

Special Issue: Transformations in Cancer Care: Values, Limits, Subjectivities

INTRODUCTION:

Therapeutic Values in Cancer Care

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Cancer is more than just a cluster of diseases. Beyond patho-physiological variations, it has been mobilized by experts and lay people to make sense of a wide variety of phenomena. The regional variability and socio-historical situatedness of experiences of cancer have been widely published in recent decades (Dein, 2006; Matthews, Burke and Kampriani, 2015; McMullin and Weiner, 2009; Manderson et al, 2005; Livingstone 2012; Bennett et al *forthcoming*). Many scholars in medical anthropology have championed a research approach that foregrounds the voices of and practices carried out by people affected by cancer, enquiring into how diverse populations (do not) seek diagnosis, (do not) undergo treatments, and attempt to carry on with their lives with and despite cancer (Hunt, 1998; Manderson, 2005; Mulemi, 2010; Porroche-Escudero, 2014; Lora-Wainwright, 2013; Stacey, 2013; Vindrola Padrós, 2011).

A focus on the dynamics structuring clinical cancer care has revealed the porous boundaries between clinics and their socio-political environments (Van der Gest and Finkler, 2004). This has included unpacking the ways in which wider sociocultural arrangements inform the narrative structure of clinical experiences (DelVecchio Good et al., 1900, 1994; Mattingly et al., 1994); the negotiation that takes place within the doctor-patient relationships (Bell, 2008 and 2009; Fainzang, 2016; Høybye and TjørnhøjThomsen, 2014); the translation of

knowledge practices into therapeutic technologies (Gibbon, 2007; Gibbon, Joseph et al., 2014; Keating and Cambrosio, 2011), and the impact of the political economy of health that affords different possibilities of care (Day, 2015; Livingston, 2012; Mulemi, 2008; Sanz, 2017; Iriart and Gibbon *forthcoming*).

The promise of technoscientific developments is slowly but continuously informing ethnographies of cancer care. Novel therapies enabled by the discovery of candidate biomarkers (Arteaga, 2021), and through the blurring between clinical drug trials and therapy, are starting to modify the temporality of cancer treatments and the clinical pathways that patients go through (Keating and Cambrosio, 2011; Cambrosio et al, 2018). Such dynamics are transforming the ways in which cancer is experienced in different milieus, reconfiguring forms of pain and suffering, and shaping the efforts people make to understand what is happening to them and what they are expected to do in and through surviving cancer (Day et al., 2017; Jain, 2013; Kerr and Cunningham-Burley, 2015; Lynn Steinberg, 2015; Stacey, 1997).

Nevertheless, this promise of improved health outcomes is intertwined with precariousness. Tensions arise when considering what treatments are made available and for whom (Jain and Kaufman, 2011). Transnational research networks that circulate biomedical resources to sites where hospital infrastructure is missing creates impermanent solutions (Petryna, 2013; Gibbon, 2017; Mika, 2017, Caduff et al, 2018); and many cancer types and geographies are left behind in terms of funding allocation for research and access to therapeutics (Bell, 2014; Carduff and Van Hollen, 2019). Furthermore, some people affected by cancer may not want to seek biomedical treatment at all or prefer to stop it altogether due

to its economic or emotional costs and/or its iatrogenic effects. This tension is what Benson Mulemi understands as a core ‘treatment ambiguity’ in Kenya through which anti-cancer treatment increases rather than alleviates suffering (Mulemi, 2010), and Julie Livingston provocatively poses with the question “Leg or Life”? (Livingsgton, 2012, p.91). The moral dilemma that this question captures is deciding whether to compromise someone’s ability to earn income, work, and fulfil everyday responsibilities for a couple of more months or years of life. To cut off a leg is to transform the intimate social body in which the patient is embedded, demonstrating not only that some cancer treatment alternatives might be as harsh as the disease itself, but also that cancer and the consequences of treatment affect many people besides patients (Arteaga, 2020). Life with or without cancer requires compromises, and expectations about treatment are an important element driving decision-making processes in the clinic. By examining these compromises, colleagues bear witness at how people involved in cancer care projects are mobilizing myriad of epistemological, political and ethical categories for thought and action. These categories or values, in turn, inform the structure of clinical dynamics, the modes through which people involved are negotiating the stakes of good care, and the social effects of cancer treatments in everyday life.

