"But you don't look sick": at the crossroads between cancer and corona

The first time I wore a mask on public transportation was October of 2019, just after starting chemotherapy. At the time, a medical requirement to prevent me from exposure to pathogens gained an alternative interpretation from the people around me: it was a symbol that something was Wrong. It changed the space people gave me on crowded trains. In one station, someone jumped at the sight of me, apologizing for my "situation," whatever that situation might have been. Coming home after teaching an evening class, someone kindly asked for permission to pray for me, all without asking a single question about what created the need for a mask in the first place. After I had spent the first four months post-diagnosis experiencing cancer as an invisible illness, I was unprepared to exist as a pariah. The mask made things different. It wasn't surgery scars that could stay hidden under clothes, or the pillow I kept in my bag to stay ready for sudden bouts of fatigue. The mask took my private affliction and set it out where strangers could see and respond to it. The response was solemn, a premature dirge I hadn't requested.

Prior to 2020, we felt almost entitled to the spread of airborne illness. Masks, it seemed, were simply not "done" in Western societies. Mask-wearing was largely considered more aligned with East Asian culture, as Rodney H. Jones notes while reminding us that "the difficulties with communicating about face masks [are] also a result of ignoring the complex nature of *meaning*." The mask is a transformative item, and the sight of one in the wild was a reminder to the normal world that sick people exist, that an illness could transcend the boundaries of hospitals and invade everyday active life. Christos Lynteris has considered that the visual of a medical mask traditionally "carr[ies] certain talismanic properties, allowing humanity

¹ Jones, 6. Emphasis his.

to persist on the edge of a[n]... 'end of the world'."² To a populace not yet confronting the epidemic overseas, I became a harbinger of what was to come.

Perhaps that reaction is what sent me vacillating between malaise and spite. It was infuriating to be in a near-constant state of sensing that my presence caused discomfort to those unlucky enough to face the unknowable plague I symbolized. It was a level of scrutiny discussed by Audre Lorde's cancer journals, wherein she writes that "the idea that the cancer patient should be made to feel guilty about having had cancer... is an extension of blame-the-victim syndrome. It does nothing to encourage the mobilization of our psychic defenses against the very real forms of death which surround us." Illness is a complicated mess, the domain of false starts. Cancer stories are at their most welcome when they speak of triumph and survivorship. They beg for sympathy when they involve the word "terminal." But the liminal space between is messily ambiguous. I could not provide the reassurances they wanted. I could never guarantee them the positivity they craved. The world hates the unknown, and I stubbornly refused to offer resolution.

By the spring term, I was less able to focus on the injustice inherent in the struggle created by becoming visibly sick. Months of chemotherapy had forced me to reconsider the general pattern of graduate life. For many of us, the nature of our precarity leaves us lacking in choice related to our scheduling. Academia is a forgiving occupation with an enormous set of liberties, but it is also prone to undervaluing its laborers. The low pay rate of adjuncts combined with the high cost of city living oftentimes leaves instructors bustling between campuses, sometimes spending more time in transit than in the classroom.⁴ Out of a mix of pride and insecurity, I only ever even informed my department chairs about my cancer when my

² Lynteris, 442.

³ Lorde, 66.

⁴ The austerity of contingent faculty has been well documented; see Emre and De Spiegeleare for an assessment of the impact of a long commute on an employee's work/life balance.

impending radiation (which required a short visit to the hospital every weekday afternoon) created some severe conflicts with my class availability. It felt like cheating, somehow, to ask a chair to switch me to an earlier class. There was worry that I was playing some kind of card, or invoking the name of "The Big C" to generate an unfair advantage for myself. While the mask told the world I was sick, asking for a favor communicated that I was broken enough to require accommodations.

