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Configurations of diagnostic processes, practices, and evidence: a conference report

2016-11-07 05:00:31

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Every two years the [Medical Anthropology at Home network](#) organises a conference to present and discuss recent work. The ninth conference, held in June 2016 in Northern Norway, was organized by [Mette Bech Risør](#) from The Arctic University of Norway and [Nina Nissen](#) from the University of Southern Denmark. To address the theme of *Configurations of diagnostic processes, practices and evidence*, the conference placed diagnosis and diagnostic processes centre-stage — as classification and practices in-the-making, exploring a wide variety of actors, and organizational and discursive levels.

Thirty-two people presented papers in eight sessions broken up by two stirring keynote lectures, one delivered by [Simon Cohn](#) — from the London School of Hygiene and Tropical Medicine, UK — and the other by [Annemarie Jutel](#) — from the Victoria University of Wellington, NZ. The papers, grounded in rich ethnographic material, offered critical reflections on new developments and transformations of socio-medical realities in Europe, the United States, Canada and Brazil. As medical anthropologists critically engaging with diagnostic practices in our respective projects, we (Natassia Brenman and Anna Witeska-M?ynarczyk) each presented papers and participated in the lively discussions that took place over the four days. In the following reflections, we seek to capture the key themes that emerged from the sessions, and to consider how the overarching aim of advancing anthropological debates on diagnosis was pursued throughout the conference.

Diagnosis as containment: an opening thought

[Simon Cohn's](#) opening keynote reflected on how we, as medical anthropologists, might maintain a focus on local practices in a world where it is increasingly hard to represent single bounded locations. Drawing our attention to this struggle to preserve spatial distinctions, he argued that diagnostic practices are as much about 'containing' as they are about 'identifying'. In a series of vignettes on non-communicable disease experiences, we saw how stretched and strained diagnostic categories are

becoming: from a doctor's confrontation with the unsettling relatedness of her patient's Type II diabetes and clinical depression, to a patient's perplexing task of dealing with multiple chronic conditions at once. The work of maintaining such eroding boundaries demands a constant splitting and re-defining of disease categories; something we were to see in many forms over the course of the conference. And so we were invited to think about how, paradoxically, current practices of 'containment' pose a challenge to the grand narrative of a single, universal classification system.

The diagnostic pronouncement in popular culture

In her keynote, [Annemarie Jutel](#) discussed the topic of a diagnosis as a *speech act*, a performative pronouncement of a physician vis-à-vis her/his patient. As she argued, the visual representations of a diagnosis taken from American pop culture evoked an aura of medical authority, a sense of inevitability of a medical verdict and its potential to irritate emotional worlds of the sick and their relatives. Yet, many ethnographic examples presented during this conference upset this image of a diagnostic pronouncement, demonstrating how diagnoses are settled in a relational negotiation in diverse clinical and non-clinical settings defined by particular styles of reasoning, organisational frameworks, normative and affective formations. Annemarie Jutel's keynote served as an inspiring and thought-provoking reference for nuanced explorations of multifaceted diagnostic practices.

Chronicity and the layering of multiple conditions

The theme of suffering from various illness conditions, raised in the first keynote, proved to be pertinent to the work of several presenters. The ethnographic attention given to the bodily experiences of patients — often over long periods of time — demonstrated that illnesses rarely materialise as a series of singular entities. [Lina Masana](#) brought this to life in her work on the experiences of people living with chronic illness, attending to the ways in which people made sense of and (re)named their accumulating conditions. She highlighted the irony of experiencing multiple, unexplained symptoms, which in themselves foreclose any legitimate diagnosis, as well as the humour that comes with trying to capture hybrid or manifold conditions in personalised disease nicknames. [Sylvie Fainzang's](#) case of the 'deviant diagnosis' also explored the emergence of a diagnosis out of chronic illness but this time as a (contested) response to a patient's medication. Deviance, then, defines the diagnosis that fails to contain the disease in a medicalized framework. It is not just the passage of time that produces this kind of disruption of what might once have fitted into a singular diagnostic category. [Camilla Hoffmann](#) deployed the notion of 'noisy bodies' to acknowledge how, in a context of low social class and

deprivation, it can be hard to differentiate the raft of bodily symptoms associated with physical and mental illnesses experienced in parallel.