Therapeutic Values in the Making

This special issue brings together ethnographic studies contributing to some of the socio-political, scientific, and therapeutic practices as they currently transform cancer care terrains in the clinic and beyond. Borne out after the multidisciplinary workshop “Crafting Values in Cancer Care” hosted by the Anthropology Department at University College London in 2018, Ignacia Arteaga invited Professor of Medical Anthropology Sahra Gibbon and

Professor of Women's Cancer Care and clinical nurse specialist Anne Lanceley to bring together a special issue that could make a significant addition to both the social studies on cancer and clinical practice in cancer care. True to that initial spirit, this collection seeks to contribute to a discussion about the ways in which therapeutic values are negotiated by patients, relatives, health professionals, and scientists. Authors in this issue capture with ethnographic detail the kinds of relationships, practices, and concerns that research participants articulate in front of the researcher and others in the field, enabling us to explore what happens at the margins of clinical protocols when evidence is in the making and cultural imaginaries around novel treatments seek to potentialize promissory futures. These themes inform a number of discussions in clinical practice, and Anne reflects about one of these in the afterword. Unpacking salience and shortcomings of the clinical logics behind the practice of informed consent, her piece demonstrates that multiple levels of uncertainty informing novel treatment possibilities pose relevant questions for patients, caregivers and practitioners.

The ways in which potential therapeutic values of novel therapies are mobilized in clinical spaces, through the language of genomics and personalization, to just name a few examples, instantiate cancer care as a movement of what Kerr and colleagues refer to as 'future-crafting', re-imagining the ways in which public is invited to participate and market and state-funded healthcare ventures (Kerr, 2021). Drawing on ethnographic methods, authors in this issue engage with the kinds of values, subjectivities and limits that are re-defined, negotiated and embodied inside and outside oncology clinics in scenarios that have favored the opening of new treatment possibilities, including public health campaigns, clinical trials and self-funded therapies. In this introduction, we provide a brief overview of 'therapeutic

values' as they emerge in negotiations to add years to life (survival) and life to years (quality of life) for people affected by cancer. We trace how anthropological concepts of hope, chronicity and personalization inform those circumstances and how patients and their relatives go through the promises, labors and fault lines associated with novel anti-cancer treatments within local contexts. We end the introduction with a reflection on the modes of experience and subjectivity that are afforded by treatment practices that aim to transform some types of cancer into treatable but not always curable conditions.

Building on Kaufman's work on 'longevity-making practices' (Kaufman 2015:216), we can understand anti-cancer treatments from an ethnographic point of view, as a coordinated set of practices through which "scientists and clinicians strive to bring together technologies to reduce foreseeable risks, to reduce uncertainty about [the impact of] medical conditions in patients' lives, and to control the symptoms and the timing of patients' deaths" (Arteaga, this issue, p.3). Followers of approaches such as evidence-based medicine might think that the therapeutic values of various longevity-making practices offered in the clinic are already decided once new health technologies go through mandated approval processes. That is, the therapeutic values of treatment approaches have been agreed upon and cost-effectiveness analyses settled in treatment algorithms and clinical protocols. However, anthropologists (and in fact often many practicing health professionals) understand that epistemological regimes presenting those values as truths are fluid and always in the making. Following anthropologist Michael Lambek's take on ethical values, we understand the concept of 'therapeutic values' as a 'criteria to act and discern action' (Lambek 2015, p.7) that are mobilized in decision-making situations where different treatment modalities are discussed in the clinic and there is little certainty about the potential outcomes.

