The politics of testing positive: An autoethnography of media (mis)representations at the ‘start’ and ‘end’ of different pandemics.

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Abstract

This paper draws on an autoethnographic ‘digital diary’ which the author began after testing positive for HIV in July 2016, until May 2021, to critically assess (mis)representations of both the AIDS and COVID-19 pandemics in the media. Drawing on insights from art, literature, queer theory and social anthropology, the paper focuses on dominant moral and political discourses to show how narratives of blame, shame and guilt about viral transmission contribute to the stigmatisation of ‘at risk’ groups. Concepts of biopower and normative judgement are used to reflect on discourses which construct those who ‘test positive’ for HIV or SARS-CoV-2 as ‘reckless’, ‘risky’ or ‘irresponsible’ subjects. The paper also analyses notes on recent media appearances made by the author to discuss their participation in the PARTNER study, which showed that HIV antiretroviral therapy eliminates the possibility of HIV transmission, including reports in The Guardian, on BBC News, on Sky News, on Channel 5 News, and in the Metro. As the former had reported that the ‘Covid-19 crisis raises hopes of end to UK transmission of HIV’, portrayals of the two pandemics are compared to explore tensions between public health and individual responsibility as normative priorities.

Keywords: autoethnography, COVID-19, HIV, media discourses, normative politics, queer theory
Introduction

This paper draws on excerpts from a ‘digital diary’ which I have kept since testing positive for HIV in July 2016 to consider how media discourses have (mis)represented the ‘start’ and ‘end’ of two different pandemics: COVID-19 and HIV. As an autoethnographer, I use my experiences of talking to broadcasters (BBC News, Channel 5 News, Sky News) and writing for newspapers (The Guardian and Metro) about living with HIV to deconstruct normative representations of, and responses to, SARS-CoV-2. Drawing on concepts from Foucault (1977; 1978; 1979), and social anthropologists influenced by his work during the early HIV pandemic (Douglas and Calvez 1990; Rubin 1984), this paper recognises that ‘in all places at all times the universe is moralized and politicized’ (Douglas 1992, 5). Art and literary theory take a central role in my comparison between the two pandemics, turning to uses of photography, metaphor and other narrative devices to construct meanings (Muncey 2005; Sontag 1988). Here, I reflect on the contradictions and problems of individualised representations of the self in the context of infectious disease, which tend to be politicised through media tropes of ‘blame’, ‘shame’, ‘guilt’, ‘responsibility’ and ‘victimhood’ (@Max_Morris, Twitter, February 11, 2021).

Given the importance of Foucault to this analysis of the politics of pandemics, I begin by outlining several related concepts: discourse, normative judgement and biopower. Firstly, discourse refers to ‘ways of communicating which limit what can be imagined’ (Morris 2018, 55) or, in Foucault’s (1979, 243) terms, the ‘grid of intelligibility’ (episteme) through which our understanding of the world is filtered. Secondly, normative judgement describes the ways in which people’s behaviours and bodies come to be (self-)regulated through the ‘perpetual penalty that traverses all points and supervises every instant in the disciplinary institutions [and] compares, differentiates, hierarchizes, homogenizes, excludes’ (Foucault 1977, 183). This concept has been useful to queer theorists in providing critiques of both hetero- and homonormativity. Finally, the term biopower represents the more ‘progressive’ – egalitarian, liberal, secular – ideologies which emerged alongside modern technologies of medicine and industry, where the sovereign power ‘to take life or let live’ was replaced by ‘positive influence over life, that attempts to administer, optimise and multiply it, subjecting it to precise controls and regulations’ (Foucault 1978, 136-137). Oksala (2013, 55) has further noted that the ‘rationality of biopower’ is compatible with a critique of individualism and economic rationality within neoliberal governmentality, where ‘the “health” of the markets implies the health of the population’ (see below).