Patient narratives and the ‘pushing back’ of conventional nosologies

Patient narratives such as those described above were always considered in relation (and at times in opposition) to those of healthcare professionals and the nosologies that guide their practice. The mutual dependency between patient narratives and the biomedical management of disease was made explicit when diagnoses are contested or withheld. Fainzang’s case study of a patient and his ‘lay’ diagnosis demonstrated how such a narrative can at once be accepted and rejected by medical authority when a doctor is disbelieving but feels too much is at stake to ignore the patient’s story. [Alessandra Fiorencis](#) used the experience of pelvic pain — often invisible and ambiguous in its pathological status — to illustrate how diagnoses are necessary to legitimate female pain in the Italian cultural context. However, delays in diagnosis keep women waiting for up to 12 years for such legitimisation. Shedding light on the historical context of how medical anthropologists and clinicians have come to understand such ‘lay’ and ‘culture bound’ experiences of health and illness, [Josep Comelles](#) deftly traversed medical texts from across Europe to illustrate how *medical concerns* have become the new folk medicine categories that push back against conventional nosology. But despite this new incarnation of ‘pushing back’, many of the papers that followed demonstrated how biomedicine continues to maintain and create new boundaries within its own nosology.

Capturing the ‘grey zones’ before and beyond illness categories

Where the focus of research lay with the biomedical gaze, we were shown how diagnostic boundaries are enacted in clinical settings. In these papers, and the discussions that ensued, it became clear that with such boundaries come spaces outside of, and between, the illnesses they seek to demarcate. These liminal, or to use [Stefan Reinsch’s](#) term, ‘grey zones’ were the focus of several papers. One such zone was defined temporally: the ever more important pre-diagnosis, or ‘at risk’ state, reminding us of what Robert Aronowitz (2009) calls “diagnosis creep”. Reinsch (co-authoring with Nicolas Henckes) observed the emergence of the ‘at risk mental state’ in French and German psychiatry, arguing that this process is made possible by scientific facts imbued with *affect*. Echoing how affect was shown to drive the maintenance of this fragile pre-diagnostic category, [Rikke Sand Anderson](#) captured the hope and fear that surrounds experiences of ‘not-yet cancer’: the newest addition to the cancer story in her field sites, which is emerging out of the Danish trend of inviting ever more bodily sensations into the cancer symptom ménage.

[Bernhard Hadolt](#) also construed the generative role of affect and emotions within the field of ‘pre-symptomatic genetic testing’ through his close observations of genetic counselling. All three conjured the notion put forward by Timmermans and Buchbinder (2010) of “patients in waiting” in a world of screening and (self) monitoring for future illnesses.

While the above papers considered the *temporal* expansion of diagnostic boundaries to pre-diagnostic states, others presented a *spatial* expansion of diagnostic boundaries. As such, diagnostic work was seen to move the boundaries of illness categories into new, less medical territories: the classroom, the private world of a childless couple, and the grieving family. The expanding use of psychostimulants (usually prescribed for ADHD) to the ‘social sphere’ of educational settings was the focus of [Johanne Collin’s](#) paper, which highlighted the implications of medicating conditions with an uncertain diagnostic status. [Anna Krawczak](#) shed light on couples’ experiences of patienthood after being ‘diagnosed’ with infertility, and questioned whether childlessness coupled with sexual activity can, or should, be considered a medical condition. And drawing our attention to an experience not (yet) considered a diagnostic category, [Ellen Kristvik](#) told the stories of eight parents who had lost a child in stillbirth, arguing that medicalizing their grief would not address their needs. Here, it is perhaps worth turning our attention to the ‘needs’ of the biomedical and bureaucratic systems, which work so hard to seize these grey areas in order to improve precision and manage the uncertainty they bring.

The productivity of diagnostic uncertainty

The relevance of Renée Fox’s work on medical uncertainty (1980) endured in our discussion of diagnostic practice and what underlies it. Our focus, however, shifted from the *nature* of diagnostic uncertainty (the limits of physicians and of medical science itself) to what it might generate or produce. [Stina Lou](#)’s work with sonographers’ screening for Down’s syndrome revealed that much of their work was about doing the “best good” with highly ambiguous ultrasound images. These partial representations were often actively managed in order to produce trustworthy images and morally sound narratives. For [Sylvie Fortin](#) too, uncertainty was the starting point for her explorations of responses to children’s functional gastrointestinal disorders. The space this uncertainty gave for different narrativizations of pain meant that some non-migrants families in a Canadian cosmopolitan milieu were better ‘heard’ in clinical settings than their migrant counterparts, setting off divergent care pathways for their children. In the high-profile American memory clinic where [Laurence Tessier](#) carried out fieldwork, diagnostic uncertainty was not simply negotiated, but relished by the experts at work there. Such disquiet, or “worry”, provided the conditions for the *feelings* of connoisseurship, which she argued work side by side with contemporary

neuroscientific *knowledge* in the production of diagnoses.

