of a therapeutic assemblage to understand the relationships among government, knowledge, and professionals

that surround the regulation of B/N in Taiwan. The therapeutic assemblage is characterised by the partitioning of administration, the loose regulation of prescription, the exclusion of addiction treatment from National Health Insurance (NHI), and the materiality and technicality of therapies. These elements contribute to the therapeutic assemblage's different territorial modes as reflected in the substance schedules that allow for diversion. This is the first grounded work in Asia that empirically examines and theoretically explains the diversion of B/N from an assemblage perspective. It suggests establishing new associations by incorporating addiction treatment into NHI. Lastly, it addresses the analytic purchase of the assemblage approach in unveiling and problematising unintended outcomes of an intervention.

[Islamophobia in the National Health Service: an ethnography of institutional racism in PREVENT's counter-radicalisation policy](#)

*Tarek Younis, Sushrut Jadhav*

In 2015, the UK government made its counter-radicalisation policy a statutory duty for all National Health Service (NHS) staff. Staff are now tasked to identify and report individuals they suspect may be vulnerable to radicalisation. Prevent training employs a combination of psychological and ideological frames to convey the meaning of radicalisation to healthcare staff, but studies have shown that the threat of terrorism is racialised as well. The guiding question of our ethnography is: how is counter-radicalisation training understood and practiced by healthcare professionals? A frame analysis draws upon 2 years of ethnographic fieldwork, which includes participant observation in Prevent training and NHS staff interviews. This article demonstrates how Prevent engages in performative colourblindness – the active recognition and dismissal of the race frame which associates racialised Muslims with the threat of terrorism. It concludes with a discussion of institutional racism in the NHS – how racialised policies like Prevent impact the minutia of clinical interactions; how the pretence of a 'post-racial' society obscures institutional racism; how psychologisation is integral to the performance of colourblindness; and why it is difficult to address the racism associated with colourblind policies which purport to address the threat of the Far-Right.

[Exploring health behaviours: understanding drinking practice using the lens of practice theory](#)

*Kath Hennell, Maria Piacentini, Mark Limmer*

Research suggests that there is no safe amount of alcohol but despite this alcohol consumption remains an important part of many [young] people's lives. Viewed as an inherently social activity, drinking alcohol provides an opportunity for socialising and connecting with friends. This study is one of the first to draw on practice theory to explore one type of intoxicated drinking occasion engaged in by young people; framed in this article as a 'proper night out'. This article argues that this hybrid entity is made up of a series of interconnected social practices that have come and now hang together to serve to normalise and routinise intoxicated drinking occasions. The operationalisation of practice theory has enabled an in-depth exploration of intoxicated drinking and provides the potential for new ways of intervening in harmful drinking practices by refocusing attention away from individual level decision-making to drinking practices.

[Pregnancy and childbirth in English prisons: institutional ignominy and the pains of imprisonment](#) (*open access*)

*Laura Abbott, Tricia Scott, Hilary Thomas, Kathy Weston*

With a prison population of approximately 9000 women in England, it is estimated that approximately 600 pregnancies and 100 births occur annually. Despite an extensive literature on the sociology of reproduction, pregnancy and childbirth among women prisoners is under-researched. This article reports an ethnographic study in three English prisons undertaken in 2015-2016, including interviews with 22 prisoners, six women released from prison and 10 staff members. Pregnant prisoners experience numerous additional difficulties in prison including the ambiguous status of a pregnant prisoner, physical aspects of pregnancy and the degradation of the handcuffed or chained prisoner during visits to the more public setting of hospital. This article draws on Erving Goffman's concepts of closed institutions, dramaturgy and mortification of self, Crewe et al.'s work on the gendered pains of imprisonment and Crawley's notion of 'institutional thoughtlessness', and proposes a new concept of institutional ignominy to understand the embodied situation of the pregnant prisoner.

[Social Theory and Health](#)

[A wager on the future: a practicable response to HIV pre-exposure prophylaxis \(PrEP\) and the stubborn fact of process](#)

*Marsha Rosengarten, Dean Murphy*

In this article we focus on public health's wager on the social implications of a daily antiretroviral pill to prevent HIV, referred to as PrEP (pre-exposure prophylaxis). The wager is shown to rely on modes of inquiry overly tied to what is known of the present in order to predict the future. Although such inquiry is not unusual when social research is called upon to assist health policy, predictive methodologies are unable to appreciate the dynamic and thus indeterminate nature of process. We ask: what mode of inquiry might practicably appreciate that what happens in the present will have a bearing on the future, without foreclosing on unknown possibles? Drawing on speculative and pragmatic philosophy, we reflect on our own qualitative research on PrEP to suggest that conventional methodological approaches can contribute to the future without seeking to determine what it will become.