The first time that Prime Minister Boris Johnson mentioned COVID-19 in a speech was on February 3, 2020 (Johnson 2020). Here, the emerging pandemic was presented through a characteristically modernist lens of economic progress, individual liberty and utilitarian rationality: ‘there is a risk that new diseases such as coronavirus will trigger a panic and a desire for market segregation that go beyond what is medically rational’. Invoking the heroic protagonist of Superman, he added,
humanity needs some government somewhere that is willing to make the case powerfully for freedom of exchange, some country ready to take off its Clark Kent spectacles and leap into the phone booth and emerge with its cloak flowing as the supercharged champion of the right of the populations of the earth to buy and sell freely among each other.

Flanked by medical experts, during the first week of daily briefings from Downing Street (March 20, 2020), Johnson went on to describe the impending lockdown measures as ‘taking away the ancient, inalienable right of free-born people of the United Kingdom to go to the pub’. This kind of exceptionalism – characteristic of political discourse in the UK during and since the 2016 Brexit referendum (Powell 2019) – has been typical of the consumerist and libertarian logics which this paper critiques from a queer perspective. As Halberstam (2011, 3) cautioned against in The Queer Art of Failure, the ‘cult of positive thinking’ has been influential within neoliberal regimes.

This paper draws on queer theory (Butler 2011; Rubin 1984; Sedgwick 1993) to critique simplistic narratives of heroes and villains, modernist progress, and normal behaviour which have shaped the grid of intelligibility through which COVID-19 has been constructed. Across the following six sections, the paper explores my ‘Motivations for Focusing on the Media’; why this led to a turn ‘From Modern to Postmodern Method’; how ‘Metaphors, Meanings and Monsters’ contribute to sense-making, or the intelligibility of pandemics; how ‘Narratives of Normativity’ display a moral disjuncture between HIV and COVID-19; and the role of autoethnographic methods of representation including ‘Art, Photography, and Finding My Voice’ through creativity. Finally, I conclude the paper by discussing the implications of biopower and normative judgement for making sense of the ‘start’ and ‘end’ of two different pandemics. It is important to note that this paper does not examine the media’s role in the construction of reality beyond my personal experiences, nor important debates around bias and objectivity in news media more broadly (see Chomsky and Hermann 1988). In addition, I use the term ‘pandemic’ to recognise that viruses such as HIV and SARS-CoV-2 are not restricted by national borders, as I know from experience.

Motivations for focusing on the media

‘What happens in Vegas doesn’t always stay in Vegas’. That was how I answered the question: ‘Can you pinpoint the circumstances that led to you being infected?’ Laughing at my response, Alix Fox – a ‘journalist and broadcaster who specialises in sex education’ – said, ‘There was no vagueness to your Vegas story!’ Sharing a nervous smile, we both knew that providing an in-depth response to this question might not be deemed ‘suitable’, so mutually drew on euphemism and humour to move past the sticky detail of how HIV tends to be transmitted. Given that Alix co-hosted a BBC Radio 1 podcast called ‘Unexpected Fluids’ and I research other people’s sex lives (Morris 2018), our avoidance of the word cum might seem coy. Before the interview began, however, we had been briefed by a Radio 5 Live (November 15, 2018)
producer on what not to say in front of a ‘BBC audience’ – a phrase which connoted a certain level of conservatism, normativity and propriety around discussion of sexuality. It is worth noting that Alix is a close friend (‘the day that we were introduced to each other, was also the day that he got his diagnosis’) and she asked about my comfortability around discussing the circumstances of my diagnosis during this briefing. Afterwards, I messaged her to note the difficulty of presenting this topic so that it ‘plays well with a BBC audience’, and she said, ‘It’s regrettable that I didn’t have adequate time to delve into deeper discussion about sexual politics’ (Facebook Messenger, November 27, 2018).