Diagnosis as an intersubjective enactment

By revisiting the Azande classics of Edward Evans-Prichard and George Foster's dyadic concepts of *naturalisation* and *personalisation*, [Sjaak van der Geest](#) reminded us of a long-lasting interest of medical anthropologists in the intersubjective aspect of healing practices. Intersubjectivity emerged as a focusing lens used by several authors to reflect upon the social dynamics behind the medical processes, such as presentations that highlighted numerous contemporary developments reconfiguring the intersubjective experience of a diagnosis. Recent changes in social realities of patients imply, among others, their increasing participation in the decision-making process. [Natasia Hamarat](#) discussed the case in which the patient's autonomy lies in the request for euthanasia. The intimate and captivating exchange between a patient who officially requested for a procedure and a doctor available for a consultation about the end-of-life options in a Belgian non-secular hospital revealed an emergence of a diagnosis understood as the "work of mutual elaboration of subjectivities" conditioned by different normative orders. The process of enactment was also central to [Fredrik Nyman](#)'s critical analysis of AIDS/HIV in "not so liberal" contemporary Sweden. In exploring what the syndrome is *becoming*, he highlighted a duality: how, on the one hand, advocates create a body with HIV as normal, and, on the other, prevention programmes engender an othering of this same body. Another portrayal of a diagnosis as a collaborative doing was given by [Jane Roberts](#), who spoke about the Pediatric Bipolar Disorder (PBD) diagnosis in the United States. In a condition of unstable biomedical evidence concerning the PBD, parents conversant in biomedical knowledge present themselves as experts on their children's behaviors and become a driving force in the making of a diagnosis. They help manage the uncertainties felt by the clinicians and hence stabilize the controversial diagnostic category. Another vignette of an intersubjective, extended beyond the clinic, collaborative 'doing of a disease' also concerned psychiatrization of contemporary childhoods. [Anna Witeska-M?ynarczyk](#) demonstrated how an ADHD label authoritatively given to a child in a psychiatric office in Poland, turned into a *contested label* in a familial setting. The author talked about the fading power of the diagnostic pronouncement in the aftermath of the clinical encounter and the necessary involvements of one of the care-givers to keep it alive.

Contemporary doctoring

Another set of papers provided a 'thick description' of the present-day realities of health providers. As Annemarie Mol remarked, today's doctoring means "tinkering with bodies, technologies and knowledge

— and with people, too” (Mol 2008:12) in a world of “complex ambivalence and shifting tensions” (Mol, Moser, Pols 2010:14). The papers devoted to the contemporary practices of diagnosis from the doctors’ point of view contrasted with the diagnostic pronouncement represented in popular culture. The authors evidenced the fluidity and temporality of diagnostic practices and portrayed the unsteady aggregates of actors, bodies, bureaucracies, organisational solutions, technologies and systems of belief. [Claudie Haxaire](#) (with Carole Noubissi-Nana and Philippe Bail) examined the ways in which general practitioners in western Brittany (France) care for their “psych-patients” who report signs of depression. In this account, the naming practice and a choice of remedies emerged from within a warm relationship developed with the long-term patients and a knowledge of their life circumstances. [Rikke Aarhus](#), who followed ethnographically the standardized diagnostic cancer pathways in Denmark, attended to the ways in which the two trends — that of empowering the patients and the encroachment of the scientific bureaucratic medicine — complicated the clinical encounter by generating new affective spaces of decision-making. She meticulously portrayed the ways in which the doctor solves the resulting ambivalences. [Torsten Risør](#) added to the analysis of the diagnostic decision-making process yet another element — the logics of organization — to argue that historically developed local organizational solutions may also put serious constraints on decisions made by the doctors. From a dynamic picture of a young health-professional in a Danish hospital, we learned how proper care was enacted in an everyday struggle with the organisational constraints and professional hierarchies. [Hubert Wierciński](#) presented the Polish primary care doctors as annoyed “victims” of “bio-bureaucratization”, forced to accept the imposed bureaucratic standards. The author followed their acts of opposition hidden in minute practices meant to help patients (e.g. prescribing cheaper drugs coded for a different diagnostic category than the one the patient suffers from). Drawing on her personal experience of doctoring, [Ana Lucia de Moura Pontes](#) (co-authoring with Luiza Garnelo) reflected on the implications of being a representative of a hegemonic national project that brings standardized biomedical care to an indigenous population in Brazil. Having worked among the *Baniwa* ethnic group, she attested to the complexity of cultural forms of care and treatment available to the local population, giving an account of how a diagnosis is being born in this multifaceted terrain.