I was determined to make it through Spring 2020 with as much normalcy as possible. My conflict was resolved through the kindness of a colleague who made a point of informing me that it was silly to not have asked sooner. The generosity of the collegiate community left me vowing to give this group of students an exemplary semester, worthy of the instructor they thought they'd be taking. Armed with a note on my syllabi to warn students of a potentially late paper return rate, I spent the first day of the semester preparing them for the complications I'd already discovered during the previous term. They were informed that my energy levels might fluxuate without much warning, and specifically forewarned about an issue I'd developed with pairing words with concepts. There was no response at first, and I assumed that they were indifferent. After I released the group, a handful of them lingered, ostensibly with questions. I'd come to expect this after the fall; some more empathetic students would usually ask for more information about my diagnosis, or share anecdotes from their experiences with parents' cancer battles. The first thing they noted, however, was pure disbelief: "but you don't look sick." It felt incompatible with the world outside of academia. How could they not be able to see what had become so obvious to strangers? I'd seen the signs of it in the dark undereye circles staring back in the mirror every morning. But this group of students didn't seem to notice what strangers on the train found so disruptive. They commented on my energetic delivery, and asked for

clarification about some semester-long assignments. It was the most normal exchange I'd had in weeks.

That normalcy continued as the term developed. We established a rhythm to the weeks, covering the material at the brisk pace intended to challenge them at an appropriate level. During this process, I was struck by the series of unspoken kindnesses that the group extended to me. They were a grade-conscious group, as was common for the culture at that college, but were happy to accept that sometimes feedback from me would be delayed for over a week. I would be mortified when, mid-lecture, I would discover that I'd lost the word for a theory's name, or even more common nouns. But the students would helpfully supply what they could, and always seemed receptive to an hours-later Blackboard announcement triumphantly giving the name of the theory when it occurred to me while I was doing something unrelated. There was no objection to the occasional cancellation of office hours on bad days. I was confident that the semester would go well, thanks in large part to the patience and compassion of my students.

When Coronavirus struck, it made the medical side of my life surreal. At the start of March, I witnessed the erosion of comfort during my daily trips to the hospital. Masks were already common among patients, with a mind for the safety of the immunocompromised, but the increasing tension was palpable. The rules changed daily and without warning, with a harshness that agrees with recommendations from crisis scholars who note that *en masse*, people require direction more than empathy during critical moments. "It is the content of the information," they explain, "that determines whether people decide to act upon a crisis, and not the way the crisis information is framed." ⁵ The waiting area had fewer seats each day, until access to it was removed altogether. Patients were asked to stay in their cars until they were needed. The

⁵ Bakker, et al., 7.

friendly sense of an extended family was evaporating, and I began to worry that the rest of my life was about to follow suit.

The distress that I felt from the chilling hospital experience started to manifest itself in directives from CUNY administration.⁶ A February 28th note insisted "There are no confirmed cases of novel coronavirus in New York City and the risk to New Yorkers remains low," only to append on March 2nd that "CUNY is taking this possible threat very seriously" after New York cases were confirmed. Two days later, faculty was urged to "be prepared to accommodate affected students to the greatest reasonable extent, including, but not limited to, facilitating enrollment after the deadline, fast-tracking academic advising, permitting make-up exams, and extending due dates of final assignments and projects." From then, it was only a week until the governor of New York would recommend a full transition to distance learning.⁷ The speed with which things had gone from ambient concern to imminent threat caught us all unprepared, even as we collectively hoped that life in New York would simply shut down for a short time, even though the an ominous specter seemed to suggest something more long-term. Cancellation notices frequently used the word "indefinitely" when describing postponements. But how long could "indefinitely" really be? The virus would most likely be resolved by the summertime, we assumed. It might even prove to be a thrilling way to practice the digital scholarship that many of us had only theorized before.8 It would be fine if we just listened to colleagues who had experience running online classes. We just needed to keep moving forward.

