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(Dis)continuities in cancer care: An ethnographic approximation to practices of disease stratification

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*Science,
Medicine, and
Anthropology*

A collaborative website covering the intersections of medical anthropology, science and technology studies, cultural psychiatry, psychology and bioethics.

By Ignacia Arteaga (<http://somatosphere.net/author/ignaciaarteaga/>), Cinzia Greco (<http://somatosphere.net/author/cinzia-greco/>), Henry Llewellyn (<http://somatosphere.net/author/henryllewellyn/>), Emily Ross (<http://somatosphere.net/author/emilyross/>) and Julia Swallow (<http://somatosphere.net/author/juliaswallow/>)

Background:

Disease stratification practices have long been used as a means to produce and make sense of cancer, distinguishing ‘types’, tumour development stages, and even patients’ sociodemographic profiles. However, interest in stratification; that is, the process of dividing oncology populations into clinically meaningful subtypes, has been re-invigorated by two recent developments in medicine and healthcare. First, an increased awareness of the multiplicity of bodies, subjectivities and lived situations that must be coordinated in order to achieve “good care” (Mol 2008, Puig de la Bellacasa 2011). Second, a growing understanding of the potentiality and challenges of genomic medicine, and the profound ways in which it is informing not only categories of cancer risk and prognosis, but also wider practices of cancer prevention, cancer surveillance, and pharmacological development (Kerr et al. 2019, Cambrosio et al. 2018). Current approaches in cancer care might therefore be reconfiguring longstanding forms of biological and social stratification, with important implications for patient experience. Only by unpacking the practices, hopes and dilemmas of multiple stakeholders can we begin to grasp what is at stake for cancer patients in the production of new disease categories and treatment options.

The workshop:

On Friday 12th June, the Department of Social Anthropology at the University of Cambridge hosted the symposium ‘[Ethnographies of disease stratification: Understanding novel clinical practices and their social consequences in contemporary cancer care](https://www.socanth.cam.ac.uk/events/symposium-ethnographies-of-disease-stratification-understanding-novel-clinical-practices-and-their-social-consequences-in-contemporary-cancer-care/)’ (https://www.socanth.cam.ac.uk/events/symposium-ethnographies-of-disease-stratification-understanding-novel-clinical-practices-and-their-social-consequences-in-contemporary-cancer-care). With the generous support of the Foundation for the Sociology of Health and Illness, seven papers interrogated current practices and consequences of stratification emerging in Brazil, Greece, Canada, France and the UK. Ethnographic work in these various sites was discussed by an audience of students and researchers in social and natural sciences, with provocations by three senior discussants.

The workshop sought to provide a multidisciplinary platform to critically examine the practices of stratification themselves and the social effects they generate for the communities with which we work. We asked how stratification practices emerge in our fields and how research participants — researchers, health professionals, patients and caregivers — negotiate their effects in everyday life. Drawing on ethnographic insights from several sites around the world, we looked at the scope, limits and consequences of disease stratification practices, and how they re-articulate older forms of social and biological stratification. Connecting longstanding and novel practices of stratification, we argued, may offer the possibility to understand wider processes of biomedical innovation and the stakes of these processes for the people who engage with cancer biomedicine today.

Overall, the conversations held during the day prompted us to question whether and how the vocabulary of stratification contributes to an improved understanding of the practices and experiences around cancer today. In this post, we present two interrelated themes within this realm: classificatory practices in research and care, and the (dis)continuities of treatment “personalisation” via targeted therapies.

Situating stratification practices within the realm of cancer research and care:

Through presentations detailing the ethnographic situations in which practices of social stratification emerge and become observable, we learned how age, “red flags” as diagnostic tools, and indigenous belonging are utilised as criteria for the coordination of health interventions in cancer. Practices of classification and prioritization structure the research and clinical work in cancer biomedicine. Classificatory practices are often required to make research outputs valid for a specific study population, to prioritise access to healthcare services, and to decide between treatment approaches. However, the criteria that is used (or not used) to sort through clinical cases might also limit the quality and equality of clinical care; engaging with some people and silencing others (see Bowker and Star, 1999).

Benjamin Derbez (with co-author Meoïn Hagège, both from University of Western Brittany) described the bias posed by studies that seek to determine the effectiveness of therapeutic treatments, when protocols to recruit research participants do not include the elderly population in randomised cancer control clinical trials in France. The exclusion of the elderly defies the idea of “universal biology” that underpins the practice of clinical trials through the definition of inclusion and exclusion criteria (see Lock and Nguyen 2010). In this context, Derbez asked: “Under equivalent living conditions, is it possible to identify biological age limits causing a man or a woman of similar ethnic origin to be considered as within the ‘adult’ or the ‘elderly’ categories?” From this talk, we learned how for professionals in Oncogeriatrics, age is *translated* into biological frailty (see Akrich, Callon and Latour, 2006), realigning the work of geriatricians and oncologists in Geriatric Oncology Coordination Units in the French metropolitan area. This realignment work, Derbez argued, in turn enables the construction of clinical evidence in pharmacological development that is made meaningful for the elderly population.

