COVID-19 narratives and layered temporality

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ABSTRACT
The essay outlines the ways in which narrative approaches to COVID-19 can draw on imaginative literature and critical oral history to resist the ‘closure’ often offered by cultural representations of epidemics. To support this goal, it analyses science and speculative fiction by Alejandro Morales and Tananarive Due in terms of how these works create alternative temporalities, which undermine colonial and racist medical discourse. The essay then examines a new archive of emerging autobiographical illness narratives, namely online Facebook posts and oral history samples by ‘long COVID’ survivors, for their alternate temporalities of illness.

At the time of writing (July 2020), the current COVID-19 pandemic has infected more than thirteen million people and claimed more than 580 000 lives worldwide.

At the time of revision (May 2021), the COVID-19 pandemic has infected more than one hundred sixty-five million people and claimed more than 3.42 million lives worldwide.

At the time of second revision (October 2021), the COVID-19 pandemic has infected more than 242 million people and has claimed more than 4.93 million lives worldwide.

Due to the timescale of academic publication, over a year separates my writing and second revision of this article. I have chosen to include the three versions of my first sentence, because it shows that, while I have been working on this piece, 4.35 million human beings have died. I want to begin this article by acknowledging that there is no narrative, whether epidemiological, sociological, or literary, that can adequately emplot the three versions of my first sentence. There is no story that can make sense of this progression. Instead, current Health Humanities scholarship is created in the breach between three versions of one sentence—in the suffering, and in the becoming.

While the three versions of this first sentence are desperately inadequate, they are also, inescapably, a form of representation. The sentence harkens back to the early beginnings of the essay as genre: a written meditation on a subject, which shows its own process of thought. In terms of content, the sentence presents my own time of writing, embedding me in a historical moment; it names the disease and it documents that disease’s spread by stating in stark terms the growing fatalities from COVID-19. During the first review, this manuscript was sent back with the comment to remove the strike-throughs, which the editorial team understandably assumed were a typographical error. With the use of typography, the strike-throughs try to make legible our necessary re-evaluations and revisions throughout the pandemic. These revisions also reflect the temporal ‘layering’ of COVID-19 narratives. Each declarative statement has within it its own future overwriting. Nothing feels stable. By the time you are reading this article, holding either the print copy of the journal or scrolling online, the numbers will have shifted, inevitably higher. Your moment overwrites my most recent revision. Finally, the last version makes us circle back to the first, continually trying and failing to make sense of the progression. The reader is trapped in a recursive time.

The most obvious gap, which the sentences do not address, is the human impact of the pandemic. The repetition of the sentence shows the impossibility of capturing loss with these facts. Visual and written art forms can creatively reframe medical and historical data to show how human experience is ‘layered’ with facts and figures. For example, the image below is a reproduction of artist Anatol Bologan’s painting ‘Viral 01’. It is the first in a series of multimedia works dealing with the human cost of COVID-19. The painting is a visual meditation on loss, as a patient with COVID-19 reaches to embrace a loved one who has died (figure 1, Bologan 2020). Furthermore, by digitally layering pandemic data visualisations behind and on top of the central couple, the artist illustrates the human pain that is not fully captured by discussions of disease ‘rates’ and ‘curves.’ The medical image of the patient’s lungs, taken from a computer rendering of a CT scan, shows an active COVID-19 infection with an uncertain outcome. The viewer assumes that the central figure may become part of one of the bars on the graph, and that his body may continue to fragment and dissolve, as it does on the left edge of the artwork. The red line across the bottom third of the image provides the base for the graph, and could represent a flattening heart monitor (figure 1, Bologan 2020).

The painting is a vivid portrayal of what I call the layered temporalities of the COVID-19 pandemic. While epidemiology offers one model for how to trace the spread of COVID-19 (geographically, spreading outwards from one or multiple epicentres) and public health offers another (as with the graphs of infection and mortality), these models do not capture the multiply unfolding temporalities of people’s lived experience of the pandemic. Each of us is a distinct nodal point in terms of the timing of this disease outbreak. Our stories of growing awareness about the disease, travel, work, social distancing and perhaps illness, healing and loss, all unfold on different patterns. These temporalities may be anchored by some shared news cycles and social media conversations, or may echo one
new beginnings and reunions. However, when public discourse focuses on the ending to disease outbreaks it can also conveniently overlook ongoing health inequities.

In this article, I focus on stories that represent the lived experience of epidemic disease, specifically those that defy the temporal closure offered by popular disease rhetoric. Specifically, I suggest that the affective engagement or embodied reading practices encouraged by Health Humanities allows us to remain sensitised to the COVID-19 stories that might be otherwise unnoticed. I propose a narrative investigation that takes up the layered temporalities of COVID-19 stories, specifically focusing on chronicity, erasure, fragmentation, revision, and repetition. This article first demonstrates how postcolonial speculative and science fiction, such as works by Tananarive Due and Alberto Morales, nuance our understanding of the lived experience of epidemics. These works highlight injustices perpetrated on those blamed for the outbreak and offer different imaginative possibilities for how we could relate to one another during a time of crisis.

The article then turns to excerpts from oral histories and life-writing by COVID-19 survivors. Studying the ‘unknowingness’ in postcolonial science fiction can inform the way in which one engages COVID-19 narratives and how they resist temporal closure. Especially for those struggling with long COVID, or for those mourning the loss of loved ones to COVID-19, triumphalist, chronological narratives of ‘flattening the curve’ or putting the pandemic behind us ring false. These first-hand stories follow different narrative arcs than crisis to cure, or pandemic’s start to pandemic’s end. In fact, more possibilities may be offered from narratives of endemicity and chronic illness than the structure of climax and resolution of traditional plague narratives. Understanding COVID-19 as both epidemic and endemic allows different critical approaches to emerge, such as allowing us to address systemic health inequities as ongoing.