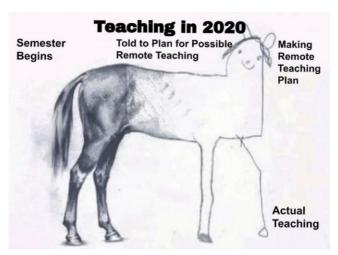
Administrative direction was muddled at best, with plans changing by the day in some cases. CUNY gave faculty several days to "recalibrate" their classes and make them suitable for virtual sessions. We all learned, very quickly, what Zoom was. Just as quickly, we learned about

⁶ Archived at www.cuny.edu/coronavirus/university-updates/

⁷ "During Novel Coronavirus Briefing"

⁸ Selwyn, et al.

its habit of terminating sessions well before the average class time was over. The institution struggled to provide faculty access to tools. And among it all, students weren't sure how to navigate the frequent rule-changes with the tasks that made up their responsibilities. Did they have to return library books even though the building was shut down? How would they manage a group presentation if the group wasn't going to present in person together? Was there still a paper due on Friday?



A meme shared in department correspondence to describe our general mood. Author unknown.

The confusion served as a reminder of our responsibility within CUNY. As educators, our job often extends past the limitations of our weekly sessions. We cover the material, but we are also wielding the weight of an uneven power dynamic. While we were scrambling to keep calm enough to present an authoritative tone to our students, they were facing the world outside. The early days of

covid were a flurry of shutdowns. What kind of academic rigor would be ethical to ask of them in the face of more pressing concerns? Before science yet understood the virus well enough to determine a full list of symptoms, students were falling ill or watching the disease decimate their families. How could anyone be expected to care about an esoteric engagement with iambic pentameter when they were trapped in the chaos, worried about the possibility of having to bury a parent? The students who had been so kind to me did not deserve to have this become their story. They now required someone to keep their crisis managed. And though the theoretical

approach⁹ would suggest holding back on full compassion until the time came for crisis resolution, the crisis at hand was shaping up to be more than a moment. The resolution could not wait until the damage had run its course. These gentle students had allowed me to dominate much of the class discourse surrounding accessibility; it was time to adapt in favor of their new needs.

My first task was to shift the burden of caretaking back toward myself, where it probably ought to have been in the first place. As some scholars of pandemic pedagogy would later surmise, "Disruptions offer opportunities. It is up to instructors to seize them to create rigorous, just, and caring instructional options students can embrace." ¹⁰ In the span of our brief morning greetings, I used an autobiographical approach to explain some mysteries of the medical process, which would become a conversation between my class and certain hospital staff as I carried their questions to my daily treatments and returned with my findings. I tried to use this dialogue to provide an opportunity for them to vocalize their own lived experiences, to share their exploits after I had. In the chaotic first virtual session, I rambled over my technological concerns, sharing what I had learned about the spread of illness from the oncology perspective, much of which overlapped with elements of the mixed governmental message. We talked about how to balance on the subway without holding on to anything. We talked about the hard parts of my illness, of how quickly the reminder of mortality can impose itself on a life that hadn't considered it before. I confessed the truth that I'd already been experiencing a life in relative quarantine, which most likely made me a resource to tap for ideas when they started to go a bit stir-crazy. We commiserated, and then got to work.

⁹ Bakker, et al., 7-8.

¹⁰ Schwartzman, 515.

In an unfortunate coincidence, the literature we would be discussing was a book which dealt with the themes of an eroding society reflecting upon the end of Empires. It seemed a little too relevant to force the planned journal exercises upon them, and I offered amnesty and extra credit to students who needed to talk about their situations with the word count that would have been used for responding to the week's readings. The confessions I received were gut-churning. Several students had sick family members, and a handful were forced to deal with sudden covidrelated deaths. Others were anxious that their packed apartment buildings would provide little protection from irresponsible neighbors. Some students pondered religion, wondering whether this was a sign of the end times. The retail workers lamented how much exposure they were forced to endure, all while working jobs that would never give them the option to work from home. Some were angry about the response from non-New Yorkers on social media, feeling as though their stories were being appropriated by the judgment of outsiders. Out of the concerns that were within my power to mitigate, it seemed as though time and focus were competing for the top worry. I posted a poll asking whether they would prefer to meet asynchronously for the remainder of the semester. Overwhelmingly, they voted to continue having class as if there hadn't been a change in format. "I like logging in at the regular time because it gives me some routine," said one, while another noted that "Blackboard collaborate classes without video is a plus for all introverts." They craved normality, and it became my job to provide it.

