

Introduction

A transcultural approach to disease

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In their spatiotemporal approach to understanding the experiential and ontological dimensions of COVID-19, Avishek Parui and Merin Simi Raj underline that the virus is both matter and metaphor. While attention focused on the biochemical nature of the growing and mutating coronavirus in the very initial stages of what became the pandemic, the repercussions of COVID-19 meant that it quickly emerged ‘as a metaphor for global contagion, crisis and panic, connecting as well as disconnecting subjects and objects while defamiliarizing standard notions and erstwhile experiences of time and space’.¹ A complex ambiguity thus emerged: while the World Health Organisation (WHO) would repeatedly remind us that ‘the virus knows no borders and [...] no one is safe until everyone is safe’, life in 2020-22 became fundamentally bordered as contact between nations, communities, families, and friends was severely restricted.² Those infected were subjected to quarantine measures; but every human body – every human *being* – was told to maintain as much isolation as possible, or as prescribed by the law, from others outside their immediate ‘bubble’. We might have been ‘all in this together’, to reprise one of the linguistic hallmarks of the pandemic, but social distancing and enforced isolation led inexorably to alienation, disconnectedness, and thereby multiple temporalities. As Parui and Raj thus argue, the globality of the COVID-19 pandemic ironically undercut ‘the ontology and experience of global time’, giving way to an ‘ambivalence of compressed spatiotemporal connectedness and existential disconnect’, in which subjects would ‘share an *infected time and space* which also necessitates a distance which is defined as a social norm, avoidance of touch and only partially visible self’.³

- 1 Avishek Parui and Merin Simi Raj, ‘The COVID-19 *Crisis Chronotope*: The Pandemic as Matter, Metaphor and Memory’, *Memory Studies*, 14.6 (2021), 1431–44 (p. 1436).
- 2 ‘A virus that respects no borders: protecting refugees and migrants during COVID-19’, *World Health Organisation*, 25 March 2021 <<https://www.who.int/news-room/feature-stories/detail/a-virus-that-respects-no-borders-protecting-refugees-and-migrants-during-covid-19>> [accessed 10 March 2023].
- 3 Parui and Raj, p. 1435 (italics in original).

The COVID-19 pandemic would dramatize the dangers of proximity and our shared sense of vulnerability like no other disease in recent memory. It reminded us that the (geo)politics of disease control is premised on a belief in seemingly protective borders, hence the egregious nationalistic rhetoric and xenophobic abuse that has emerged at times of pandemic, from ‘Spanish flu’ to ‘Chinese virus’, equating flows of migration and contagion. From a neoregulatory perspective of political power, borders are regarded as potentially toxic places of encounter and exchange where disease spreads uncontrollably. Yet here – precisely, at the border – a further spatiotemporal reality emerges, for lived experience tells us that once we contract a disease we cross into a defamiliarized space. As Susan Sontag famously stated:

Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.⁴

How do we understand what life might be like ‘in the kingdom of the sick’, especially in the context of a disease that spreads at an exponential rate and is likely to infect a large proportion of the population? In the COVID-19 pandemic, we turned to literature – and as we did so, we engaged in a further act of border-crossing.

As Samuel Earle wrote in the *New Statesman* with regard to the boom in ‘pandemic-lit’, ‘[s]ometimes we turn to novels to make sense of our world, and sometimes to escape it. Yet in hard times, we often ask them to do both at once: to make sense of our world, all the better to escape it’.⁵ In 2020, we entered into the fictional world of one novel in particular. A global bestseller during the initial wave of the COVID-19 pandemic, Albert Camus’s *La Peste* has habitually been read as an allegory of the Nazi occupation of France in spring 1940. Yet, as Alice Kaplan and Laura Marris have observed, during COVID-19 ‘that reading tradition was transformed’: ‘unhinged from allegory’, the book on a disease that kills rats, then humans, and which politicians subsequently struggle to

4 Susan Sontag, *Illness as Metaphor and AIDS and its Metaphors* (London & New York: Penguin, 1991), p. 3. Many critics have nonetheless pointed to the irony of Sontag’s statement, given that she famously argued that ‘the most truthful way of regarding illness – and the healthiest way of being ill – is one most purified of, most resistant to, metaphoric thinking’ because of the negative, stigmatizing implications of seeing patients as afflicted or embattled. Sontag, p. 3.