Hope is a primary anchor point informing these negotiations, as it is cultivated and reproduced in the grey zones of treatable but not yet curable cancer conditions. Hope as a social practice to create lives worth living for those affected by cancer (Mattingly 2010), though, emerges differently at the bedside of a dying child, when a bowel cancer patient has run out of options, when new hormonal treatments are offered to metastatic breast cancer patients, or when a clinical trial testing an immunotherapy vaccine to arrest the growth of brain cancer tumors is discussed with the researcher in the room. In those spaces, the work of hope has also a diverse range of social effects. Fortin, de Gall and colleagues (this issue), for example, mobilize the rhetoric of hope to critically engage with biomedicine's discourses that overlap treatment possibilities with therapeutic efficacy, pinning down the technological imperative to add years to life, sometimes at all costs. Drawing on ethnographic fieldwork in a hematology-oncology transplant unit in a Montreal pediatric hospital, Canada, the authors describing the ambivalence that patients' relatives and health professionals voice when accepting further invasive therapies for the sick child when there is little chance of survival. This is complicated when we recognize that the transition between treatment modalities in the clinic (curative on one hand, palliative on the other) is silenced or resisted by many relatives. Their paper illuminates how patients' relatives might not to want to shoulder the responsibility of saying no to an option that has a remote chance of success, mainly because 'palliative care' tends to be equated by families with 'end of life'.

Treatment Infrastructures

Therapeutic values of novel treatments seek to transform the place of cancer in society. From this perspective, socio-political arrangements informing the roll-out of new health technologies are visibly pronounced. As Arteaga shows in her article, treatment possibilities

are nested within wider infrastructures of research and care, and socio-political considerations around the financial sustainability of publicly funded health services. This includes how considerations about what is deemed cost-effective and for whom, become issues through which the state manages entire populations. How state apparatuses might influence chances of life and death can be seen in examples of what Wahlberg and Rose (2015) termed “the governmentalization of living”.

In this issue, Greco’s discussion on how hyper-capitalism and an ethos of entrepreneurship in the UK and France leaves many people affected by metastatic breast cancer unmoored of a sense of identity and position in society due to the ambiguities and uncertainties about the future posed by new treatment approaches. Greco shows that patients in France and UK might not really know whether they would be able to go back to work or should instead retire from work early and use up their savings, because they do not know how long they are going to survive and how fit they will be to carry out what were quotidian tasks in the past. This sharply contrasts with Schoenfeld’s description of social medicine approaches matching pharmaceutical development and public health in Cuba by which people with cancer are sought to be enfolded within society. There, ‘charismatic time’, understood as the imagination of life freed from its temporal *and* economic constraints (Schoenfeld, p.11), drives the promise of state-owned lung cancer therapies. Instead of understanding participation in biomedical innovation as based on people’s ability to pour their savings onto therapies (Greco), undertake exhaustive forms of patient work to enroll on trials and withstand the inbuilt-chance of randomization protocols (Llewellyn), or having to expose body-vulnerability through fundraising efforts (Arteaga); Schoenfeld illuminates alternative scenarios that reflect Cuba’s robust universal healthcare system, following the socialist

model of the state as caregiver. And yet, we must be careful to not get caught up and unintendedly reproduce the promises articulated by biomedical innovation regimes. Sociologists Hedgecoe and Martin (2008) warn us against how social science analyses of specific technologies might reinforce “dominant set of expectations promoted by innovators, which are claimed to sign a clear break with the past”, when there is still considerable doubt about the extent to which transformations are occurring (2008:825). This is also the case of the Cimavax therapeutic vaccine for advanced lung cancer in Cuba. Schoenfeld argues that the efficacy of Cimavax is still to be proved: Its mobilization by leading Cuban scientists amounts to “an aspirational move of reimagination, rather than a reflection of a predictably significant prolongation of survival” (Schoenfeld, this issue, p.9).