In addition, as I have shown elsewhere, those living in an environment with endemic disease can also use this status to gain authority and make demands on medical systems (Howell 2014). Furthermore, Health Humanities scholarship that engages with chronic pain acknowledges that ‘reading less in search of narrative coherence or self-authorship’ allows a heightened appreciation for the ‘value of textual fragments, episodes and moments’ (Wasson 2018, 106). By examining COVID-19 narratives using the methods of postcolonial studies and critical oral history, Health Humanities scholars can resist the stories’ instrumentalisation within national and medical discourses.

**DEFYING CLOSURE AND CURE: POSTCOLONIAL AND SPECULATIVE FICTION**

We have never lived through this pandemic. However, we have talked about epidemics before. Written and visual narratives of epidemics may consolidate a chaotic series of events, give a sense of purpose and directionality and also to attempt to capture for the reader the experience of the disease. Such methods are a way to engage our attention and to create or direct readers’ anxiety about future epidemics, or, conversely, to comfort us that the epidemic is safely over. However, to write and to read a story set during an epidemic is to work within a set of expectations and constraints. Our cultural values, scientific knowledge base and previously established disease discourse all play a role in how we discuss the current moment. For example, Patricia Wald identifies a certain ‘vocabulary of disease outbreaks’ as beginning during the AIDS crisis in the 1980s and being reinterpreted within the outbreak films and science writing of the 90s (Wald 2008, 2). In this case, the vocabulary of ‘emerging infections’ which many of us now use in fact originated within a particular set of political,

![Figure 1](image-url)
Most important for my purposes, postcolonial fiction destabilises medical narrative: geographies are interdependent rather than independent. Medical fiction disrupts specific colonialist underpinnings of economic growth (King 2002, 776). Postcolonial science fiction challenges the control of disease for protection of western society. Former colonial medical and contemporary global public health organisations as suffering from abject poverty and ill health and in need of external intervention. Contemporary global health organisations have not eradicated the worst is averted. Colonialist narratives of cure rest on specific conventions: the ‘coercive time’ that West-Pavlov discusses is temporality ‘inculcated’ by colonial education, which embodied a ‘forward vector of progress and incremental acquisition of civilization’ (159). What would happen, he asks, if one were to ‘abandon the sequence’ this time ‘relies on altogether’, taking up instead ‘a notion of overlapping, non-segmented temporal planes’ with ‘many acts with agency’ (166)—what Dipesh Chakrabarty calls ‘interlocking of presents, pasts and futures’ (Chakrabarty 2000)? Postcolonial authors experiment with temporality in their works to unmoor narrative from its structural human existence according to the restrictive but profitable mechanisms of late capitalism’ (West-Pavlov 2012, 5). Rather, he suggests that one cultivate an awareness of reading as ‘digestive’ and an understanding of literature as a ‘playful re-working of the putatively factual givens of reality’, which gestural towards a ‘plethora of temporariness subsisting under the threshold of an all-embracing and coercive time’ (9).

One example of the ‘coercive time’ that West-Pavlov discusses is temporality ‘inculcated’ by colonial education, which embodied a ‘forward vector of progress and incremental acquisition of civilization’ (159). What would happen, he asks, if one were to ‘abandon the sequence’ this time ‘relies on altogether’, taking up instead ‘a notion of overlapping, non-segmented temporal planes’ with ‘many acts with agency’ (166)—what Dipesh Chakrabarty calls ‘interlocking of presents, pasts and futures’ (Chakrabarty 2000)? Postcolonial authors experiment with temporality in their works to unmoor narrative from its colonialist associations with progress. In speaking about Salman Rushdie’s Midnight’s Children (1981), Randall Stevenson (2019, 211) demonstrates that the literary text ‘illustrates a range of tensions between imperially imposed temporality and influences indigenous to countries colonialism sought to subjugate’. Time is ‘an unsteady affair’ (citing Rushdie, 1981, 79), whereby postcolonial fiction ‘magnifies and valorises unsteady, divergent temporariness’.

For the purposes of the current analysis, the most important aspect of narrative structure and time is its inter-relationship with science. Tobin observes that science follows an ‘arrow of time’ similar to that of traditional chronological narration in stressing
causation and effect, hypothesis and proof (8). I would add that this assumption about science is similarly influenced by colonial and national consolidation of the scientific process—recent scholarship has shown that there are narrative multiplicities possible in indigenous scientific knowledge as well. If colonial science ‘instrumentalises nature’, then critics like Masood Raja, Jason Ellis and Swaralipi Nandi suggest that postcolonial science fiction can, by stressing incomprehensibility, ‘magic’ and the unknowable, call into question these scientific logics underpinning narrative (Raja, Ellis, and Nandi 2011, 5). This is not just a theoretical practice, but an embodied one. As Michel Foucault has shown, biopower inscribes control of the life course through social expectations. Arne de Boever, following Edward Said, claims that ‘historically, the rise of the novel coincides with the rise of what Foucault calls governmentality and biopower’ (De Boever 2013, 9). By changing the colonial-scientific temporal logic of narrative, one can attempt to redefine the stakes of one’s own life course. Elizabeth Freeman argues that ‘temporality is a mode of implantation through which institutional forces come to seem like somatic facts’ (Freeman 2007), cited in (West-Pavlov 2012, 5). In the case of an epidemic, the ‘somatic facts’ of infection, illness and healing, on both a national and personal level, are quickly identified according to a normative timeline, which may or may not align with an individual’s lived experience. Instead, as Paula Henrikson and Christina Kullberg observe, ‘lived time is contextually dependent’ (citing Hartog 2003, 14).

Questioning the narrative patterns of science, and particularly colonial science, does not lead one to an antisCIENCE or anti-medicine stance. To argue that disease treatment is not equally available to all, and that this inequality both reflects pre-existing colonial priorities as well as reinforces existing racial and national disparities, is not to argue against medical research or treatment. Medical research and treatment are needed. Rather, the critique focuses on two aspects of medical narrative logic: one which claims that Western medical science is the apex of modernity, and that this modernity is offered or given to others, and the other that depicts disease eradication in a chronological and definitive arc. By understanding these logical assumptions as constructed rather than inherently ‘true’, one may approach stories of chronic illness, or stories of repeated or ongoing outbreaks, not as unusual but as endemic to a global system of medical inequality.