5 Samuel Earle, ‘How Albert Camus’s *The Plague* Became the Defining Book of the Coronavirus Crisis’, *New Statesman*, 27 May 2020 <<https://www.newstatesman.com/long-reads/2020/05/the-plague-albert-camus-coronavirus-resurgence>> [accessed 10 March 2023].

contain, suddenly provided ‘insight into the experience of a global health crisis’.⁶ The fact that the novel is set in the port city of Oran in north-west Algeria is also significant, because for the vast majority of readers, it takes us into unfamiliar cultural territory, just as disease does. Amidst such a cultural background, this special issue of *Francosphères* emerges from the premise that acts of border-crossing are crucial to generating rich appreciations of the function and lived experience of disease. It suggests that it is precisely at those spaces where people, cultures, and disciplines meet that informed understandings of disease emerge. Transnational, interdisciplinary approaches to disease are thus essential if we are to grapple with its manifold ramifications.

As Robert Peckham of the University of Hong Kong wrote in the early stages of the COVID-19 pandemic, an understanding of the social and political facets of coronavirus was as urgently needed as their biomedical counterparts, in order ‘to make sense of biomedicine’s worldliness and disease’s entanglement with social and political processes’.⁷ Such ‘entanglements’ are often found in the interdisciplinary field of the medical humanities. Yet, in the context of attempts to generate a more multi-dimensional or, as the *Edinburgh Companion to the Critical Medical Humanities* also puts it, ‘entangled’ understanding of disease, its construction and circulation across diverse languages, societies, and cultures remains largely overlooked.⁸ As the editors of the *Companion* acknowledge, even where the cultural factors that condition understandings and articulations of disease are explored, they still tend to come from an ‘implied or assumed generality of a UK or US mainstream’ in the medical humanities.⁹ A distinctive sub-field of French medical humanities has developed in recent years, with the aim of integrating French cultural and philosophical production relating to the diseased body into broader discussions that are dominated by Anglocentrism. Yet, as the editors of a recent special issue on the French critical medical humanities put it, that sub-field to date has been characterized by ‘a distinctive / critical pulse on the dynamic interface between the embodied experience of illness and disease, and the republican institutions

6 Alice Kaplan and Laura Marris, *States of Plague: Reading Albert Camus in a Pandemic* (Chicago & London: University of Chicago Press, 2022), p. x.

7 Robert Peckham, ‘A Health Emergency is no Time to Sideline the Medical Humanities’, *Times Higher Education*, 10 February 2020 <<https://www.timeshighereducation.com/opinion/health-emergency-no-time-sideline-medical-humanities>> [accessed 8 March 2023].

8 Anne Whitehead and Angela Woods, ‘Introduction’, in *The Edinburgh Companion to the Critical Medical Humanities*, ed. by Whitehead et al., pp. 1–31 (p. 8).

9 Whitehead and Woods, ‘Introduction’, p. 2.

of health and medicine that shape everyday life in France today'.¹⁰ Our special issue of *Francosphères* aims to enlarge the framework of reference for analyses of disease in French, by crossing social, cultural, and political frontiers that take us outside the Hexagon. Moving beyond the geographical, cultural, and linguistic landscape of the *métropole*, our focus on cultures of disease across francosphères contributes to the creation of a more global medical humanities by building on an important series of recent studies into disease in modern France, while deliberately extending the scope of enquiry to a broad range of experiences and in relation to some lesser-discussed diseases in the medical humanities.¹¹

The special issue brings together a number of scholars probing literary engagements with epilepsy, Alzheimer's disease, Hodgkin's lymphoma, and Ebola in order to ask how the interaction of the medical with the literary generates articulations and understandings of disease in different cultural settings, including Belgium, Canada, West Africa, and the imaginary francophone city of Tourmens; one of the articles explores a narrative by France's most read contemporary *romancier*, yet set in the United States, which reflects the global impacts of dementia as a transcultural phenomenon. The main lines of inquiry emerged from a conference, 'Languages of Disease in the Contemporary Francophone World', held in February 2021 and organized by the Institute of Languages, Cultures and Societies (ILCS). Our conceptual and thematic focus intersects with the journal's overarching aim to question the presence of French language and culture across frontiers and borders, and maps onto *Francosphères'* vision to promote academic engagement with creative works across multiple 'spheres' in the French-speaking world. The collection of articles that follows showcases a transcultural and intercultural French studies approach to disease, as it begins to study the words, expressions, and codes used to linguistically frame and communicate diseases in different francophone cultural contexts, and what these can tell

10 Enda McCaffrey and Áine Larkin, 'Introduction: The Critical Medical Humanities', *Essays in French Literature and Culture*, 58 (2021), 5–13 (pp. 5–6).