[Mythical dementia and Alzheimerised senility: discrepant and intersecting representations of cognitive decline in later life](#)

*James Rupert Fletcher*

Dementia is a growing global health concern as worldwide incidence increases amidst population ageing. How people affected by dementia understand the condition is important in influencing their emotional and behavioural responses to it. Improved knowledge of these understandings could inform support that is better tailored to people's needs. The biomedical research community articulates an understanding of 'mythical dementia' comprising a syndrome of cognitive decline caused by numerous discrete neuropathological processes. In this paper, I draw on data from interviews with people affected by dementia to explore how their understandings of dementia differ from the biomedical 'mythical dementia'. People affected by dementia articulate understandings of 'Alzheimerised senility', attributing personal change to a combination of illness, ageing and personality, within a broader context of comorbidity and semi-naturalised decline. These understandings resemble traditional notions of senility, but they are Alzheimerised through the introduction of biomedical ideas. These findings are important in the contemporary political context of early diagnosis promotion.

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

[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.

### [Medical Humanities](#)

#### [Graphic illustration of impairment: science fiction, Transmetropolitan and the social model of disability](#) (*open access*)

*Richard Gibson*

The following paper examines the cyberpunk transhumanist graphic novel *Transmetropolitan* through the theoretical lens of disability studies to demonstrate how science fiction, and in particular this series, illustrate and can influence how we think about disability, impairment and difference. While *Transmetropolitan* is most often read as a scathing political and social satire about abuse of power and the danger of political apathy, the comic series also provides readers with representations of impairment and the source of disability as understood by the Social Model of Disability (SMD). Focusing on the setting and fictional world in which *Transmetropolitan* takes place, as well as key events and illustration styling, this paper demonstrates that the narrative in this work encompasses many of the same theoretical underpinnings and criticisms of society's ignorance of the cause of disability as the SMD does. This paper aims, by demonstrating how *Transmetropolitan* can be read as an allegory for the disabling potential of society as experienced by individuals with impairments, to prompt readers into thinking more creatively about how narratives, seemingly unconcerned with disability, are informed and can be understood via disability theory.

[Ethics in cross-cultural encounters: a medical concern?](#)

*Arild Kjell Aambø*

Modern medicine's investment in the disembodied, objective 'science' of biomedicine, where patients are transformed from suffering subjects to objects of investigation, calls for heightened ethical awareness. Around the world, ethical codes of conduct emphasise beneficence and non-maleficence. Lately, we have also seen a quest for autonomy and equitable healthcare for diverse populations. However, these tenets alone do not effectively address the problems which regularly occur in transcultural consultations. By developing a 'space for reflection' based on selected writings of the moral philosophers Axel Honneth, Emmanuel Levinas and Hans Jonas, my aim is to cast light on this issue. Given the differing aspects of the doctor-patient relationship, clearly there are no clear-cut rules to obey. However, a thematic analysis of a quote from a Somali, female refugee, supported by some other studies on medical practice, suggests that, metaphorically speaking, within the developed space for reflection, medical practice has worked itself into a corner. By neglecting the patient as a social being, lacking openness to alterity, and not conveying needed information, they make it very difficult for patients to take responsibility for their situation. In spite of doctors' benevolence, the result is alienation, increased suffering and thus, potential harm. Similar tendencies are reflected in a number of recent studies on medical consultations. Therefore, rather than blaming the single doctor for moral deceit, we should see these tendencies as a 'forgetfulness of recognition' that affects the medical profession, a disturbance which source probably is hidden in doctors training.