Furthermore, reading literary descriptions of physical symptoms and suffering causes an embodied reaction in the reader specific to the disease being invoked. In Postcolonial Poetics, Elleke Boehmer claims that reading “sets off a cascading set of inferences, which the reader processes at different simultaneously unfolding cognitive (semantic, sensory, kinaesthetic) levels, their responses modifying and adjusting as the communication develops” (Boehmer 2018, 8). When considering the multisensory experience of reading about illness, one must assume that in specific scenes of suffering, and throughout the work, we are plunged into the space-time of disease particular to that disease itself. The structure of illness from disease (acute vs chronic) is also embedded in the chronology and structure of literary texts (for more, see Howell 2018). By creating this affective response in relationship to a fictional disease, these following literary works invite the reader to reflect on how we behave towards one another during times of health crisis, without the specific anchor of a named plaque. I suggest that critical engagement with specific literary works about epidemics allows us to practice the radical, speculative exercise of imagining a more equitable present as well as future. These works subvert the Patient Zero myth and disease stigmatisation; encourage us to consider what a decolonised medical praxis would look like and allow us to be aware of our own experiences of embodied reading.

The Rag Doll Plagues by Alejandro Morales (1992) explicitly critiques colonial medicine’s exploitation of Mexican bodies during a fictional, mysterious illness called La Mona in 1788 Mexico City. The book directly engages the colonial value systems that are embedded with the treatment of epidemic disease. The novel self-consciously invokes the tradition of colonial judgmentalism towards ‘uncivilised’ populations, in order to turn this stereotype on its head. Morales’s narrator, Don Gregorio, the First Professor of Medicine, Anatomy and Surgery in his Majesty’s Empire, is a Spaniard who visits colonial Mexico to ‘implement these new [medical] procedures’. In addition to improving sanitation, the ‘new procedures’ he introduces ‘to the native population’ includes a great deal of cauterisation, surgery and amputation, as if seeking to quite literally cut out all that is rotten and diseased in the colonies, including the ‘hedonistic carnal acts’ he witnesses (28).

Each section of this tripartite novel shifts locations and times, thus disrupting colonial narratives of progress. This ‘collapsing of linear time’ is emphasised by the ‘phantasmic atemporal characters Gregory and Papa Damian, who appear in each of the three books of the novel’ (Joyce and Garay 2013, 141). Morales’s novel follows a tradition, as with the work of Gabriel García Márquez (1988), which undermines colonial assumptions of medical progress. When García Márquez’s character Juvenal Urbino returns to his Caribbean home from medical training in Europe, he brings back all the disparaging assumptions about indigenous subjects’ inadequate hygiene and backwardness with him. The novel describes Urbino as arriving home with ‘the beard of a young Pasteur’ (106).

The clearest articulation of The Rag Doll Plagues’ critique of colonial medical legacies can be found in its last section. Don Gregorio’s descendants discover that residents of Mexico City, who are called ‘Mexico City Mexicans’, have a uniquely healing property to their blood that perhaps has been caused by their survival of La Mona in the 18th century. These Mexican citizens become valued and commodified, their blood used for infusions to cure people during a ‘major plague’ (183). Through reverse-colonisation via transfusion, ‘Mexican blood would gain control of the land it lost almost two hundred and fifty years ago’ (195). Morales’s novel points towards the double-edged sword of biological essentialism: whether being decimated or valued for their blood, disparaged or fetishised for their relationship to biological essentialism: whether being decimated or valued for their blood, disparaged or fetishised for their relationship to biological essentialism: whether being decimated or valued for their blood, disparaged or fetishised for their relationship to biological essentialism: whether being decimated or valued for their blood, disparaged or fetishised for their relationship to biological essentialism: whether being decimated or valued for their blood, disparaged or fetishised for their relationship to biological essentialism: whether being decimated or valued for their blood, disparaged or fetishised for their relationship to biological essentialism: whether being decimated or valued for their blood, disparaged or fetishised for their relationship to biological essentialism: whether being decimated or 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By showing the breakdown in social relationships, pandemic fiction can inspire the readers to imagine a different world, where we choose to relate to one another during a time of crisis with more humanity. Tananarive Due’s short story ‘Patient Zero’ (2010) engages the harvesting of immune groups’ blood or body parts for study or the development of antibodies, with or without their consent. ‘Patient Zero’ is narrated by a 10-year-old boy, Jay, who is the subject of study in a research facility during a future pandemic. Jay has recovered from ‘Virus-J’, while everyone else around him dies. He is thus labelled the ‘Patient Zero’, and made both the subject of study as well as the recipient of hostility and misunderstanding.

Due uses the innocent voice of a child narrator to undermine the stigmatisation that occurs during a pandemic. The Patient
Zero is a mythic figure who reassures us that pandemics have a traceable beginning. Jay questions his label at the first patient: “that was when I first learned how people tell lies, because that wasn’t true. Somebody on my dad’s oil rig caught it first, and then he gave it to my dad. And my dad gave it to me, my mom and my brother” (Due 2001, 9). His sense of injustice highlights the uncertain timeframe and geography of pandemics. Jay’s own temporality is different from the official timeline. This official timeline has the goal of certainty rather than truth.

This work of speculative fiction also plunges the reader into the experience of being experimented on. Jay recounts that the doctors and nurses at the containment facility “take so much blood from me all the time, until they make purple bruises on my arms and I feel dizzy” (12). He continues,

“I think they have even taken out parts of me, but I’m not really sure...I had surgery on my belly a year ago, and sometimes when I’m climbing the play-rope hanging from the ceiling in my room, I feel like it hasn’t healed right, like I’m still cut open. ... I don’t hate anything like I hate operations” (12).