11 Recent studies include: David Caron, *AIDS in French Culture: Social Ills, Literary Cures* (Madison, WI: University of Wisconsin Press, 2001); Stéphane Spoiden, *La Littérature et le SIDA: archéologie des représentations d'une maladie* (Toulouse: Presses Universitaires du Mirail, 2001); Jean-Pierre Boulé, *HIV Stories: The Archaeology of AIDS Writing in France, 1985–1988* (Liverpool: Liverpool University Press, 2002); Larry Duffy, *Flaubert, Zola, and the Incorporation of Disciplinary Knowledge* (Basingstoke: Palgrave Macmillan, 2015); Steven Wilson, *The Language of Disease: Writing Syphilis in Nineteenth-Century France* (Oxford: Legenda, 2020); Loïc Bourdeau and V. Hunter Capps (eds), *Revisiting HIV/AIDS in French Culture* (Lanham, MD: Lexington Books, 2022); Sarah Jones, 'Stendhal's Consumptive Heroine: *Lamiel* and the Romantic Conception of Tuberculosis', *French Studies*, 77 (2023), 31–47.

us about the individual and societal experiences and conceptions of disease. These perspectives are important for many reasons, not least because metropolitan France's republican universalism results in colour-blind policies and a refusal to share ethnic statistics, making a targeted public health response to some of the most marginalized, vulnerable communities most affected by disease particularly complex.

A focus on countries in the French-speaking world allows for a reorientation of disease from its association as a predominantly medical concern towards a consideration of the vital socio-economic and cultural issues that affect health and well-being, including pre-existing inequalities in health systems. Such an approach complements that taken by physician-anthropologist Eugene Richardson in *Epidemic Illusions: On the Coloniality of Public Health*, in which he demonstrates that the practices of the major global health authorities are often underpinned by the values, norms, and perspectives drawn from the global North. At a time when the global response to the COVID-19 pandemic has been coordinated by the WHO, Richardson's book reminds us that the ideal of universalism eludes global health, and indeed points to the global North's very 'complicity' in health inequalities.¹² The research presented in this special issue, drawing on French-language literary sources, builds a picture of health-related inequalities across francosphères. Contributors attend, in part, to the ways in which texts on disease can present a challenge to political and structural issues, a phenomenon that has been highlighted during the pandemic by Michael Rosen's collection of prose poems on his experience of COVID-19, which mount a political challenge to the government and a more societal challenge in relation to widespread age discrimination.¹³ Much arts and humanities-based research on COVID-19 has stretched beyond what has been termed the 'first wave' of the medical humanities, which was centred on individual and shared experiences of the clinical encounter, towards a role in generating understandings of the longer-term social and economic effects of the pandemic, as well as its impact on culture.¹⁴ The reverse is also true, in that artists and other cultural figures in the French-speaking world have been at the forefront of disease-prevention initiatives. In Haiti, for example, where a significant lack of engagement with international organizations followed the cholera outbreak of 2010, itself the result of contamination by infected

12 Eugene T. Richardson, *Epidemic Illusions: On the Coloniality of Public Health* (Cambridge, MA: MIT Press, 2020), p. 65.

13 Michael Rosen, *Many Different Kinds of Love: A Story of Life, Death and the NHS* (London: Ebury Press, 2021).

14 Whitehead and Woods, 'Introduction', p. 8.

UN peacekeepers, public health messages about COVID-19 were coordinated by the Haiti Response Coalition but led by local rappers, musicians, and cartoonists, and disseminated in French and Haitian Creole.¹⁵

Humanities and the medical sciences are inextricably linked, due to the ways in which scientific knowledge production, including frameworks of ‘health’ and ‘illness’, are always filtered through a cultural lens. The turn to a more critical (or ‘second wave’¹⁶) medical humanities has witnessed greater harnessing of the creative and intellectual strengths of feminist and queer theory, disability studies, and postcolonial studies, among others, to disrupt the historical silos of academic knowledge in order to reconceptualize patients’ experience, medical cultures, and clinical ethics. Research at the critical interface of French studies and the medical humanities has tended to place a particular emphasis on health as an embodied human experience, on examining synergies between illness and life writing, thinking beyond the space of the clinical encounter.¹⁷ In that vein, our primary interest within this special issue is to explore the language and languages used to explore a diverse range of experiences of disease, care, recovery, and loss, and to probe the representation of marginalized subjects in mainstream cultural forms. Issues addressed in the articles that follow span the treatment of medical terminology by writers and artists, as well as narrators’ articulations of shifting subjectivity (and various iterations of ‘je’) through an experience of diagnosis and treatment. However, we also aim to ask what literature might be able to do in terms of shedding light on the cultural specificities of care-giving and healthcare practices across the French-speaking world. We wonder which narrative genres go some way to articulating embodied sensation, which textual forms help to make sense of pain, and how writing can testify to the sensory and emotive experiences of a long-term illness. Finally, the articles explore how asymmetrical power dynamics, systemically and institutionally embedded, find voice in literary form, and what writers and artists can contribute to an interrogation of the duty of care, writ large.