[Prosthesis and the engineered imagination: reading augmentation and disability across cultural theory, representation and product design](#) (*open access*)

*Raymond Holt, Stuart Murray*

This article argues for the value of considering the interaction of literary/cultural studies, disability studies and engineering/design studies in the ongoing development of a critical medical humanities research frame. With a specific focus on prosthesis, but also considerations of embodiment, technology and augmentation as concepts in both cultural/disability theory and engineering/design, we note how the shifting and plastic ideas of 'the prosthetic' as used within cultural studies have never been in conversation with

scholars who work on prostheses in engineering design or the processes through which such technologies are produced. Additionally, we show that the increased use of systems engineering in the design and construction of prostheses creates fractured ideas of disabled bodies that frequently ignore both the cultural meaning and lived experience of technology use. In design and engineering, prostheses are literal objects, often made to order for a diverse range of clients and produced across different working platforms; in cultural studies, the word creates multiple resonances around both augmented bodies and non-embodied states increasingly understood in terms of assemblage and supplementarity. Working from this, we outline how questions of metaphor, materiality and systems weave through the different disciplines. The article claims that a critical dialogue between the working methods of literary/cultural studies and engineering/design, for all their obvious differences, possesses the potential to create informed and sophisticated accounts of disability embodiment. Our conclusion brings the strands of the enquiry together and points to the merits of engineering the imagination, and imagining engineering, as both a subject and method in future medical humanities research.

[Estranged relations: coercion and care in narratives of supported decision-making in mental healthcare](#) (*open access*)

*Meredith Stone, Renata Kokanovic, Felicity Callard, Alex F Broom*

Supported decision-making has become popular among policymakers and mental health advocates as a means of reducing coercion in mental healthcare. Nevertheless, users of psychiatric services often seem equivocal about the value of supported decision-making initiatives. In this paper we explore why such initiatives might be rejected or ignored by the would-be beneficiaries, and we reflect on broader implications for care and coercion. We take a critical medical humanities approach, particularly through the lens of entanglement. We analyse the narratives of 29 people diagnosed with mental illness, and 29 self-identified carers speaking of their experiences of an Australian mental healthcare system and of their views of supported decision-making. As a scaffolding for our critique we consider two supported decision-making instruments in the 2014 Victorian Mental Health Act: the advance statement and the nominated person. These instruments presuppose that patients and carers endorse a particular set of relationships between the agentic self and illness, as well as between patient, carer and the healthcare system. Our participant narratives instead conveyed 'entangled'

relations, which we explore in three sections. In the first we show how ideas about fault and illness often coexisted, which corresponded with shifting views on the need for more versus less agency for patients. In the second section, we illustrate how family carers struggled to embody the supported decision-making ideal of the independent yet altruistic nominated person, and in the final section we suggest that both care and coercion were narrated as existing across informal/formal care divisions. We conclude by reflecting on how these dynamic relations complicate supported decision-making projects, and prompt a rethink of how care and coercion unfold in contemporary mental healthcare.

[Beyond Messiaen's birds: the post-verbal world of dementia](#) (*open access*)  
*Stuart Wood*

This paper investigates the use of verbatim musical transcription as a research method in dementia care. It reports on an art-based ethnographic study (Aesthetic Research in Everyday Life (Aeriel)) in which verbatim transcription was applied to everyday interactions in dementia care, making use of musical—instead of verbal—notation. Starting from the notion that medical and healthcare settings can be sites of ‘found performance’, the paper reviews literature relating to artistic methodologies within medical humanities, music, ethnography and dementia care. From this review, it proposes a research design and method of verbatim musical transcription as a potential avenue of investigating communication between carer and cared for in dementia care. The paper offers an illustrative example from Aeriel and draws conclusions from the synthesis of verbal and musical data analysis. Findings indicate an important advance in studies of dementia care communication towards a concept of the ‘post-verbal’ enabled by a musical research method and the clinical applications that it offers.

[Culture, Medicine, and Psychiatry](#)

[A Point in the Heart: Concepts of Emotional Distress Among Albanian-Speaking Immigrants in Switzerland](#)

*Mirëllinda Shala, Naser Morina, Corina Salis Gross, Andreas Maercker, Eva Heim*

Cultural variability regarding concepts of distress for common mental disorders (CMD) has been reported extensively in cultural clinical psychology across the globe. However, little is known about

illness narratives in social communities from Southeast Europe. The purpose of this paper is to identify cultural concepts of distress (CCDs) among Albanian-speaking immigrants in Switzerland and to integrate the findings into literature from other parts of the world. Twenty semi-structured qualitative interviews were conducted using the Barts Explanatory Model Inventory (BEMI). A set of concepts was described through content analysis and semantic network analysis. The results show complex expressions of distress, which are mainly associated with post-migration living difficulties. Social problems and life-changing events mark the onset of the most common symptoms. Self-management and social support were described as the most important coping behaviors. Participants expressed trust in physical health care but little belief in psychotherapy. There is indication that mental illnesses are stigmatized in this population. It is therefore important to use non-stigmatizing terms in health communication. Moreover, individuals from this community consider suffering to be part of life, and they assume that this suffering must be endured with patience. It is vital to address these beliefs in psychological interventions.