Alongside the sexual politics of HIV, this paper focuses on narrative devices which filter our understanding of pandemics. With the emergence of COVID-19 and lockdown measures imposed to prevent transmissions, several HIV organisations adopted a triumphalist tone in the media. On Twitter, for example, the National AIDS Trust (NAT) shared a Huffington Post (June 4, 2020) article which read, ‘The coronavirus lockdown may have one surprising positive impact – to end the transmission of HIV in Britain’, and the Terrence Higgins Trust (THT) shared an Independent (June 11, 2020) article which read, ‘The coronavirus outbreak could put an end to the transmission of HIV in the UK’. After I saw several politicians sharing these posts, I wrote

I have some complicated feelings about this. It seems to be a message coming from HIV-negative people, mainly, and we’ve had so many ways to ‘end’ HIV recently – from PrEP to U=U. Perhaps we should stop talking about COVID-19 as a once-in-a-lifetime ‘opportunity’ to stop a different pandemic. (Notes, June 9, 2020)

I had two main reasons for talking to the media about my experiences with HIV. Firstly, my boyfriend (Alex) and I were participants in the PARTNER study, demonstrating that when someone is on highly effective antiretroviral therapy, it becomes impossible to transmit the virus (Rodger et al. 2019). Secondly, given the blame and shame I had experienced after ‘coming out’ (see below), I wanted to challenge out-dated and unscientific stigma around HIV.

The interview with Alix led to a string of invitations to appear in the media to discuss the study, including BBC News, Channel 5 News, and Sky News, which provided me with an insider perspective into how news stories are constructed, sometimes in contradictory ways. For example, the latter two interviews happened on the same day (May 3, 2019), where I gave almost identical responses about HIV (e.g. ‘we have a cultural hangover from the 1980s’). On the one hand, Sky News filmed us outdoors, for better lighting conditions, where the journalist adopted a conversational tone to describe the ‘landmark study’. On the other, Channel 5 News filmed us indoors, closing the blinds to create dim lighting, and the journalist adopted a melancholic tone when saying, ‘At the age of just twenty-four, Max’s world came crashing down’ – invoking a sense of lost innocence – before adding, ‘After six months of extreme stress and anxiety, he met Alex, who’s been his partner ever since’. Here, the piece cut to a clip from the infamous 1987 ‘tombstone’ advert, which contributed to the ‘conflation of HIV with death’ (Notes, February 21, 2021) and, as I have argued elsewhere, ‘became
deeply ingrained in the national consciousness’ (Ashford, Morris and Powell 2020, 610). Relatedly, in an interview for the Museum of Contemporary Art (December 6, 2013), the autoethnographic photographer Nan Goldin described ‘The Ballad of Sexual Dependency’ (a series diarising queer life and death in New York City) by saying: ‘I thought there was day and night, and I lived at night. I seriously didn’t know, until about 1989, that the colour of everything is changed by the light of the day’. Similarly, Muncey (2005) used photographs in her autoethnography to contrast light and dark, noting the ‘claustrophobia’ of indoor spaces.

In a BBC News article (November 17, 2018), which accompanied the Radio 5 Live interview, I elaborated on the mental health impacts of HIV stigma: ‘I started having panic attacks... I couldn't breathe. I couldn't go outside. It only takes one person treating you differently before you begin to wonder if that’s how everyone sees you’. When Alix asked me to describe ‘the mental journey that you’ve been on’, I said, ‘HIV has definitely had an impact on my mental health. Not because of the virus itself, but because of other people’s attitudes’. For example, one experience has influenced almost everything I have written about HIV, including this paper. Five days after my diagnosis, I ‘came out’ to a professor who had been a friend and mentor for many years:

Professor: Is there any impulse for you to bareback with other positive guys?

Author: As I said, when undetectable there is no risk, less than someone who doesn’t know their status [U=U].

Professor: I know Truvada [PrEP] has once failed, is it literally no chance?

Author: At the clinic, they said it was 100% non-transmission between HIV+ and HIV-partners, even when barebacking, if undetectable.

Professor: Yeah. That’s the risk. If I’m looking to have sex with someone HIV-positive (which, frankly, I wouldn't) I’d ask myself if they can be trusted to have taken their meds regularly. I’d come to the conclusion that they were reckless in the first place, hence how they got it, so why wouldn’t they be reckless now?

Author: Being reckless once doesn’t define a person’s behaviour forever, and that kind of assumption is unhelpful to say the least.

Professor: But with strangers, how do you know?