Turning first to language, we are curious about the use of language by writers who give expression to a lived corporeal and psychological experience of disease. Understanding that translation can stand varyingly as a barrier or

15 ‘Tanama Emerges as National Voice for Covid-19 Prevention in Haiti’, *haitian-truth.org*, 29 July 2020 <<http://www.haitian-truth.org/tanama-emerges-as-national-voice-for-covid-19-prevention-in-haiti/>> [accessed 15 March 2023].

16 Whitehead and Wood, ‘Introduction’, pp. 1–2. See also William Viney, Felicity Callard, and Angela Woods, ‘Critical Medical Humanities: Embracing Entanglement, Taking Risks’, *Medical Humanities*, 41 (2015), 2–7.

17 See McCaffrey and Larkin, ‘Introduction’.

bridge in medical practice, we question how such experiences are *translated* in fiction, drawing on the autobiographical or on formal medical records. What terms are laid out for a reader to work with? How does imagery function to render the pathological and affective imaginable? And, in terms of timeframe and structure, how is the temporal reach of an illness given textual shape? What are the afterlives, memories, scars of experiencing disease, and how are these articulated in visual and different textual representative forms? These terms are employed differently depending on genre, as Claire Jeantils explores in her article ‘L’écriture à l’épreuve de l’épilepsie: à propos d’une mutation des genres littéraires dans le panorama éditorial français’. She asks whether testifying through fiction is a desirable approach given the particular limits on bearing witness to epilepsy. Pursuing this question in her article, she draws out, on the one hand, testimony’s intent on establishing some kind of logic, reason, or origin for a disease, and at the same time who or what might be to blame. On the other hand, she reveals how testimony brings an incisively close perspective on symptomatology. The at times overlapping roles of fiction and testimony, in terms of broaching these dimensions of ethics and suffering in particular, have been discussed beyond the medical humanities, for example in post-conflict settings both in transitional justice and cultural memory work. In terms of the afterlives of diseases, this overlap (between fiction and testimony) also shares with those contexts the pertinent question (though beyond the scope of this special issue) as to which forms of narrative are archived, beyond the official medical record. But in the vast range of experience within illness (physical, psychological, social, linguistic, emotional, and sensory), and in the way they work with shifting states of consciousness, these accounts also stretch the boundaries of genre in new and exciting ways.

The special issue draws attention to some of the ways in which fiction also has the potential to reframe how we think about what disease engenders. Beyond reflecting primarily on pain, or loss, novels open up the spectrum of experience under focus to include shifts in identity and values, the emergence of new ways of communicating, and a transformation of the body and mind. Fiction’s presentation of dementia as a potentially ‘transformative experience’ is a central argument in the article by Avril Tynan, ‘The story isn’t over: narrating a future with dementia in Guillaume Musso’s *Central Park*’. Tynan’s analysis of dementia in Musso’s novel presents a case study of how an illness’s afterlife, or life-after, could be conceived. Crucially, Tynan suggests that this focus on transformation avoids foreclosing possible futures, instead inviting readers to imagine dementia as a kind of beginning, as well as one of loss or ending. This argument speaks to similar debates in trauma studies on implied

linearity and closure, in discussions of post-traumatic stress disorder (PTSD), for example. Tynan's article underlines the fraught processes of 'doing care well', particularly in attending to the spectrum of possible interpretations of illness. Caroline Verdier's article, 'Putting Hodgkin's lymphoma into words: Anne François's *Nu-tête*', extends our reflections on the ways in which the lived experience of disease can stimulate transformation. Verdier focuses on Hodgkin's lymphoma, a relatively rare cancer of the immune system and a lesser-studied illness in the medical humanities, through an analysis of Belgian writer Anne François's relatively overlooked novel *Nu-tête*. Whereas most pathographies usually focus on only one side of the illness account, François gives a voice, simultaneously, to both the patient and the oncologist, lending a polyphonic structure to the narrative. The text concentrates on the hair loss experienced by the protagonist as a result of treatment for her cancer, with patient experience focused on the stigmatizing effects of disease and the ways in which individuals are 'marked' as cancer patients. In a defiant act that seeks to reorient loss into an act of control, the patient makes the decision to shave her head, embracing her right to claim her diseased body as her own.