[“A Résumé for the Baby”: Biosocial Precarity and Care of Substance-Using, Pregnant Women in San Francisco](#)

*Ashish Premkumar, Jennifer Kerns, Megan J. Huchko*

In the United States, the historical condemnation and punitive legal consequences of substance use during pregnancy—ranging from incarceration to termination of parental custody of a newborn—render pregnant women in state of biosocial precarity. Yet pregnant women who use illicit substances who desire to parent must generate a legible narrative for bureaucratic groups, such as Child Protective Services, through engagement with biomedical care in order to demonstrate parental capacity. Based on longitudinal interviews with pregnant women who were actively using illicit substances and attempting to parent after delivery, we posit that the relationship between biosocial precarity and biomedical care is a procedural interaction that is rooted in the potential to parent, described as the ability to have a “take-home baby.” In order to achieve this goal, the need for engagement in biomedical care and the creation of a biomedical narrative, described as a “résumé for the baby” is required. The relationship between care and biosocial precarity is a unique, underdeveloped concept within medical anthropology and has important consequences not only for the ethical turn within anthropology, but also how applied researchers consider engagement with this highly marginalized, vulnerable population.

[Moral Experiences of Crisis Management in a Child Mental Health Setting:  
A Participatory Hermeneutic Ethnographic Study](#)

*Marjorie Montreuil, Catherine Thibeault, Linda McHarg, Franco A. Carnevale*

Restraints and seclusion are routinely used in child mental health settings for conflict and crisis management, but raise significant ethical concerns. Using a participatory hermeneutic ethnographic framework, we studied conflict and crisis management in a child mental health setting offering care to children aged 6–12 years old in Quebec, Canada. The use of this framework allowed for an in-depth examination of the local imaginaries, of what is morally meaningful to the people in the setting, in addition to institutional norms, structures and practices. Data collection involved participant observation, interviews, and documentation review, with an interpretive framework for data analysis. We argue that the prevalent view of children shared by staff members as “incomplete human becomings” led to the adoption and legitimization of authoritative norms, structures and practices guided largely by a behavioral approach, which sometimes led to an increased use of control measures for reasons other than imminent harm. Children experienced these controlling practices as abusive and hindering the development of trusting relationships, which impeded the implementation of more collaborative approaches staff members sought to put in place to prevent the use of control measures. Study results are discussed in light of conceptions of children as moral agents.

[Perceived Feasibility, Acceptability, and Cultural Adaptation for a Mental Health Intervention in Rural Haiti](#)

*Caroline Zubieta, Alex Lichtl, Karen Trautman, Stefka Mentor, Diana Cagliero, Augustina Mensa-Kwao, Olivia Paige, Schatzi McCarthy, David K. Walmer, Bonnie N. Kaiser*

Mental healthcare is largely unavailable throughout Haiti, particularly in rural areas. The aim of the current study is to explore perceived feasibility, acceptability, and effectiveness of potential culturally adapted interventions to improve mental health among Haitian women. The study used focus group discussions (n = 12) to explore five potential interventions to promote mental health: individual counseling, income-generating skills training, peer support groups, reproductive health education, and couples' communication training. Findings indicate that individual counseling, support group, and skills training components were

generally anticipated to be effective, acceptable, and feasible by both male and female participants. That being said, participants expressed doubts regarding the acceptability of the couples' communication training and reproductive health education due to: a perceived lack of male interest, traditional male and female gender roles, lack of female autonomy, and misconceptions about family planning. Additionally, the feasibility, effectiveness, and acceptability of the components were described as dependent on cost, proximity to participants, and inclusion of a female health promoter that is known in the community. Given the lack of research on intervention approaches in Haiti, particularly those targeting mental health, this study provides a foundation for developing prevention and treatment approaches for mental distress among Haitian women.

