

Prototyping a social worlds perspective on the transgender brain

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Since the mid-90s, neuroscience has produced a number of prominent studies concerned with the brains of transgender persons. As social scientists, it is relevant to inquire into the social implications of such research, and to understand neuroscientific knowledge production as a social process, impossible to envisage as something purely scientific. To approach these questions, this paper prototypes an interrogation of the “trans brain” from a Social Worlds Perspective, introduced by Anselm Strauss, further developed by Adele Clarke, and with roots in Chicago-style interactionism,. This enterprise rests on the basic assumption that the trans brain is not solely an epistemic object; its meanings and implications – its “realness” – is multiple, dynamic and constituted by actions and symbolic interactions amongst groups of actors engaged in the trans brain from various perspectives, or “universes of discourse”. How these multiple perspectives and engagements are to be understood is an empirical question, linking to issues such as access to care; boundaries between health/pathology conceptions of sex/gender, and subjectivities. This paper will discuss how a Social Worlds perspective can advance an understanding of the trans brain as a social-political, hybrid and multiple object with agency, that is not only discursive but also material and embodied.

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Pharmaceutical marketing, corporate “impression management” and regulatory failure in Europe: off-label promotion of enzalutamide

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In June 2016, The Association of the British Pharmaceutical Industry (ABPI) suspended the Japanese pharmaceutical giant Astellas' membership for a year. Astellas' suspension followed a year-long investigation by the ABPI's self-regulatory authority – the Prescription Medicines Code of Practice Authority (PMCPA) – into allegations of covert off-label marketing of the prostate cancer drug enzalutamide (Xtandi) during a European meeting convened by Astellas. We use documentary data to analyze the investigations into Astellas' misbehavior and discuss implications for pharmaceutical industry crime control. Our case study provides a unique glimpse into a ruthless company culture reflected in both the co-ordination of off-label marketing across Europe and the deceptive “impression management” by very senior managers. “Impression management” refers here to the senior managers' attempt to influence regulators' perceptions about the facts of the case and of the company's commitment to ethics and self-regulation by providing self-assessed beneficial or inaccurate information. This case also reveals an inflexible and relatively impotent nature of pharmaceutical industry crime control at both national and supranational European levels. More broadly, our study highlights troubling aspects of the relationship between pharmaceutical companies and healthcare professionals in Europe.

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“IT IS NOT A PILL” –ENGAGINGA RANDOMIZED CONTROLLED TRIAL OF PERSON-CENTRED CARE

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Person-centred care is an institutionalized form of patient-participation, which seeks to improve healthcare by recognizing the individual patient's unique experience and by acknowledging the patient as an active and responsible participant in his or her own care. It is also conceptualized as a reaction evidence-based medicine opposing its alleged reductionist and exclusionary tendencies. Therefore, person-centred care is often conceived as the direct antonym of evidence-based medicine, taking into account the combined biological, psychological and social identity of the patient which evidence-based medicine reduces to a set of signs and symptoms.

In this paper, I analyse a paradoxical case in which a randomized controlled trial, often portrayed as the 'gold standard' of evidence-based medicine, is used to evaluate person-centred care. Drawing on interviews with researchers conducting this trial and on research documents and papers I examine how person-centred care and evidence-based medicine are interwoven and what tension emerge. More specifically, I discuss how the tensions are understood, reflected upon and handled in practice. How do researchers combine an ambition to prize the uniqueness of the individual with an aim to extrapolate from knowledge of a few to produce guidelines for the many?

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13 Medical Sociology

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Integrated medicine: Discourses and practice of integration of indigenous or traditional medicine into healthcare systems in the Sub-Saharan African Region

This paper departs from the discourse and practice of integrating indigenous or traditional medicine (TM) into health care systems, considered important for improving health care services. The interest in integration can be understood from the socio-economic challenges, but also the paradox where in spite of the current level of technological development and scientific knowledge in medicine and health, people whether in the rich north or the poor south continue to be vulnerable and suffer from ill-health.