Beyond the body, we are also interested to explore the domestic and institutional spaces of care as represented in cultural forms. How does a patient or doctor navigate pain and power in a hospital room? How is an operating theatre remembered? What dynamics of power and agency are normalized and imposed in a given space? In 'Réinventer le langage du soin: *L'École des soignantes* de Martin Winckler', Cristina Robu addresses a utopian literary imagining of the clinic as site of a non-hierarchical, anti-patriarchal, and holistic medical practice. Robu examines this fictional world, and the imaginative possibilities it offers, for example through the horizontal relationships within a medical training school founded as 'un espace-temps d'accompagnement'. The system itself undergoes treatment as a quasi-patient, deconstructed and reinvented through gestures and language of solidarity and collective care. Such voices as those of Winckler, who is also a practising doctor, are vital as these questions around duties of care are posed to political leaders. The politics and economics of these spaces of care are being thrashed out in ongoing industrial action. How these literary insights – slower modes of bearing witness – could feed into real-world change remains to be worked out, but this work attends in the first instance to how these spheres of care also overlap with other national, digital, and cultural spheres.

We are delighted that a previously commissioned interview with Véronique Tadjó has been included within our special issue. This speaks to many of the issues we have discussed in terms of responding, in a broad

sense, to disease. Tadjó, who has published poetry and prose on love, myth, travel, and tragedy, wrote *En compagnie des hommes* in 2017 as her literary response to the Ebola crisis of 2014 in Guinea, Liberia, and Sierra Leone. From the perspective of a wide range of human and non-human characters, the text relays the rapid spread of the epidemic. The text reads as a communal work of bearing witness from medical staff, gravediggers, patients, and families who speak of their experiences faced with the danger of the disease. In their interview with Tadjó published here, Hugo Bujon and Ninon Vessier invite the author to expand on her understanding of the term ‘resilience’. This near-ubiquitous term, that permeates literature on health but also institutional policies from university to national levels, equally requires further probing. Tadjó describes resilience variously as an attitude, a form of endurance, a form of interacting, and a defence or protection. The author rightly underlines, in the interview as in *En compagnie des hommes*, that humans have this kind of survival in common with non-humans. However, in general the networked or communal implications of responding to crisis remain underemphasized in health contexts that focus on bodies as individual entities. Could it be that the semantics of automation and strength that ‘resilience’ interlocks with risk co-opting it into discourses of productivity more than care or solidarity? The Ebola virus itself is one of the narrators personified in *En compagnie des hommes*, and in this way, Tadjó underscores the need for multiperspectival consideration of disease and health through literature. The entanglements and interdependencies to which she alludes in the interview need to be factored into our understanding of concepts such as ‘resilience’, ‘recovery’, and ‘care’, as well as the language we use to articulate them.

This special issue represents a step towards a more transcultural framing of disease, in French and francophone studies and beyond. Given the interconnectedness of societies, levels of global mobility, and the inevitability of new epidemics and pandemics, working across borders to further understandings of the operation and impact of disease is an urgent concern. Transnational French studies has a significant role to play in this endeavour, not least because many francophone countries, especially in West Africa, are especially affected by communicable disease. Indeed, we would like to have included further studies with a francophone African cultural perspective on disease in this special issue. The WHO and *Médicins sans frontières* are presently engaged in disease-prevention and control measures against HIV/AIDS, Ebola, tuberculosis, cholera, and famine in several countries in Africa where French is a widely spoken language. Partnership between literary and cultural studies scholars, global health bodies, and NGOs is a

much-needed next step. Similarly, future work in the broad field of health humanities can look to enrich the humanities at large by drawing upon skills forged in the hard sciences to reorganize knowledge and place it in the service of problem-solving that is both local and global. For the latter, when steps are taken to decentre the foundational ideas of Western medicine, artists, writers, and health practitioners can make use of the ways other medical traditions, including indigenous and folk practices, overlap and inform one another. The research presented in this special issue begins the important work of expanding spheres of reference for work on disease, yet it also points to tantalizing future directions in transnational and transcultural approaches to disease across francosphères.