Jay’s physical symptoms are not from the virus but from his doctors’ search for the virus’s cause. These are described in visceral detail, so that the reader can imagine being dizzy from multiple blood draws, or aching from multiple surgeries. The story invites us to balance the cost of specific individuals’ pain against the larger goals of scientific discovery, especially during times of uncertain and emerging knowledge when that pain may or may not lead to a cure.

The text is important in terms of Health Humanities’ critical engagement with scale—if one is the only person who suffers from an undiagnosed illness, does that make one’s suffering less legitimate? If someone recovers from an illness that kills many, which community will welcome them? As a story by a black American author about one boy being blamed for a pandemic, ‘Patient Zero’ also invites us to read within the framework of America’s historical and present medical abuse of bodies of colour. From Tuskegee to COVID-19, black Americans have received inadequate or abusive medical treatment. The erroneous creation of race as a biologic category has been used to justify medical experimentation on groups of black people since the times of slavery (see Roberts 1997, 2011; Hogarth 2017).

It is outside the scope of this article to fully address the continuities and divergences between colonial medicine practised by Britain in India, for example, with colonial medicine in Mexico, alongside medical exploitation of black Americans. Narrative experiments also will reflect authors’ distinctive cultural and historical associations with time and the body. However, while different national literatures invoke distinctive histories of medical treatment, reading these works in conjunction offers specific insights. One becomes more aware of the political stakes of aggrandising medical ‘modernity’, and one can see more clearly the power differentials that relate to who lives and who dies during a pandemic (see discussion of biopolitics and the right to ‘make live and let die’, in Michel Foucault 1976; 2003). This practice encourages reading disease, not as an inherent manifestation of biological and historical circumstances, but also as a symptom of longstanding injustice.

These conversations are unfortunately timely due to the racial disparities exemplified by COVID-19 illness and death rates (Chowkwanyun and Reed 2020). In a recent article, authors Yoshiko Iwai, Zahra Khan and Sayantani DasGupta exhort medical professionals to practice what they term ‘abolition medicine’: ‘imagining... ourselves into a more racially just future invested in enriching communities’ and (thereby) working ‘toward a future of health and social justice’ (Iwai, Khan, and DasGupta 2020, 158). As of 12 June 2020, the Centers for Disease Control (2020) showed that ‘age-adjusted hospitalisation rates’ for ‘American Indian or Alaska Native’ as well as black people are approximately five times, and Hispanic or Latino people four times, that of non-Hispanic white people. According to the CDC, this is due to factors such as dense population, caused by housing segregation; proportionately higher risk of living in a food desert and depending on public transport or being an essential worker and having no sick leave. The devastating effects of COVID-19 on communities of colour are exacerbated because ‘racism, stigma and systemic inequities undermine prevention efforts, increase levels of chronic and toxic stress and ultimately sustain health and healthcare inequities’ (Centers for Disease Control 2021). This moment is revealing the faultlines within our systems and making clear the impact of ongoing stress and violence on the bodies of people of colour. Health Humanities research is engaging the overlapping categories of systemic violence that have caused unnecessary and avoidable human suffering.

Examining postcolonial pandemic fiction is relevant to our current moment. The ‘Patient Zero’ is a temporal trope used to exoticise and blame racialised subjects, whether in a formerly colonised country such as Guinea or in an American context. This individual is often identified with marginalised groups, an easy scapegoat to protect normative group identity. One observes the Patient Zero myth uncritically reproduced within contemporary scholarship. For example, in a preface to the newest edition of Epidemics and Society: From the Black Death to the Present, seminal medical historian Frank Snowden (2020) connects COVID-19 with Ebola through the image of human-non-human transmission in an ‘exotic’ locale: in 2013, “a small child played in the hollow of a tree near the garden of his home in Guinea... The misfortune of the four-year-old boy was to inhale viruses shed in the dejecta of the displaced bats” (ix). Guinea in 2013 becomes Wuhan in 2019: ‘this sequence of events, transposed to an urban context, probably occurred at a bushmeat “wet market” in Wuhan, China’, where ‘unhygienic passageways become a “giant petri dish”’ (ix–x).

This new preface to Epidemics and Society risks invoking the same colonialist judgmentalism critiqued by García Márquez and Morales, and risks ‘othering’ the Patient Zero as in Due’s short story. In fact, as Kelly, Keck, and Lysteris (2020, 1) demonstrate in Anthropology of Epidemics, ‘While the viruses that spill over from wild animals to remote village populations occupy pride of place in these end-of-the-world fantasies, today the pathogens that could spark global pandemics might as easily evolve in antimicrobial-rich hospital environments in Europe and the United States’. Both histories and works of fiction about pandemics ask us to project ourselves into a disease’s beginnings; however, popular disease rhetoric is often based on the assumption of the self as inviolate, threatened by external forces. ‘Patient Zero’ invites us to enter into the experience of vulnerability, not only of the uninfected but of the ‘carrier’ by employing the voice of a child. Therefore, even as our physical bodies are in quarantine from pandemic illness, or to avoid pandemic illness, we can recognise the ways in which our stories are embedded in embodied experience, and how affective reading practice connects our own bodies to others’.

Plague has its own vocabulary. The texts by Due and Morales use a haemorrhagic framework of metaphors and images to describe the effects of disease on the body. The images are drawn from bacterial infections causing acute and immediate
suffering. When reading COVID-19 narratives, whether first-person accounts written by sufferers, health practitioners, family members or fictionalised accounts, Health Humanities scholars must engage with this disease’s unique descriptive lexicon. Patients’ narratives offer experiences of respiratory distress and isolation; technologically-mediated communication; neurological and cognitive aftereffects. Healthcare practitioners find themselves cast in roles they did not audition for. The study of postcolonial science fiction and speculative fiction suggests that one keep in mind the ways in which authors can portray health injustice by subverting the linear temporality offered by medical discourses.