Author: Given the level of irrational judgement people face, why would they be honest with you, anyway?
Professor: It’s not irrational to protect yourself. They should be honest, unless they are unethical. (Facebook Messenger, July 26, 2016)

He added, ‘I ask people if they have a [sexually transmitted disease]. If they do, any, I don’t have sex. Full stop. That’s reasonable’, ‘It carries more stigma because it has a higher probability of death’, and ‘It’s not judgemental. It’s wise. Your [sic] an idiot to trust people to take their meds’. I was unable to sleep that night, spending several hours talking to a volunteer for the suicide prevention helpline Samaritans instead. In the following months, other academics within the professor’s sphere of influence began to treat me differently, which had a devastating impact on my wellbeing, until I received mental health support:

The psychologist suggests that because the sociology professors who ostracised me from their ‘cult’ (my term) present themselves as having ‘no sexual hangups’, their sexual stigma came as a shock, and something that threatened my life (emotionally, socially, professionally)... That response to my HIV status immediately after diagnosis, from the least expected place, triggered a fight or flight response (anxiety), which became a generalised fear that something catastrophic could happen to me anywhere and anytime...
(Twitter, March 27, 2019).

The professor’s words (‘unethical’ ‘reckless’, ‘idiot’) have been repeating in my mind again, as the world is in the midst of a new global health catastrophe, where a similar vocabulary has emerged to describe the behaviours of so-called ‘covidiots’, alongside blaming individuals for a perceived ‘failure’ to act ‘responsibly’ (Logie 2020).

From modern to postmodern method

One upside to being ostracised by this academic clique was how it transformed my worldview, providing an opportunity to rethink methods and concepts – including postmodern, feminist and queer theory – which had been discouraged by its charismatic leader, the professor. If modernism has constructed metanarratives, in the form of big stories about the medical, social, technological ‘progress’ of society, postmodernism ‘pays closer attention to micronarratives, the untold personal stories of the abnormal, deviant, and subaltern’ (Notes, October 18, 2020). Drawing on Hall’s (1986) analysis of the Prison Notebooks, modernist metanarratives tend to be economically reductive, erasing or minimising the role of ideology, defined by Gramsci as ‘any philosophy which has become a cultural movement, a “religion” ...implicitly manifest in art, in law, in economic activity and in all manifestations of individual and collective life’ (quoted by Hall 1996, 431). By comparison, postmodernism can be defined as ‘a radical scepticism towards the grand narratives, positivist methods, and binary logics characteristic of modernism... a rejection of the “religion” of modernism’ (Morris 2018, 55), while embracing more creative methodologies. This paper therefore represents a break from
the professor’s religion of modernism, which held that science and reason are superior to art and literature, through autoethnography.

Combining the terms auto (self), ethno (culture) and graphy (writing), autoethnography is a postmodern approach to storytelling which draws on ‘personal experience to describe and critique cultural beliefs, practices, and experiences’ (Adams, Jones and Ellis 2015, 1). While this paper adopts a mix of methods, including description, observation, and layered accounts, the main approach is one of personal narrative, which Ellis, Adams and Bochner (2011, 279) have characterised as being among ‘the most controversial forms of autoethnography for traditional social scientists’. I have chosen not to label this autoethnography as either ‘analytic’ or ‘evocative interpretivist’, as the term ‘postmodern’ reflects my political focus more appropriately, seeking to ‘democratize the representational sphere of culture by locating the particular experiences of individuals in a tension with dominant expressions of discursive power’ (Neumann 1996, 189). However, as Doloriet and Sambrook (2012, 84) have noted, these approaches ‘are not necessarily discrete, may overlap and an autoethnography may include more than one position’. In Autoethnography as Feminist Method, Ettore (2017, 3) has further suggested that ‘criteria in judging the value of autoethnography include copious detail, temporal structure revolving between past and present, emotional integrity of the author reflecting deeply on one’s actions, a plausible journey of transition’ alongside ethical considerations and researcher reflexivity.