Therapeutic Value as Treatment Efficacy

The synchronization between the rolling out of treatment options, disease stage, and patients’ fitness to endure therapy are especially nuanced in contexts of metastatic disease (Sanz 2017). Without such a synchronization, treatment efficacy cannot be produced, and there is no therapeutic value to mobilize. Llewellyn shows that for people affected by glioblastoma (a form of brain cancer) in the UK in a context where treatment possibilities have been historically scant, timely access and luck in the randomization process of double-blind clinical trials are some of the few resources patients might use to gain more years. He describes how patients aiming to access novel immunotherapy vaccines must participate in a tissue economy that requires patients and their relatives to perform a kind of patienthood defined by the familiarity with medical literature and its associated jargon and insight into the mechanisms that inform eligibility requirements. Patients and relatives must self-advocate in order to anticipate their chances of participating in personalized brain cancer

therapies and harvest tumor tissue in the right way to produce the immunotherapy vaccine that is on offer. As Arteaga shows for the case of Ali, a British South Asian patient in his 30s affected by advanced colorectal cancer in London, it is only when participation in the biomedical economy aligns with all these different temporalities, that treatment efficacy, as the therapeutic value that is at stake, is achieved at the personal level. Yet, treatment efficacy will still depend on randomness of being part of the right trial group (Llewellyn), or having the right tumor mutation that is targeted by the immunotherapy (Arteaga). In both contexts, and as Llewellyn put it, the promises of personalization, in these cases of experimentation with novel therapies, are structured around “a regime of hope” rather than a “regime of truth” (Llewellyn, this issue, p.6).

This is the case that Arteaga describes in relation to the rolling out of Pembrolizumab, an immunotherapy drug dubbed by health professionals in the colorectal cancer clinic as “game-changing” for people affected by advanced bowel cancer who harbor a specific genetic mutation that stands for a ‘biomarker’ of interest. A positive test for a biomarker used as a companion diagnostic not only infuses clinicians and eligible patients with hope, it also impels some of them to galvanize efforts to attain access to therapy by other means. In this case, an understanding of the promised efficacy or therapeutic value of immunotherapies such as Pembrolizumab would be incomplete if we do not look at what happens above and beyond these policy decisions primarily based on clinical trial results. Arteaga argues that the efforts made by patients to gain access to Pembrolizumab before they run out of treatment options, and the outcomes brought about by those efforts, can be understood as an extension of the practices that political scientist Barbara Prainsack (2017) considers as “personalization from below”.

And here is where cancer as a plural disease, with varied materialities, comes to the fore. Following Carrol and Parkhurst's approach to Medical Materialities (Carrol and Parkhurst 2019), we can conceive of tumor tissues, biomarkers and mutated genes have, by the virtue of their changing physical properties, a capacity to act upon the body and the world. Biomarkers signal biological mechanisms amenable to observation by researchers in wet labs. Pharmacogenomics promises the ability to manipulate some of these mechanisms [through the targeting of biomarkers], and therefore turn on or off the expression of certain proteins during oncogenesis (Arteaga et al 2019). The articles in this special issue show how it is not only the pharmakon what can afford desired results in patients' bodies halting tumor growth but also the circumstances of their access. In other words, therapeutic values only become meaningful in interactions that include chemical or biological agents as well as timely access to translational infrastructure. For Arteaga's case, Pembrolizumab might only produce desired effects if the patient has a specific genomic makeup. A key issue in Llewellyn's case is the foresight patients must have to harvest their own tissue and freeze it, to accrue the 'currency' that is needed to participate in this emergent tissue economy of immunotherapeutic vaccines. This landscape is altogether different for the case of children affected by blood cancers in Montreal described by Fortin and colleagues, whereby stem cell engraftment is made possible through allogenic donation: the tissue harvested in others' bodies. The source and materiality of these tissues bring a myriad of complications. In stem cells transplants, the advantages of not having to foresee the need to freeze malignant tissue are offset by the small chances of survival after donation: (blood) tissues extracted from other bodies must adapt to one's phenotypic and genomic makeup.

And yet, the symbolic meanings attached to tissue in these therapeutic economies change, as the value of brain tumor tissues or specific deleterious mutations affecting colorectal cancer patients is appraised in positive terms, whereas blood cancer tissue remains unequivocally malignant. As Llewellyn argues, “tumor tissue is becoming fundamentally wrought otherwise by new sociomaterial practices (Llewellyn, p.10). However, this should not tempt us to reify bodily materials. As Arteaga shows for the case of the genomic mutation that is targeted by Pembrolizumab, in many of these scenarios, we cannot obviate that the properties of tumor tissues might change over time, redefining the durational effects of any desired change. This leads us to the issue of temporality in what has been recently understood as “chronicity” in cancer care, and how “chronicity” is affecting cancer sufferers’ understandings of themselves and their place in the world.