Back in 1978, the Alma Ata Declaration recognized TM and its practitioners as an important resource, for achieving health for all by the year 2000. In 2002, the WHO recognized that TM and practices are indispensable to indigenous and local communities. Later, the African Union (AU) declared the period 2000-2010 as the Decade of African TM and in 2011 the Decade was extended to 2020. Meanwhile, WHO declared 31st August of every year as the African TM Day (ATMD). While integration of the two systems is clearly critical for meeting the emerging health needs or averting the rising costs of western medicine, the main question is whether integration aims to or has promoted the unique elements of both systems as part of improving health care.

Since cultural familiarity for those who still use TM is often mentioned as a justification for integration, the question is whether there is any serious reflection on the cultural change taking place since the colonial intervention when TM was outlawed or as a result of the ensuing modernization processes. Cultural familiarity notwithstanding, only some elements of TM mainly herbal medicine appear to be chosen for integration. The question then is whether this does not lead to isolating herbal medicine from spiritualism or the major aspect for which people continue to consult indigenous healers. How does this affect the holistic perspective of TM? Moreover, as some case studies from Kenya indicate, there seem to be little focus on the changing state of TM or the impact of the changes on the use, the users and healers of traditional medicine.

Empowerment and stigmatization: Patient organizations, gynecological cancer and changing identities

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Gynecological cancer (GC) is easily seen as a shameful low-status cancer and is often associated with stigmatizing ideas about sexual lifestyle. This stands in contrast to a prevailing cancer survivorship discourse of the empowered, optimistic and heroic cancer survivor. Patient organizations (POs) work to change how GC is perceived by improving support for involved patients and their relatives, and by influencing research, media and policy. In this presentation, I present an ongoing online and offline ethnographic study on GC POs in Sweden and in the UK. The project's aim is to gain knowledge about how GC POs challenge and/or reproduce ideas concerning what it means to be a GC patient and how they enact, negotiate and represent their cause (what they are fighting for). This focus enables insights on POs' individual and organizational identity formation processes, including possible cross-national differences and gender and sexual politics involved. To gain knowledge about how POs work, POs' activities are observed, key figures are interviewed and information material is analyzed. By combining cancer survivorship studies and PO studies from medical sociology and STS, the project hopes to push a scholarly discussion of cancer patient identity beyond a dichotomy between empowered survivors and stigmatized victims.

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From case to disease outbreak: valuing, counting, classifying genes in disease control

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This paper explores how genetic evidence is valued, negotiated, and understood in disease surveillance. In doing so, it explores how the emergence of new genetic technologies lead to changes in theories about disease, risk, and contagion. Are new phenomena then seen as risky, normal, or deviant?

In disease surveillance, the introduction of whole genome sequencing (WGS) has led to disparate cases of disease now being identified as part of larger disease outbreaks. For example, a case of salmonella in the UK can now be linked to other cases of salmonella across Europe—thus constituting a novel form of outbreak.

A problem for disease surveillance is that there are no precedents for how to handle the knowledge emerging through whole genome sequencing. Dilemmas include: What constitutes a genetic relation? How much genetic likeness constitutes an outbreak? And how much genetic likeness is enough to impose legal measures?

This development brings to the fore several questions related to the negotiation of new standards for evidence, professional judgement, and genetic classification. This paper explores these dilemmas through ongoing fieldwork at the European Centre for Disease Control and Prevention, and more specifically through two recent European outbreaks of Salmonella.

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Dislocated experts in semi scientific arenas: The return of the lived experience

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Arenas in which scientific and expert knowledge interact with the public debate and understanding are central to analysis of knowledge coproduction. Such arenas are important and useful platforms for communication to and interaction between actors in the field of public health: researchers, practitioners, clinicians, patients, and the publics. But how is knowledge communicated? And what and whose knowledge claims are emphasized? This study investigates an arena positioned as an initiative for assembling research and expert knowledge with the purpose of creating better interventions and solutions to addiction related problems. The study focuses on how repetition and enchantment of certain key concepts (boundary concepts) enables a ritualized communication and interaction in coproduction of addiction knowledge both including and excluding actors and claims. The repetition and enchantment of the disease model and victimized children legitimize the future hopes and expert status of lived experience actors (NGO's and journalists) and their knowledge, and simultaneously exclude existing interventions and expert