I am aware of, and honestly still troubled by, the knowledge that students didn't vocalize everything. The transition to a virtual world allowed for greater physical accessibility, but much was lost in translation. I'm reminded of Morgan Jerkins' discussion of performing fortitude: "I thought that the pain in and of itself was in fact admirable... I thought: This is how I will become strong, through how well I can obscure pain. I was never taught that the world would nurture me,

so I perfected the ways of hiding." Hiding is easy to do in a pandemic. With no impetus to travel and meet in person, there is no reason to burden others with the knowledge we would be pressed to expose otherwise. Washed out by the glowing screens, we all look pale and listless. As everyone gains a little weight from inactivity, no one notices when the medication causes bloating or facial inflation. In a world where we all look sick, no one does. It creates a convenient anonymity, but it also leaves room to fall through the cracks. Throughout the city, the students who did well pre-pandemic would continue to do well, but the ones who were borderline found avenues to fall further. I could sense that something was wrong but could not quite put my finger on it.

Lorde's cancer journals consider the ease with which the sick and the desperate are able to disappear: "pain does not mellow you, nor does it ennoble, in my experience... The status of untouchable is a very unreal and lonely one, although it does keep everyone at arm's length, and protects as it insulates. But you can die of that specialness, of the cold, the isolation. It does not serve living." With all the effort we were putting into appearing prepared and competent, I wondered, were we serving the people who are afraid to admit to their challenges? The covid-positive were quickly becoming exiles, given distance and blamed for a community spread that was out of their control. What could be done to keep them from becoming more ghosts of illness? As the evidence of disparity mounted, how could I signal to them that they could still compete?

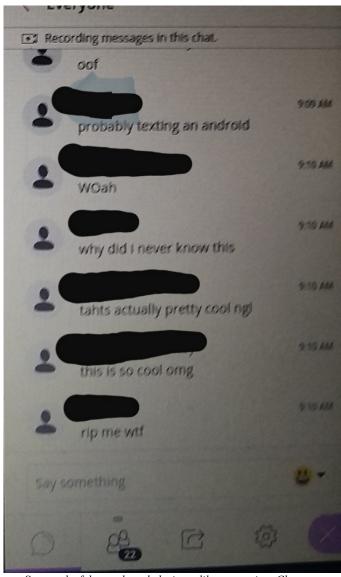
As before, I turned to a confessional approach to lecturing. Part of approachability comes from modeling humanity. Although my home wasn't bustling with small children or noisy roommates like some of my colleagues, I'd been experiencing trouble with some of the same tech

¹¹ Jerkins 130-1

¹² Levander and Decherney

¹³ Lorde, 41.

accessibility that was alienating my students. Aside from my phone, the only device I own with an attached camera is an ancient, beat-up Chromebook, useful mostly for checking email while traveling away from home. It had a hard time multitasking Netflix with a Google doc, and now it would serve as a primary teaching device, tasked to juggle the faces of tens of students as well as projecting my own. I openly discussed the contempt I felt when propping it up on my kitchen counter and finding a sufficient angle to let people see me without a background distractions. My survey of the class took the form of grousing with the intent to generate a response from the ones who'd skipped the opportunity to submit survey data earlier. Wasn't it just the most annoying thing when people with power over you insist on video conferencing? The ensuing cross-talk helped me determine which students were choosing to hide chaotic living situations. From there, I learned that I could steer accessibility into adopting upcoming presentations by running students' slideshows from my end rather than asking that each group of students determine the tasks among themselves, easing at least a bit of the burden on those who may have been struggling. During more private conferencing with each group, I tried to be clear that ours would become a community that leaves no one behind, and also keeps track of those who need a little extra help. If we could get everyone through the semester together, we would all emerge better for having accomplished it.