Autoethnography has been characterised by some as an ‘egoistical’ or ‘narcissistic’ method (Roth 2009). However, given that this paper draws on Foucault and others to deconstruct individualist notions on the ‘self’, I embrace the irony of using a self-focused method to examine definitionally collective problems; elsewhere, for example, I have noted that pandemics ‘cannot be adequately prevented or understood at an individual level’ (Ashford, Morris and Powell 2020, 611). A more significant critique of autoethnography is that, because those involved may be easily identifiable, it is unethical. As Ellis (2007, 4) has noted, autoethnographers have a heightened responsibility to consider ‘relational ethics’ and ‘acknowledge our interpersonal bonds to others’. Ettore (2017) adds that how we tell stories should be ethically accountable and generate empathy rather than spite. Therefore, while everyone named in this paper was sent advance copy of the paragraphs they were mentioned in, and gave permission, I have used generic titles such as ‘producer’ or ‘professor’ to protect the identities of others. While I recognise that this cannot guarantee full anonymity, almost every topic and theme of this paper has already been published, and this paper merely provides further contextualisation through reference to private conversations and diary entries. Furthermore, none of the encounters described in this paper occurred in a ‘research setting’, so I have weighed these concerns against the value of sharing an HIV-positive person’s story for a special issue of Culture, Health and Sexuality on Viral Times: Rethinking COVID-19 and HIV.

The ‘digital diary’ which this paper draws on is comprised of a patchwork of sources including emails and notes from my smartphone, alongside private conversations and public
posts on social media platforms such as Facebook, Instagram, and Twitter. The latter could be characterised as more of a confessional than a diary, given its public accessibility. Nonetheless, because I have used this platform as a sounding board for spontaneous thoughts and feelings (since February 2009), it supplements the other sources. Relatedly, Muncey (2005) drew on a combination of artifacts, metaphors and ‘snapshots’ of her life to tell a complex story and problematise the political construction of ‘authority’ and ‘truth’ in academic research. As a postmodern, qualitative method which celebrates the creative and sometimes chaotic elements of a researcher’s life, as communicated through a first-person narrative, it is my view that autoethnography should embrace an unstructured approach such as this. My digital diary may not be as formal as a fieldwork diary, but everything described here happened during my time as a doctoral student and early career researcher, which has informed the analysis. The news sources mentioned here have been selected based on entries in my digital diary, rather than representing a systematic review of media content.

Metaphors, meanings and monsters

The first journalistic piece I wrote about the politics of testing positive was for the ‘Academics Anonymous’ series by The Guardian (May 25, 2018), titled: ‘When I admitted I was HIV-positive, my fellow academics excluded me’. Here, I elaborated on themes including the ‘responsibility of individuals’ and ‘falling out of favour with the clique’ surrounding the professor. As several people noted in the comments section, the editor’s choice to use the word ‘admit’ in relation to my status implied ‘guilt’. One posted, ‘The implications of disclose and admit are widely different’, another posted, ‘One admits to a crime, not an illness’, and another posted, ‘The author writes that he “disclosed” his HIV status. The headline writer helpfully translates this as he “admitted” he was HIV-positive’. It is worth noting that it was also an editorial decision to make this piece anonymous, which may have further contributed to a sense of secrecy and shame. Muncey (2005, 76) described a similar experience, writing, ‘I felt this anonymity denied my voice’. Building on Foucault’s ideas, Sedgwick (1990, 4) also noted how ‘silence is rendered as pointed and performative as speech, in relations around the closet’ and that ‘ignorance is as potent and multiple a thing as knowledge’, referring to slogans by ACT UP (AIDS Coalition to Unleash Power) including ‘I am out, therefore I am’ and ‘silence=death’.

In The Guardian piece, I also mentioned Sontag’s (1988) argument that the ‘perception of HIV as a deadly (gay) plague led to “a social death that precedes the physical one”. There may be no physical death anymore, but the legacy of the epidemic continues through the social and sexual exclusion many of us still face’. In the context of COVID-19, I have reflected on the significance of metaphors as a literary device for making sense of pandemics:

I’ve seen lots about the ‘war’ with #Covid_19, so wanted to remind everyone what Susan Sontag (1988) wrote: ‘We have had wars against poverty, now replaced by “the
war on drugs,” as well as wars against specific diseases, such as cancer. Abuse of the military metaphor may be...