Moving from research to treatment practices, referral and triage, Steph Meysner (University of Liverpool) described one of the consequences of prioritising red flag symptoms in the diagnosis of head and neck cancer in Northern England. Through the analysis of two patient itineraries, we learned that “warning” or “dangerous” symptoms are not conceived as independent outcomes from patients’ sociodemographic characteristics, their assumed behaviours, and the health professionals who use them to describe clinical cases. Looking at the use of red flag symptoms to understand the problem of “late presentation” of patients affected by head and neck cancers, Meysner described the dire consequences of a long-standing form of social stratification based on professionals’ assumptions. Even though red flag symptoms are useful to identify some patients and speed up diagnosis,

confounding red flag symptoms with stereotypes held by some health professionals in primary and secondary care poses the risk of delaying the diagnosis and treatment of some people who seek healthcare advice early on.

Another source of internal differentiation within treatment approaches concerns the current revitalization of indigenous forms of healing within national health services. Cathy Fournier (with co-author Robin Oakley, both from Dalhousie University in Halifax) invited us to reflect on the overall incongruence of treatment experiences that people affected by different types of cancer report when one's own vision of the world and belonging is not acknowledged in the therapeutic relationship in a Canadian cancer clinic. Fournier explained that: "Not only is our body, mind and spirit separated during the clinical encounter, but we tend to be stripped away from our physical and social environment as well." Thinking about her own cancer experience and deploying an indigenous analytical framework of multiplicity, she elaborated on how indigenous forms of healing could indeed complement other forms of therapy, rather than being assimilated into mainstream forms of care.

The molecularisation of cancer care:

The biomedical ability to target specific molecular features of tumours is driving clinical innovation towards more precise diagnoses and more effective treatments by way of "stratification"—that is, the process of dividing oncology populations into clinically meaningful subtypes based on molecular biomarkers. While these innovations raise hopes for more effective treatments with fewer side effects, they provoke major dilemmas around individual and population-wide treatment decisions, equity of treatment access, and the social configurations of care.

a. The problem of access

Drawing on sociological and anthropological approaches to medicine, several presentations demonstrated some of the ways in which current practices of stratification in cancer research and care may reproduce longstanding inequalities, raising questions of access to treatment and social justice. Falia Varelaki and Jorge Alberto Bernstein Iriart discussed the difficulties of navigating access to new cancer targeted medicines and diagnostic tests in Greek and Brazilian oncology, respectively. Combining perspectives from patients and clinicians, both demonstrated that as public healthcare institutions become unable to afford some of the biomedical innovations for all their eligible users, the economic cost of receiving new treatments is transferred to patients and their families, while a moral cost is also shared by clinical staff members.

Falia Varelaki (University of the Aegean) explained how the use of an Oncotype diagnostic test in Greece transforms the citizen into a medical consumer. This molecular test is used by clinicians to assess the risk of distant recurrence from breast cancer among patients who have had tumours resected. The higher the risk score, the higher the possibility that chemotherapy after surgery will be beneficial. However, it is a test that costs five times the minimum wage in Greece and may only be reimbursed by the public health service after it has been purchased by patients. The demand for cash in order to access the test, Varelaki argues, puts the responsibility for health on the shoulders of patients, creating frustration for those who, even when eligible, cannot afford it. In the stark words of one of her female research participants: "Either you have money and you plan your treatment, or you don't have money and you plan your death."

Frustration at seemingly impossible access to health interventions also appears ethnographically when looking at experiences of oncologists providing cancer care in Brazil. Jorge Bernstein (from University of Bahia with co-author Sahra Gibbon from University College London) explained in his presentation that treatment protocols were different depending on both patients' health plans and the cancer centre that they would access in

Salvador city. Thus, variations in care and treatment depended on the economic status of the patient, but also on the specific agreements that centres have secured with the pharmaceutical industry or other research studies that provided health interventions on trial. Some pharmaceutical companies offered diagnostic tests for free, with the hope that patients could request the associated high cost drugs in court – a procedure, called judicialization, now officially disincentivized in the city of Salvador, and which takes time and requires resources that are limited for many patients. These differences, in turn, created an ethical conundrum for clinicians, who sometimes reflected on whether they should prescribe only what families could afford without recurring to courts. As Jorge explained: “The doctor is, as a result, at the centre of an ethical conflict between the imperative to do the best for his patient and the institutional and governmental pressures to reduce costs of high-cost drugs through the courts.”