Furthermore, postcolonial and social justice scholars stress the importance of oral history as a critical methodology that can complicate official narratives. Historian Indira Chowdhury argues for the practice of oral history to understand science in the postcolonial context, specifically the ways ‘scientific practice has adapted to local and contingent factors’ (Chowdhury 2013). Quoting writer Chimamanda Adichie, Christine Lemley argues that critical oral history can subvert the ‘danger of a single story’: in the case of Adichie’s experience, the dominance of a Western-centric, stereotypical viewpoint of her upbringing in Nigeria. According to Lemley, critical oral history ‘exists to contextualise story and create spaces through which people who are underrepresented in dominant systems use agency to identify and act on struggles to build new possibilities’ (Lemley 2013, 7). In the context of a pandemic, critical oral history offers diversity in terms of venue, perspective, and positionality to stories of illness and healing. Genres of study include interviews, as well as drawings, documentaries and material objects. In the section that follows, I draw on social media postings, emails and interviews in order to demonstrate how critical oral history about COVID-19 can contribute to postcolonial Health Humanities scholarship.

COVID-19 STORIES AND LAYERED TEMPORALITY: HEALTHCARE WORKERS AND LONG COVID SURVIVORS

Text message, 11 February 2021: Why did you come [to the home] when you knew you had a known COVID-19 exposure and no negative test?

Reply: It had been 10 days.

Email sent to all faculty and students, from Texas A&M University, received 6 September 2021: Close contact is defined as being within six feet for a cumulative 15 minutes over 24 hours with someone who tested positive for COVID-19. Vaccinated individuals do not have to quarantine, while unvaccinated must quarantine.

Oral history excerpt, ‘B’: I said, I am going to be walking and I’m going to leave (the hospital) at the date in which you [the doctors] prescribe, which I believe was the 21st of January. If I remember correctly: [...] All these difficult, very difficult things but I wasn’t going to take any other sort of answer and I left on January 21st. (B, interview 2021)

During a pandemic, official time and personal lived time diverge. COVID-19 is morphic, variable, emerging; both respiratory and neurological in its effects; both acute and chronic in manifestation. However, the guidance set by public health entities such as the CDC must by necessity be standardised, in order to provide individuals guidance on how to behave to curb the spread of disease. Our success as a nation is then measured by how well we have followed official time and its interlocking health guidelines; our individual success is measured by how well we have avoided illness or progressed towards healing on a specific timeline. We exercise bodily autonomy in the individual interpretation of that time, and our body’s relationship to it. We create space for alternate temporalities through narrative and art, as well as through other means.

In the first excerpt above, the speaker reminds someone of his individual responsibility and how he had broken a social contract by not heeding that responsibility. In the official email, Texas A&M University leadership places responsibility on the teacher or student for calculating the minutes they have been exposed to someone who is COVID-19 positive within 24 hours, in order to determine if they should quarantine. In the third excerpt, oral history participant ‘B’ sets his own goal for his discharge date after 3 months in the hospital with acute COVID-19, as a motivation to get well. The very length of his hospitalisation belies the CDC’s implied average timeline of illness: even ‘seriously ill’ people can expect to re-enter society after 20 days, the website reads (https://www.cdc.gov/coronavirus/2019-ncov/hcp/duration-isolation.html).

One may form an appreciation for alternate and divergent illness temporalities through studying narratives of COVID-19. By so doing, one may also bear witness to the ongoing human impact of the pandemic. This analysis in no way undermines quarantine, masking or self-monitoring practices. Rather, it stresses that individual lived time is very different from official guidance, and official guidance insistently overlooks systemic inequalities. For example, 2 weeks’ quarantine (during the pre-vaccine era of COVID-19) for someone who is self-employed might be a hardship that pushes that person closer to financial precarity. Racism and xenophobia can make the time one waits for equitable and humane medical treatment interminable. Time spent away from one’s small children due to an exposure; time spent away from one’s beloved in hospital; time spent asking one’s body to perform tasks that used to come easily; time spent waiting for a referral to a specialist to study a little-known symptom: these minutes, hours and days are agonisingly slow. Trauma and post-traumatic stress disorder can cause someone to revisit the same time again and again, compounded by lack of widespread understanding and acknowledgement of one’s illness.

Our temporalities are acutely distinct, and also shared; fractured, and also continuous. Historically important, but not yet historical. The disease is both personally isolating, and creates global interconnection, as patients read others’ narratives from Italy, China or New York online, predicting what might be their future symptoms. Stories from the COVID-19 pandemic reflect this unique temporality: they capture something of the world in which they occurred, emerging as photo essays, texts, vlogs, Facebook posts, Tweets, scraps of paper slid under the door of a shared household, or notes written by practitioners on the glass separating a hospitalised patient from the hallway. Some of the first overtures at narrating hospitalised patients with COVID-19 suffering were performed by their healthcare practitioners. Rafael Campo, a poet and medical internist, has spoken about the challenge of communicating with and hearing the stories of severely sick patients with COVID-19. He says “some patients living with this disease are literally silenced. When that tube goes in someone’s throat to support their breathing, it physically takes away the voice” (Gibson 2020). In response, he has turned to writing poetry as “a kind of a channel for some of the experiences that I’m having and that we’re having”. He says that healthcare practitioners’ writing can “shed light on what people are actually experiencing who have this illness and who are dying from it and who don’t have that voice, which is so necessary for us to hear”.

Original research

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In his poem-in-draft ‘The Doctor’s Song’, Campo incorporates some of the foregoing imagery in the first few lines: ‘The ventilator’s rise and fall/The yellow gown’s swish down the hall’. These are markers of embodied time: one imagines oneself in the setting of the hospital, seeing the rhythm of the ventilator and hearing the sound of the gowns. It is implied that these are repeated, ongoing sounds. Even while an individual’s case comes to a crisis, leading to discharge or death, the healthcare practitioner’s experience is of inexorable time, where case after case succeeds the other. Campo captures the doctor’s own frustration:

The stethoscope won’t be an instrument of hope:
It merely amplifies the gallop, makes audible the broken heart.

The space that a poem creates between each line emphasises the gaps in the doctor’s knowledge. The speaker’s stethoscope amplifies the patient’s ‘broken heart’, but also, by implication, the doctor’s own, facing that which cannot be controlled.