...inevitable in a capitalist society, a society that increasingly restricts the scope and credibility of appeals to ethical principle, in which it is thought foolish not to subject one’s actions to the calculus of self-interest and profitability. War-making is one of the few...

...activities that people are not supposed to view “realistically”; that is, with an eye to expense and practical outcome. In all-out war, expenditure is all-out, unprudent—war being defined as an emergency in which no sacrifice is excessive. But the wars against diseases are...

...not just calls for more zeal, and more money to be spent on research. The metaphor implements the way particularly dreaded diseases are envisaged as an alien “other,” as enemies are in modern war; and the move from the demonization of the illness to the attribution of fault...

...to the patient is an inevitable one, no matter if patients are thought of as victims. Victims suggest innocence. And innocence, by the inexorable logic that governs all relational terms, suggests guilt’ (from AIDS and Its Metaphors). Let’s think carefully about our language. (Twitter, March 20, 2020)

Sontag’s experiences with cancer informed her critique of how HIV was portrayed as a bodily ‘invasion’. Like Sontag, I am concerned with how metaphors which perpetuate blame, disgust and fear can produce additional harms, especially where long-term disability (rather than death) is the outcome of viruses, such as people living with ‘long covid’ (Mahase 2020). The metaphor of alien invasion has also been used to characterise viral pandemics which, in turn, has shaped positive people’s self-perceptions. For example, in another autoethnography about testing positive for HIV, Willis (2011, 268) wrote:

In scenes reminiscent of the Alien films, the HIV particles attach themselves to the skin of each of my CD4 cells and inject their DNA into the CD4 cell’s cytoplasm. The alien DNA uses the cell’s own reproductive system to produce multiple copies of itself, finally bursting through the walls of the cell...

If the body horror metaphor of choice for HIV was an alien, for COVID-19 it might have been a werewolf. The only weapon which can stop this mythical monster is a ‘silver bullet’, a phrase which has come to represent (magically) simple solutions to the complex problem of COVID-19. This particular topic came up during my last appointment with an HIV doctor:

When I mentioned that I was working on an article about how metaphors have been applied to viral pandemics, including werewolves—if hopes for a ‘silver bullet’ in the form of a vaccine are anything to go by—he nodded and said, ‘Yes, and vampires have
been used to mythologise all sorts of diseases travelling from the East’, before asking a nurse to extract several vials of my blood. (Notes, October 9, 2020)

Supporting this observation, media analysts have noted how cultural representations of vampires – including in films such as *Bram Stoker’s Dracula* – have ‘long been used to shore up disgust and hatred for the “deviant”, especially in the context of sexually transmitted disease’ (Azzarello 2008, 151-2). The ‘silver bullet’ metaphor appeared most often in media coverage when scientists sought to temper optimism about the efficacy of the vaccines, including headlines such as: ‘WHO raises fears there may never be a “silver bullet” to beat COVID-19’ (Sky News, August 3, 2020) and ‘Vaccine will “not return life to normal in spring”’ (*BBC News*, October 1, 2020). The latter piece quoted a doctor who said, ‘the vaccine has been portrayed as a silver bullet and ultimately it will be our salvation, but it may not be an immediate process’. The desire for simple solutions or forms of salvation reflects the binary construction of one-dimensional monsters who are (incorrectly) thought to be easily ‘vanquished’. As I have noted elsewhere (Ashford, Morris and Powell 2020, 598):

> In the 1980s and 1990s, AIDS found a solution – of sorts – with condoms becoming a social and medical response, and thereby a signifier for salvation, protection, and responsibility (terms which have been similarly applied to masks, social distancing, and vaccines during the current crisis).