[From Treatment to Containment to Enterprise: An Ethno-history of Therapeutic Communities in Puerto Rico, 1961–1993](#)

*Caroline M. Parker*

Unpaid work is now a central therapy in Puerto Rican therapeutic communities, where substance users reside and seek to rehabilitate each other, often for years at a time. Once a leading treatment for addiction in mainland United States, therapeutic communities were scaled back in the 1970s after they lost federal endorsement. They continue to flourish in Puerto Rico for reasons that have less to do with their curative powers than with their malleability as multi-purpose social enterprises and their historical co-option by state, market and family actors who have deployed them for a variety of purposes. Their endurance from the 1960s to the neoliberal present obliges us to recognize their capacities as what Mizruchi calls abeyance mechanisms whereby 'surplus' populations, otherwise excluded from labor and home, are absorbed into substitute livelihoods. Having initially emerged as a low-cost treatment, in a context of mass unemployment and prison-overcrowding they now thrive as institutions of containment and informal enterprise.

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

[Words with weight: The construction of obesity in eating disorders research](#)

*Sandra Gotovac, Andrea LaMarre, Kathryn Lafreniere*

In current public health discourse, obesity is conceptualized as a disease epidemic, with treatment being weight loss. The pursuit of weight loss as a treatment for the “disease” of obesity is in direct contradiction to the history of research in eating disorders, which has demonstrated the risks for the development of eating disorders. In this study, we critically examined the eating disorder literature to explore this contradiction. We analyzed 30 of the top-cited articles in the eating disorder literature between 1994 and 2011, asking: how is the concept of obesity examined in eating disorder research? We identified tensions related to body mass index and the perceived associated risks of lower or higher body mass index, assumptions of the “causes” of fatness (i.e. overeating and inactivity), and the anti-diet voice challenging the prescription of dieting for those in fat bodies. In our analysis, we highlight the problematics of, for instance, prescribing a body mass index range of 20–24 in eating disorder recovery, how many studies in eating disorders do not problematize the presumption that a higher body mass index is necessarily associated with ill health, and a lack of cultural sensitivity and acknowledgment of intersectional spaces of belonging. We discuss these themes in the context of biomedical discourses of obesity contributing to the cultural thin ideal. We argue that biomedical discourses on obesity contribute to the thin ideal nuanced against discourses of healthism that permeate our society. Rather than an ideal of emaciation, it is an ideal of a healthy, productive person, often constructed as morally superior. The moral panic around obesity is evident throughout the eating disorder literature, which is a concern given that we would hope that the aim of eating disorder treatment would be to promote wellness for all—not only those who are thin.

[To follow a rule? On frontline clinicians’ understandings and embodiments of hospital-acquired infection prevention and control rules](#)

*Rick Iedema, Christine Jorm, Claire Hooker, Su-Yin Hor, Mary Wyer, Gwendolyn L Gilbert*

This article reports on a study of clinicians’ responses to footage of their enactments of infection prevention and control. The study’s approach was to elicit clinicians’ reflections on and clarifications about the connections among infection control activities and infection control rules, taking into account their awareness, interpretation and in situ application of those rules. The findings of the study are that clinicians responded to footage of their own infection prevention and control practices by articulating previously unheeded tensions and constraints including infection

control rules that were incomplete, undergoing change, and conflicting; material obstructions limiting infection control efforts; and habituated and divergent rule enactments and rule interpretations that were problematic but disregarded. The reflexive process is shown to elicit clinicians' learning about these complexities as they affect the accomplishment of effective infection control. The process is further shown to strengthen clinicians' appreciation of infection control as necessitating deliberation to decide what are locally appropriate standards, interpretations, assumptions, habituations and enactments of infection control. The article concludes that clinicians' 'practical wisdom' is unlikely to reach its full potential without video-assisted scrutiny of and deliberation about in situ clinical work. This enables clinicians to anchor their in situ enactments, reasonings and interpretations to local agreements about the intent, applicability, limits and practical enactment of rules.