Together, these presentations illuminate how the incorporation of new tests and treatments widens existing health inequalities, significantly affecting the already unequal distribution of health outcomes in the population.

b. Molecular stratification and the (im)possibilities therein

Biomarkers signal biological mechanisms amenable to observation by researchers in wet labs. Pharmacogenomics promises the ability to manipulate some of these mechanisms, and therefore turn on or off the expression of certain proteins during oncogenesis. Targeted treatment approaches such as immunotherapy have made significant gains with the discovery of these markers, reconfiguring local understandings and capacities for treatment, and therefore the “local biologies” of cancer (Lock et al, 2001).

Examining the potential of targeted medicines for the treatment of breast and bowel cancer, Ignacia Arteaga (University of Cambridge) and Cinzia Greco (University of Manchester) discussed the multiple ways in which the development of targeted medicines to treat specific subtypes of cancer are relationally situated within the landscape of personalised medicine in the UK. Arteaga and Greco looked at the promissory potential of novel approaches to treatment for metastatic cancer and the practices required from patients to take part in this endeavour (see Prainsack, 2017). They analysed the complex processes patients go through in order to obtain this type of treatment, including fundraising in the community, mortgaging a house, or publicizing personal stories via the internet to crowdsource the cost of the drug. More specifically, from Arteaga’s work, we heard about a pharmacogenetic approach to metastatic colorectal cancer that targets one aspect of a tumour’s genetic makeup: microsatellite instability. The ability to distinguish high versus low instability in tumour tissues enables clinicians to understand why some patients’ cancer are resistant to widely used chemotherapeutic agents (such as 5Fu), which allows clinicians to choose different treatment approaches. One such treatment approach is immunotherapy, which seems to offer the possibility of prolonging the survival of some patients who would otherwise be facing a lack of therapeutic options. However, it also adds new health challenges, as patients’ bodies deteriorate and tumours evolve. The benefits are promissory, but only partial, as a wide segment of the population does not carry the molecular mutation or cannot pay for the treatment. As Greco’s work showed, there are many situations in which the promise of targeted therapies cannot materialise, and the real potential of personalised medicines diminishes. Some of these include the existence of molecular receptors not yet amenable for intervention (such as Triple Negative Breast Cancer); unanticipated ways in which tumours’ biologies evolve; strong and debilitating side effects; high costs of therapy that are not affordable and the inability to carry out successful biopsies because of the position of the tumour in patients’ bodies. Looking at the treatment experiences of women with metastatic breast cancer, Greco argued that this kind of failure makes clinicians resort to older and less fashionable treatment approaches that nevertheless still work as the main staple for several subtypes of cancer. Importantly, these do not pose the same financial challenge for services and patients than new targeted medicines do.

Conclusion: “The elephants in the room”

A lively discussion took place with discussants Professor Sophie Day, Dr Maryon McDonald and Dr Carsten Timmermann. They reflected on the theoretical utility of the concept of stratification for the analysis of cancer experiences and treatments, where distinctions never seem to be clear-cut and mechanistic understandings of the body gloss over the complexities and unknowns of tumour development for many types of cancer. Moreover, they discussed the relevance of ethnographic approaches to critically unpack the promises and limitations of personalisation practices in medicine, allowing for greater attention to the practices and experiences that make up hyped treatment approaches. The discussion included encouraging awareness of the ways in which scientific evidence is constructed and communicated; and the ways in which research participants navigate the ethical issues that arise from these practices in the communities where ethnographies take place.

The discussion which followed with the audience, including a mix of students and professionals involved in health research, from genetics, to business, philosophy and the social sciences, converged towards an identification of the “elephants in the room” that were present throughout the day. Themes included, first, the potential financial unsustainability of ever more expensive drugs to treat ever smaller disease populations based on (often provisional) genomic knowledge. A second aspect concerned the uncertainty that affects the work done by researchers, patients, clinicians and even policy-makers. ‘Not-knowing’ structures practices and experiences of biomedical innovation as much as what we know about cancer (see Kerr et al, 2019). A final point concerned the need for a long-term view of the effects of integrating new clinical practices in order to assess their transformative potential; and the ethical stakes we find in situations in which biomedical innovation practices and claims for social justice meet.

Note: This event has been jointly organised by a group of postdoctoral researchers: Ignacia Arteaga, Cinzia Greco, Henry Llewellyn, Emily Ross and Julia Swallow

Statement of authors’ contribution: The first draft of this post was written by Ignacia Arteaga, Cinzia Greco, Henry Llewellyn, Julia Swallow and Emily Ross critically revised the draft, offering essential improvements.

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