In a poem about cardiac and respiratory symptoms, the poem as a form also makes us mindful of these symptoms through our embodied reading. We breathe in the pauses between lines, or feel the scansion’s echo in the rhythm of our own heartbeats. Finally, with the line ‘The Doctor’s Song is not heroic’, Campo undercuts the expectation that doctors’ heroism in the face of a pandemic should be the focus of COVID-19 narration. From the comment in Campo’s interview that his patients are ‘silenced’, one assumes he agrees that it is important to hear more stories by patients themselves.

Therefore, in addition to literary works like poetry, first-person narratives of COVID-19 illness are necessary to understand the ongoing and debilitating temporality of the disease. The following narratives were collected under a grant-funded, cross-disciplinary oral history project titled ‘Global Health and the Humanities’ (IRB2018-1513M). My collaborators included Violet Showers Johnson and Laura Dague, as well as graduate researcher Michelle Yeoman and undergraduate assistant Trinity Buchanan. We are following the Oral History Association ethical guidelines, including gathering informed consent, performing advance training for interviewers, including diverse voices, using open-ended questioning methods within interviews, recording and transcribing the oral histories, identifying an open-access repository for anonymised transcripts, and making research publications available to interviewees (https://www.oralhistory.org/oha-statement-on-ethics/). Oral histories were conducted from 2018 to 2019 with participants in Sierra Leone and Sierra Leonean diasporic communities in Dallas, Texas. These interviewees were asked questions about their experiences with the 2014–2016 Ebola outbreak in West Africa and with endemic malaria.

The follow-on project included COVID-19 oral histories collected via an online video conferencing platform, with subjects based across the USA. Future research outputs will engage from a comparative perspective the role of oral histories in illuminating global health crises. However, for the purpose of this article, only the COVID-19 oral histories are excerpted and analysed. Participants for these interviews were recruited using social media networks and posting boards related to COVID-19, and selected to represent diversity of perspectives. All excerpts used in publication are anonymised to the level that the participant should not be identifiable. Readers who have certain first-hand experiences of COVID-19 may find the following descriptions difficult to read. If a reader were to wish to avoid this section, the conclusion to this article’s argument appears with the paragraph beginning ‘Often, psychology’.

First, SurvivorCorps Facebook Group Posts (2020) provide a platform for patient advocacy and social justice work. They also provide an opportunity to study how illness narratives of chronic debility can be used as a form of protest against those who might suggest that falling numbers marks a tapering off of the pandemic’s human impact (SurvivorCorps). As ‘a grassroots solution-based movement’, the online support group SurvivorCorps seeks ‘to mobilise the sharply increasing number of people affected by COVID-19 to come together, support and participate in the medical and scientific research community efforts’. The Facebook group is open membership, which means that anyone can join and post. It provides a venue for those who have never received formal medical treatment to commiserate, and for those who have received medical treatment to compare diagnoses and interventions. Members post pictures and ask questions about their own symptoms, drawing on the shared knowledge of the group; they post one-line or two-line obituaries of loved ones who have died. The moderator publicises survivors’ interviews in news outlets and opportunities for members to participate in academic research studies. As the public group grows and gains more recognition, the experiences shared by this group are also driving science and social science policy and research. Punctuation and spelling have been kept verbatim in the examples that follow.

‘Long COVID’ sufferers use the forum to validate each-others’ experiences, using a form of collective as well as individual story-telling. They are co-constituting a narrative of chronic illness within a sociohistorical context that instead encourages closure and healing. One of the methods through which they do this is by stating how long their symptoms have persisted at the beginning of their narratives. One poster writes, “I was a firefighter/paramedic at the time of infection. I am on day 130. I have a collapsed lung—was never hospitalised, and have experienced about 70 symptoms” (SurvivorCorps Facebook Group Posts 2020).

Many posters document their difficulty receiving proper treatment. One poster received a false negative test, and spent months suffering without adequate medical support: “after 4 lung x-rays 3 EKGs and 3 C Scans, and one new primary Doctor later…visit to a lung specialist…it was determined that the negative COVID-19 test administered was a false negative…next step for me a scheduled Bronchoscopy which allows doctor to visualize scar tissue and nodules that have formed in my lungs” (SurvivorCorps Facebook Group Posts 2020). Another says that when she started feeling ill she “called my doctor’s office and they said I should be given a test because of my asthma and to call the walk in. I called, was asked a bunch of questions, and told i didn’t qualify”. A final poster shares, “I have not been able to receive any medical care due to lack of belief and insurance and workers comp issues”. For some of these individuals, a timeline of COVID-19 illness never officially ‘began’ on their medical records. Their stories are only available in private diaries and through social media. In order to provide ongoing treatment, their future practitioners will need to piece together a health history invisible to digital patient charts and laboratory results. This process of recreation will be a narrative one, whereby patients craft their own timeline and causality in reporting the long-term impact of their illness. Finally, the number of long COVID-19 survivors who are uninsured or underinsured needs further investigation—oftentimes these sufferers may have avoided hospitalisation and tried to cope at home. This economic inequality directly impacts how the data about their suffering, whether medical or narrative, will be accessed and analysed in the future.
Common descriptions emerge across narratives, which capture the cyclical and inexorable temporality of illness with COVID-19. Specifically, many call the illness a rollercoaster, with the associations of a frightening and unexpected ride that ends up where one began. On a roller coaster, emotions are intensified, but movement is circular. A further example reads, “107 days later I still continue to fight off this horrific rollercoaster of a virus. This virus is relentless…” (SurvivorCorps Facebook Group Posts 2020). Many keep a log or journal of exactly how many days they have been sick. Another poster is still suffering after 4 months: “It was a roller coaster for about 2 weeks in isolation of my room”. A final poster says, “Hi, I am ___ and I have been riding the Coronacoaster for 16 straight weeks”.