Some colorful crowdspeak during a library session. Chat was surprised to learn that "Ask a Librarian" was staffed by humans.

I began to see my role morph into a sort of livestreamer over that of a traditional lecturer. Given the opportunity, many students preferred to engage in synchronous sessions as if they were spending an hour or two with a makeup or game streamer. In the normal version of those exchanges, a hobbyist goes about something they're passionate about while participants in a live chat express themselves in more direct conversations. The streamer engages with chat, but chat is also free to communicate without the pressure of committing to fully articulated thought. A wash of crowdspeak¹⁴ emerges, reactions communicating that the audience is engaged and alert despite their invisibility. In the hopes of establishing informal communication as the norm, I extended the rules of my "class

participation" guidelines to include emoji and internet shorthand, and found that literary discussion became something multi-layered. The audio participants responded to the text and one another, while the text chat carried on in a more reactionary capacity. By the time we welcomed a guest librarian into a session, they felt free to carry on and make their emotions known, even when language failed them. At the very least, it was a way to engage the students struggling to wrangle class software on suboptimal devices while I read aloud particularly poignant

¹⁴ See Taylor, 44-65.

contributions for the students calling into class via phone. If my classroom had to become a virtual space, it seemed to still serve the purpose of offering an escape and the opportunity to focus on something other than the oppressive news cycle.

It was in this way that we trudged through the remainder of the semester. We met twice-weekly from our homes and began our pandemic alone together. Although the world had changed, our commitment to finishing together did not. Our compassion for one another formed a recursive loop, which reverberated as needed until the end of the course. On the last day, I asked the class to find a way to change their situation to make it feel more like a comfortable final experience. I taught from my living room instead, offering a different backdrop than what they'd grown used to seeing. One student brought a comically large bowl of popcorn onscreen, which they would eat dramatically during the salacious elements of the day's topical Shakespeare. Some more introverted students turned their video on and conceded to be seen one last time. We'd found a way through at least the first few months of the transition into the new normal of 2020.

Hi Professor,

Attached to this submission should be my Final Research Paper, I hope that you enjoy what I wrote. Also thank you for being such a kind and caring professor. You were very funny and although we switched to online learning nothing really had changed, which was very nice, since it felt like I was still going to class normally, with the exception of sitting at home. You helped raise my confidence in me and I have to thank you for that. So i'm gonna stop rambling and say thank you again, i hope you have a great day and a great summer.

A student left this message while submitting a final essay.

I was touched enough to take a photo and send it to my Mom, the way very adult and incredibly cool people do.

A year later, the world seems poised to go outside again. But as our lives become more accessible, I hope that we won't forget some of the understanding that we've gained. The immunocompromised do not normally have the ability to make the world stop to focus

exclusively upon us and our needs. As recent times have shown, many people grow belligerent at being asked to change the daily patterns of their lives. Now that we've formed new habits, perhaps it won't be so strange when masks remain out in the open. Hopefully, it won't be an inconvenience when a colleague asks to join department meetings virtually. Covid may be the most imminent biological threat, but it is far from the only one. As most of the population waits anxiously for vaccinations, I work with medical professionals in the interest of delaying the progression of a disease that has no cure. The concessions made to keep pandemic life I hope that we will hold on to the empathy that we've gained and continue to support people in need, even if we catch them during a moment of hiding. In this world of separateness, we've learned how to respectfully show unity. Even when we can see each other in natural lighting again, we won't always be able to identify the sick or disabled by sight. If a mask is truly a metaphorical talisman keeping us from teetering into the end of the world, this experience at isn't something to be feared anymore. We've looked at the end of the world and found small pockets of reprieve despite we can continue to serve that purpose for one another in perpetuity.

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