Experiencing Therapeutic Values: Issues of Subjectivity and Temporality

“Chronicity” is an important temporal attribute of re-framing of diseases that have become treatable but not curable. And with it, it brings a particular mode of experience. Schoenfeld writes: “As biomedical knowledge of cancer accumulates, the idea of a boundary between the condition of having and not having cancer cells in our body is increasingly becoming indistinct.” p. 10). Again, as in relation to the theme of hope, the articles in this special issue illuminate how chronicity is variously mobilized in with different effects. For Schoenfeld’s research participants involved in clinical research in Cuba, “*cronicidad*” is the aspiration that Cuban oncology practitioners hold to that would enable them to offer advanced cancer patients the possibility of remaining integrated to society with the illness. This is altogether opposite to the idea that Greco develops through the concept of “crisis of presence”. In France and the UK, Greco seeks to explore the sense of anomie and uprootedness that

metastatic breast cancer participants when cancer becomes chronic—when it is treatable but not curable. Here, people struggle to find a place in the world because of the way in which insurance companies and work opportunities, for example, place expectations that jeopardize present and future opportunities to maintain a stable identity after the sequelae of treatments.

And yet, for some people, remote chances of treatment success are all that is available, and this has a significant impact on people's understandings of themselves and their place in the world. In the ethnographic cases analyzed in this issue, patients and their relatives are asked to come to terms with statistical distributions that offer probabilities rather than deterministic futures. This distinct mode of experience combines the need to live in the present *and* proactively orientate oneself toward the future. This can lead to the experience of 'statistical panic', an affect that propels patients to be both, scared of the options and find resolution amidst the crisis (Woodward, 2008). In this context, developing treatments to halt the growth of advanced cancer infuses people's experiences of their bodies and the world with a different type of temporality. Drawing on Robyn's words, one middle-aged British participant, Greco cogently expands on this rearticulated temporality due to the variability of people's prognoses. This issue is not only relevant in terms of risk communication approaches in clinic, it affects the decisions available to patients and their relatives as they plan an unknown future where insurance premiums might already conceive a diagnosis as a financial liability too high to cover.

The tension between aggregated statistical accounts and individualized futures also sheds light on the difficulties of personalizing treatment approaches when promising data that is assembled about the prognosis of cancer always relays on the contrast made with those left behind; those for whom treatment either did not work or was not available. Answering the

question of who those left behind are is an important backdrop to understand the limitations that treatment personalization. Public messages advertising new therapies tend to gloss over issues of toxicity, long term consequences and unknown effectiveness when calling something “game-changing”, whether the change is expected in terms of lower side effects and/or prolonged survival. This contrast demonstrates that despite financial and emotional investments in novel treatments, the promises of biomedicine are still contingent on a myriad of factors.

Personalized medicines in the changing terrains of cancer care, where personalization means not only use of genomic information to guide therapeutic decisions, but also an ability to fully participate and navigate new experimental regimes of care, underscores the need for patients, relatives and health professionals to constantly negotiate the relationship between them as individual citizens and as part of a ‘target population’ as it is seen by the state. Treatment personalization trends depict therapies’ failures and successes as based on either, personal stories of those able to afford treatments who “made it”, or aggregated accounts of individualized survival statistics. And yet, contributions in this special issue show that when considering the circumstances informing treatment practices, the advocacy for more equity and solidarity cannot be disentangled from the therapeutic values that experimental approaches might offer.

Acknowledgements

We thank Lenore Manderson, Victoria Team, Rebecca Marsland and James Staples and a considerable number of anonymous reviewers of *Medical Anthropology* for bringing this

special issue to fruition. The idea to prepare this issue, and some of the articles contained therein, were born at the conference ‘Crafting Values in Cancer Care’ that took place in September 2018 at University College London. We thank the Cancer Network, the Octagon Fund and the Department of Anthropology at UCL for their generous support for that event.

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