Together, the ‘long haulers’ experiences are being studied as emerging medical knowledge. Neurological and psychiatric symptoms, less well understood by the medical community, are being documented by symptom surveys based on members’ experiences (Lambert, Natalie and SurvivorCorps 2020). Some symptoms, like hair loss and sadness, were not previously represented on the CDC list. These posts are also developing a new lexicon for illness narratives. Metaphors such as ‘coronacoaster’, as well as precise physical descriptions, offer their fellow sufferers, as well as interested readers, a new way to understand the lived experience of the disease.

Although this creation of new knowledge and community is a mobilising and unifying experience for many members, some are also experiencing mental distress from not feeling supported adequately medically or not understood within wider discussions of the disease. They express a drastic shift in physical ability and sometimes feeling alienated from their pre-COVID identity. One poster says, “I feel like I’ll never be the same again” and another says, “I’m praying that we all eventually make it back to who we were before this”. Notable is the language of identification—not I’ll never feel the same again but I’ll never be the same again; not we can make it back to where we were (in terms of lifestyle) before this but to who we were.

This demonstrates what chronic illness scholars have pointed out as a risk in terms of a balance between one’s ambition for one’s life and one’s daily ability: ‘The tension within the experience of chronic conditions lies in the uncertainty whether this separation or alienation [with the world one inhabited before] can be reduced’ (Barnard 1995, 42). Added to the uncertainty inherent in all chronic illnesses is the extra uncertainty for COVID-19 survivors because they are infected with or recovering from a disease about which much is still unknown. However, scholars of chronic illness and literature also have pointed towards the creative potential offered when authors create a ‘chronic poetics’. Hillary Gravendyk claims that chronic poetics provides a mode through which the reader co-constitutes meaning with the text. She defines chronic poetics as the ‘perception and artistic practice that allows the shared conditions of embodiment to emerge from the text’ (cited in Day 2017, 95), especially the work’s focus on ‘simultaneity, chronicity, duration and other forms of embodied perception’ (Day 2017, 95).

Online forums and groups provide a particularly promising avenue to study COVID-19 narratives, because the real-time and communal nature of the storytelling that occurs in these settings can capture the temporality of pain in new and multifaceted ways. Social media can make pain visible, by incorporating photos, screen shots and condensed stories; it also creates ‘networks of voices engaging and reinterpreting pain’ through ‘multimodal communications’ (Gonzalez-Polledo and Tarr 2014, 1467). In the process of ‘sharing pain experiences and meanings’, participants create new kinds of storytelling, where the ‘teller and audience’ meet within the story. Thus, ‘new forms of patient expertise emerge through communicating about chronic illness online’. As the SurvivorCorps community demonstrates, patients can use storytelling (and information sharing, and grassroots campaigning) to exercise ‘transformative agency’ to affect “not only their own health care, but also the quality of health care for others” (Hinson and Sword 2019, 106).

This article began by introducing, and then intentionally revising, a ‘global’, or ‘public health’ chronology of the SARS-CoV-2 pandemic, to show the constant changes in our current temporality. It then created a framework for analysis of temporal innovations in pandemic literature by analysing examples from late-20th-century-postcolonial and speculative fiction. This final section has examined online COVID-19 narratives from 2020, and now turns to very recently gathered and transcribed oral histories from October 2021. Articles have their own internal chrono-logic. By ending with these recent oral histories, I am both introducing emerging original Health Humanities research, as well as illustrating the ongoingness of COVID-19 survivors’ own stories. Specifically, the genre of recorded and transcribed oral history offers unique opportunities to understand the temporality of COVID-19 as full of nuance and multiplicity. Oral histories are digressive and capacious narratives, originating before editing and streamlining have imposed a chronology of illness. Interviewees return to a specific moment of significance multiple times; their stories wind through and around difficult experiences. Audio recordings include the patter of conversation that one engages in to feel at ease. They also show the mundane temporality of chronic illness as it impacts daily life.

The extracts that follow are from an interview with a middle-aged father and former army medic, who was working in a prison when he contracted COVID-19. He was hospitalised from October 2020 through January 2021, and is seeking medical retirement due to the ongoing physical effects of his illness. When asked if he could think of one moment that illustrates living during the time of COVID-19, ‘B’ (alias) responds with a historically significant mortality marker before turning to a brief encapsulation of his own illness. The interviewee first says, “we just surpassed the deaths for the Spanish flu, which is just crazy” (“B. Interview,” Global Health and the Humanities project, 2021). Both this marker, as well as his narrative of symptoms that follows, stresses the ongoing nature of the pandemic, in both its national and personal impact. B explains,

So for the rest of my life, I’m going to be dealing with permanent issues, including pulmonary fibrosis, scar[s] on my heart. I had a heart attack during my period when I was in my medication-induced coma. I have vision loss. I have to wear glasses now, prior to COVID, I had 20/15, 20/20 vision. So I have to wear actually prism glasses because my balance was affected. Also, I have significant memory loss, short- and long-term memory loss. (“B. Interview,” Global Health and the Humanities project, 2021)

This list is matter-of-fact and declarative. However, timing shifts between past crises (“I had a heart attack”), present condition (“I have vision loss”) and future predictions (“for the rest of my life”). The final sentence, regarding B’s memory loss, implies what an effort it may be to deal with the physical symptoms, and to recall and organise these symptoms into a recognisable order. The embodied effort of telling a story—the mental exhaustion, thirst and sadness that come with the telling—are integral to the texture of this recording. Temporal layering and fragmentation are part of the unique quality of COVID-19 storytelling.

B’s story is interrupted at one point when the sensory memory and trauma of his extended hospitalisation causes him to be...
overcome with emotion. His story is a necessary companion to Rafael Campo’s poem. While the doctors treating patients with COVID-19 may be wrestling with uncertainty and loss as they see the rhythm rise and fall of the ventilator, it becomes apparent that for at least some of their patients, the sensory memories of the hospital’s temporal rhythm (especially procedures done repeatedly) are not rhythmic but intrusive and traumatic. B says,

I have a lot of problems with ... I recently had to go into the emergency room for chest pain... When I got there, there were many triggers that occurred when I was there. So be it the smell of the deodorizer disinfectant cleaner that they use on the floor to the fluorescent lights, to the Hoyer lift that was above me, that they used to have to transfer me when I couldn’t move, when I was bedridden. All those things came back to me and I’m sorry, I...