[The tinkering m-patient: Co-constructing knowledge on how to live with type 1 diabetes through Facebook searching and sharing and offline tinkering with self-care](#)

*Natasja Kingod*

Danish adults with type 1 diabetes value peer-to-peer interaction through the social media platform Facebook as a way to quickly exchange knowledge on essential everyday self-care for chronic illness. In this praxiographic study, following informants into online and offline social dimensions, I explore how they use Facebook to exchange self-care knowledge based on practical experiments and negotiations between bodies, technologies and daily lives. When in doubt about how to self-care on a daily basis, Danish adults with type 1 diabetes look to Facebook for inspiration and peer support. A synergistic process of online searching and sharing and offline tinkering with self-care generates person-centred knowledge about how to live with illness that is situated to individual needs and unique daily lives. Facebook can be viewed as an emergent space for biosociality through which knowledge about how to self-care become co-constructed by peers based on their pragmatic experiences of self-care on a daily and ongoing basis.

[The silver lining of greying: Ageing discourses and positioning of ageing persons in the field of social health insurance](#)

*Sarah Van den Bogaert, Melissa Ceuterick, Piet Bracke*

Contemporary ageing discourses and policies perceive being

active as the key to a good later life and thereby focus on individual responsibility and self-care. Drawing on website articles and press releases of Belgian sickness fund agencies, this study analyses the ageing discourses and positioning of ageing persons of these organisations. A discourse analysis was performed using positioning theory to analyse how sickness fund agencies discursively construct the ageing process and position ageing persons, and to investigate how these positioning acts are related to sickness fund agencies' roles as social insurer, social movement, social entrepreneur and private insurer. Our results reveal three storylines on ageing; ageing as a medical problem, ageing as a new stage in life and ageing as a natural life process. These storylines are applied to construct ageing and position ageing persons in different ways. Depending on their role, sickness fund agencies take on a different position drawing on these different storylines. We also show how these storylines reproduce the moral framework on how to age well and thereby disempower ageing persons. Our results underline the importance of multidimensional perspectives on ageing.

[Informal use of restraint in nursing homes: A threat to human rights or necessary care to preserve residents' dignity?](#)

*Christine Øye, Frode F Jacobsen*

Use of restraint in nursing homes is highly controversial and fundamentally transgresses human rights and freedom of movement and choice. While different forms of formal restraint use in nursing homes are broadly delineated, the use of informal restraint is less understood. The aim of this article is to identify different kinds of informal restraint, and how staff use informal restraint under which circumstances. This article illuminates informal restraint use based on an ethnographic study in four nursing homes in the Western part of Norway. We have identified five different forms of informal restraint use which are as follows: (1) diversion of residents' attention; (2) white lies; (3) persuasion and interpersonal pressure; (4) offers and finally (5) threats. These different forms of informal restraint are actions by staff against residents' will, limiting residents' freedom of movement and their personal preferences. In addition, we have identified 'grey-zone restraint' which comprises actions by staff towards residents which lie in-between formal and informal restraint. The use of informal restraint can be explained by institutional circumstances such as location, architecture and institutional collectivist constraints in relation to care work. Moreover, and paradoxically, informal restraint can be explained as a consequence of neo-liberal policies

with establishment of extended premises for freedom of movement and practices of resident preferences in nursing homes. Informal restraint practices call into question whether these practices are compatible with fundamental human rights and the preservation of residents' dignity.

[Solidarity after nature: From biopolitics to cosmopolitics](#)

*Kim Hendrickx, Ine Van Hoyweghen*

What is sustaining the divide between nature and nurture, even though sciences like epigenetics have been challenging it for at least two decades? Evelyn Fox Keller asked this question and considered it a logical problem rooted in terminological confusion within the sciences. In this article, we propose a complementary diagnosis of the problem: the nature-nurture divide is (re-)mobilized when society faces questions of inclusion and solidarity. With examples stemming from the fields of insurance and health care, immigration policy and epigenetics, we demonstrate how the nature-nurture divide is performed through techniques of classification for a politics of solidarity. We identify a common operation to these different examples that we coin 'biopolitical imputation'. We use this term to draw attention to how (Western) societal institutions, including science, create solvable problems out of complex situations, defining human actors and their agency along the lines of the nature–nurture divide as a moral guide. We argue that the tenacity of the nature–nurture divide is therefore not only a logical problem needing better scientific concepts, but also a cosmopolitical problem asking for a more profound reflection on the ontology and ethics of solidarity in order to move beyond the biopolitics of nature versus nurture.

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