Uncertainties of age and self, and a desire to stabilise

A number of medical anthropologists conducting research *at home* turn their attention to previously unmedicalized sites, tracking the ways in which the biomedicalization of public health, through increased use of pharmaceuticals and diagnostic technologies, has impacted upon the performances of medical practice. David Armstrong pointed at pediatrics,

psychiatry, basic medicine and geriatrics as those medical arenas in which a contemporary desire for stabilisation is voiced most clearly (1983). From the papers discussing psychiatrization of childhood we could see how the techniques of surveillance medicine used in pediatric psychiatry address the question of instability among others by offering anticipatory care. Three other papers presented novel ways in which old bodies and their social surroundings are managed and stabilised. [Leila Jylhäkanga's](#) paper on the everyday experience of dementia in Finland revealed a process of transforming home into a place of care. The author showed how through minute practices the outside institutionalized forces, also in a form of a diagnosis, came into people's intimate lives as new challenges. [Marian Krawczyk](#) conducted research in a Canadian hospital-based palliative care ward. She approached the longing for a "coherent dying process" by attending ethnographically to the "emotional labour" undertaken by palliative clinicians in order to facilitate a "good" death of their patients. These papers point to the anxiety around end-of-life care, with experiences of ambivalence and emotional unrest being common among patients and clinical providers alike (see also Natasia Hamarat).

The final set of papers served as a broad commentary on the contemporary reconfigurations in the field of "therapeutic culture". [Natassia Brenman's](#) paper followed the process of repositioning in mental healthcare. She explored the services in the voluntary and community sector of mental health in England, arguing for a growing relevance of new social contexts of care for the theory and practice in medical anthropology. In these decentralized sites diagnostic practice is not reproduced but appropriated anew in order to meet the service-users' needs in given historical and political conditions. This raises questions about the ways in which a shifting politics of place will transform situated traditions of care, the practice of doctoring and the patients' worlds. Other papers provided critical remarks on these questions, yet most of all they challenged the boundary between normalcy and madness as set by psychiatric categorizations. Three authors — [Susanne Ådahl](#), [Elisa Alegre Agís](#) and [Angel Martínez-Hernández](#) — represented the lived reality of mental illness as a bodily commentary on the social condition. Susanne Ådahl's account of voice-hearing is a historically grounded reflection on the political process of contestation of a medical paradigm of schizophrenia understood as a single disease model. Elisa Alegre Agís offered an insightful look into a diagnosis of a severe mental disorder in Spain, highlighting a subjective hermeneutic labour performed by the female patients. These accounts illuminated various trajectories that the individual meaning-making processes may take depending on the social networks and resources available. Lastly, Angel Martínez-Hernández created a moving portrayal of an anthropologist who listened and observed the ways in which madness was managed by the expert system and how it became

frozen in nosological categories. This raises questions about the ways in which this type of otherness can be approached, and the social mechanisms explained through which people are moved into the “realm of the ob-scene”.

Final Thoughts

Shared by all presenters was a profound recognition of the on-going efforts by the actors involved in the multifaceted diagnostic processes and practices explored throughout the conference to tame the unruly and uncertain, which, after all, are inscribed not only into medical practice but into the human condition as such. Accordingly, we were repeatedly brought up close to the affective work of a multitude of actors (although an absence of auto-ethnography can be noted) both inside and outside clinical settings. This affective work was shown to be highly generative: from enabling the emergence or contestation of new conditions, to producing diagnostic knowledge and expertise, to stabilising that which is incoherent and disorderly. Perhaps this would be a useful point of departure for thinking about where this productivity is most powerful. Indeed, the lack of explicit discussion around power was a key concern raised in the closing reflections of the conference. We might ask: whose emotions hold generative power, and why? Why is it that in some cases, the enactment of new or pre-diagnostic conditions gains traction, whilst in others, contestations loaded with affect and emotion fail to engender change in the way disease experiences are understood and named? Finding a place for considerations of power, in amongst our sensitivity to dispersed networks of actors, and the complexities of affective practice, is one challenge we might set ourselves for future anthropological explorations of diagnosis.