Interviewer: No, please. Yeah. Take your time and I understand, this is difficult.

BB: It still affects me emotionally.

This transcript shows a dialogue that unfolded as a lived conversation via Zoom. Therefore, in reading it, one is immersed in the temporality of the interview: not the same temporality as the recording, but an individual reading of that temporality as reflected in text. When B breaks off, it is a temporal as well as spatial break for the reader. However, one does not know if the pause was 3 seconds or 3 minutes. Therefore, one does not know how long to hold one’s breath out of concern for the speaker’s well-being. Perhaps our eyes need to leave the page for a moment. Perhaps our heartbeats quicken. The next line, “it still affects me emotionally,” registers as a thunderclap through its very understatement. These are just some possible embodied responses to reading—however, they are meant to suggest that it will be important to reproduce first-person narratives of COVID-19 illness in their original form. One must be attuned to the way the genre influences how one reads, and to how one’s own embeddedness in this moment influences interpretation.

Often, psychology and brain sciences presuppose that trauma disrupts the teller’s access to ‘natural’ narrative ordering: ‘an essential dimension of psychological trauma is the breaking up of the unifying thread of temporality’ (Stolorow 2003, 158).

However, postmodern and postcolonial criticism, as previously demonstrated, offer us the possibility that time is co-constituted between physical and cultural realities. Narrative shows us, not the ‘reality’ of a universal time, but how disparate one person’s experience of lived time can be to another’s. That is to say, the same chronological time of hospital staff, organised by shift changes, regular cleaning of the floors and daily functions performed for the patient’s body, are registered by the patient’s subjectivity as acutely traumatic and recursive time.

More work needs to be done understanding COVID-19 survivors’ experiences from a disability studies perspective. Rebecca Garden argues that ‘narrative, particularly first-person accounts, provide a critical resource by representing the point of view of people with disabilities and by offering a means of examining the social context and social determinants of disability’ (Garden 2010, 70). One goal of disability studies is increased accessibility for disabled persons. Accommodating disabled and chronically ill ‘long haulers’ may mean reconfiguring our understanding of the pervasiveness of chronic COVID-19, and encouraging communities to understand these long-term effects.

One of the challenges of oral history and auto/biographical scholarship is discussing the import of others’ experiences in terms they have not used themselves. Not all posters or interviewees cited herein associate themselves with antiracist or disability rights activism. Instead, this article means to use critical oral history in order open up analytical frameworks useful to analyse the emerging stories of COVID-19, making space for the multiplicity of these speakers’ own experiences. This is an important intervention, as many of the patient stories thus far have been curated by the organisation publishing them—whether this is a public health organisation using the story for educational purposes, or a hospital advertising the quality of its care. For example, a story titled ‘Grateful to be Alive’ represents the experience of Ernesto Castro, a patient at UC Health, Greeley, Colorado. Castro’s experience is framed using illness narrative clichés such as “he fought for his life”. The article stresses the heroic nature of the hospital workers (“Health workers greeted him and jumped into action”). His interviewer encouraged a specific kind of testimonial storytelling, so that when he is directly quoted it is to commend his practitioners: “If it wasn’t for the UC Health staff, I don’t think I’d be here” (UC Health 2020).

Postcolonial and disability studies can help one to focus on the lack of health access and health inequity during a time of pandemic, and to help us to envision radical new ways of storytelling that do not impose closure on narratives of illness with COVID-19. Health Humanities scholarship regarding chronic pain and chronic illness narratives demonstrates the importance of cultivating an aesthetic appreciation for non-linear or fragmented narrative structures. In uniting these approaches, the project is to create discursive space, and interpretive flexibility, around these narratives. By so doing, one may help resist their instrumentalisation within medical or nationalist discourse.

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NOTES

1. For more on the cultural values of endemic and epidemic disease in narrative, see The Endemic Pandemic by Larsen (2020) and Endemic: Essays in Contagion Theory by Nixon and Servitje (2016). Specifically, Nixon and Servitje claim that “Epidemic discourse so thoroughly structures our world that it is endemic to our processes of social construction” (2).

2. We may assume, based on Western norms of storytelling, that human subjects seek to unify their sense of self through narrative. However, as Angela Woods has demonstrated, some of us do not have “the propensity or orientation towards narrativity; the feeling of deep psychological continuity with one’s past self, married with the desire to frame experience, tell stories and revise the past” (Woods 2011, 73).

3. Rosemary Jolly has pointed towards the importance of self-questioning in memoirs by Western subjects: the doctor-writer’s misunderstanding, she suggests, demonstrates the ‘limits of colonial diagnostic knowledge’ and ‘works against the narrator-as-doctor

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enacting the colonialist fantasy of remedying, or ministering to, the chronically ill indigenous subject’ (Jolly 2016, 528). These works make visible in a specific way how colonialist medical practices do harm.

4. For more on medical experimentation in colonial settings, see Africa as Living Laboratory by Tilley (2011) and Bacteriology in British India: Laboratory Medicine and the Tropics by Chakravarty (2012).

5. Recently, Elaine Freedgood also questions our assumptions about 19th century realism. Freedgood suggests that our perceptions of this literary past rests on post-1970s aesthetic valuation and that we thereby overlook 19th century novels ‘oddness’. She also questions the ‘aesthetic racism’ that has valued realism in the novel (Freedgood 2019).

6. ‘The logics of dispossession and elimination, which are key tenets of a settler colonial model, were not isolated to British imperialism; they were also central to Spanish and Portuguese imperial projects’ (Castellanos 2017, 778).

7. Rishi Goyal’s recent work stresses how the label of healthcare workers as ‘heroes’ serves to distract from the ‘deep institutional betrayal’ they were subjected to (inadequate supplies, protections and support) during the pandemic (Goyal 2020).

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