Other new directions inspired by the conference papers may be to address issues of gender and social difference/inequality more specifically, illuminating contestations of diagnoses embedded in hierarchies of clinical practices, systems and social structures. An explicitly critical approach to diagnosis *per se*, its construction and rationale from within both biomedicine and non-conventional medicine, could be valuable in showing its intrinsic relationship with disease, evidence and experience. Following this, we challenge future research to develop methodologically and theoretically rich representations of multi-layered diagnostic processes, taking into account varied contexts of configurations, such as technology, organisation, discursive structures, and not least, multiple agents with different interests.

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Natassia Brenman is a PhD student at the London School of Hygiene and Tropical Medicine, currently exploring issues around access to mental health care in the UK through an ethnographic project based in the voluntary sector. She has worked in a global health context as a research consortium collaborator for PRIME (Programme for Improving Mental Health Care), and her ongoing interest in psychiatric diagnosis stemmed from her master's research in Medical Anthropology and Sociology, completed at the University of Amsterdam.

Anna Witeska-Młynarczyk received her PhD from the University College London. Her doctoral project was [an ethnographic study on memory of communist time in Poland](#). Currently, she works at the Anthropology Departments at the University of Warsaw and at the Adam Mickiewicz University in Poland. She is also a part of the [Childhood Studies Interdisciplinary Research Team](#). Her recent ethnographic project focuses on the experiences of Polish children in an early school age (6-13 years old) who were diagnosed with ADHD. Her interests lay at the intersection of medical anthropology, psychiatry, childhood studies.

Nina Nissen, PhD, is an associate professor at the Department of Public Health, University of Southern Denmark. Her research focuses on the diversity/diversification of medical knowledge and therapeutic practices, and the interplay between health care, gender (and other social

differences), and personal and social change processes. Much of her research is carried out in interdisciplinary contexts. Her methodological interests include the creation of synergies between medical and visual anthropologies.

Mette Bech Risør is a professor in medical anthropology, at the General Practice Research Unit, UiT The Arctic University of Norway. Her research interests cover illness experiences, diagnostic processes, body-sensation-symptom relations and healthcare-seeking practices with a specific view to both medical and everyday life knowledge production. She has gained long-term experience in interdisciplinary research working with and in medical settings on e.g. contested illness, e-health and life after cancer.

NB and AW were joint lead authors; the conference report was jointly initiated by NN and MBR, who both supported and contributed to the writing. To reflect these different inputs, the two lead authors and the two co-authors are each listed in alphabetical order.

AMA citation

Brenman N, Witeska-Młynarczyk A, Nissen N, Risør M. Configurations of diagnostic processes, practices, and evidence: a conference report. *Somatosphere*. 2016. Available at: <http://somatosphere.net/2016/11/configurations-of-diagnostic-processes-practices-and-evidence-a-conference-report.html>. Accessed November 8, 2016.

APA citation

Brenman, Natassia, Witeska-Młynarczyk, Anna, Nissen, Nina & Risør, Mette Bech. (2016). *Configurations of diagnostic processes, practices, and evidence: a conference report*. Retrieved November 8, 2016, from Somatosphere Web site: <http://somatosphere.net/2016/11/configurations-of-diagnostic-processes-practices-and-evidence-a-conference-report.html>

Chicago citation

Brenman, Natassia, Anna Witeska-Młynarczyk, Nina Nissen and Mette Bech Risør. 2016. Configurations of diagnostic processes, practices, and evidence: a conference report. *Somatosphere*. <http://somatosphere.net/2016/11/configurations-of-diagnostic-processes-practices-and-evidence-a-conference-report.html> (accessed November 8, 2016).

Harvard citation

Brenman, N, Witeska-Młynarczyk, A, Nissen, N & Risør, M 2016, *Configurations of diagnostic processes, practices, and evidence: a conference report*, *Somatosphere*. Retrieved November 8, 2016, from <http://somatosphere.net/2016/11/configurations-of-diagnostic-processes-prac>

tices-and-evidence-a-conference-report.html>

MLA citation

Brenman, Natassia, Anna Witeska-M?ynarczyk, Nina Nissen and Mette Bech Risør. "Configurations of diagnostic processes, practices, and evidence: a conference report." 7 Nov. 2016. Somatosphere. Accessed 8 Nov. 2016.<<http://somatosphere.net/2016/11/configurations-of-diagnostic-processes-practices-and-evidence-a-conference-report.html>>