In my own imagination, when weaving around ‘middle-class families... taking up pavement space’ (Twitter, February 19, 2021), I have tended to picture them as zombies rather than werewolves: ‘They can’t bite you if they have a mask on or are at least two metres away’ (Notes, December 19, 2020). Watching a science-fiction comedy film with Alex, I also wrote: ‘My favourite part in apocalyptic satire is when the character’s political ideology changes in the face of catastrophe... it speaks to the absurdity of doing things “normally” in a crisis’ (Notes, January 25, 2021). This mix of horror metaphors (alien, vampire, werewolf, zombie) may be a feature of the pop-culture references which saturate my mind, but the argument proposed by Sontag (1988) is that metaphors are both necessary for making sense of medical information and distort perceptions of existing medical solutions, whether in the form of HIV antiretrovirals or COVID-19 vaccinations.

**Narratives of normativity**

The last journalistic piece I wrote about the politics of testing positive was for the ‘Labels’ series by *Metro* (July 18, 2019), titled: ‘I’m HIV-positive and that doesn’t make me “reckless” or “risky”’. Here, I drew on ‘the professor’s words’ to argue that fears about HIV-positive people as being ‘risky’, ‘reckless’ or ‘killers’ emerged in the 1980s, ‘when sexual health was thought of in terms of individual responsibility, rather than public health or education’. Similarly, a simplistic dualism between economic harm and public health has characterised
many disagreements over the political response to COVID-19 (i.e. ‘lives vs. livelihoods’). Writing under my own name, *Metro* provided an opportunity to challenge some of the normative responses I had given to broadcasters about love and relationships, including: ‘How would I ever find a boyfriend now?’ (*BBC News*, November 17, 2018) and ‘How am I going to be able to have a normal relationship?’ (*Sky News*, May 3, 2019). In both examples, normative coupledom was constructed as a form of salvation and safety.

In the context of COVID-19, emergency laws have prohibited casual sex while ostensibly monogamous relationships have encountered few regulations. As the headlines reported: ‘Sex with someone you don’t live with is illegal from today’ (*Metro*, June 1, 2020) and ‘Couples in “established relationship” now officially allowed to have sex under Covid rules’ (*Mirror*, September 23, 2020). Around this same time, I reflected on Rubin’s (1984) essay ‘Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality’, writing:

I made a prediction on Twitter that the 2020s would see the next significant period of sexual conservatism (Rubin saw this coming in the early 1980s in response to HIV). I had not anticipated that another pandemic would be the trigger for that cultural turn, or something that precipitated it, but COVID-19 has changed both attitudes and laws. (Notes, October 12, 2020)

Rubin’s (1984, 267) essay began by suggesting that it is ‘when we live with the possibility of unthinkable destruction, that people are likely to become dangerously crazy about sexuality’. Her model of the ‘charmed circle’ and ‘outer limits’ of sexual respectability highlighted how socio-legal definitions of ‘bad, abnormal and unnatural’ sexuality police the boundaries of what constitutes ‘good, normal and natural’ sexuality (at the centre). Rubin further noted that ‘AIDS has already affected sexual ideology. Just when homosexuals have had some success in throwing off the taint of mental disease, gay people find themselves metaphorically welded to an image of lethal physical deterioration’ (Rubin 1984, 299). On the one hand, this theory could be applied to the laws noted above which have regulated casual sex. On the other, unlike HIV, the behaviours which increase the transmission of COVID-19 are strikingly normal, in places of work, education, prayer, leisure and consumption (offices, schools, churches, bars, cafés, pubs and restaurants), not to mention families:

I’ve begun to clarify some of my thinking on the similarities and differences between HIV and COVID-19 discourse tonight. The issue is normativity. By defining ‘at risk’ behaviours, individuals, and groups (queer people, sex workers, people who use drugs) the former reified boundaries between the centre and periphery, keeping the ‘deviants’ out; conversely, the latter has sought to sure-up normative behaviours (Notes, November 24, 2020).

One example of such normative priorities can be seen in the emphasis placed on Christmas, where – despite other religious festivals such as Eid al-Adha and Rosh Hashanah...
not being granted exceptions – *The Guardian* (October 30, 2020) reported that ‘scientists and public health advisers said imposing new national measures could “save Christmas from the coronavirus” and allow families to meet during the festive season’.

Connecting this with queer critiques of Christmas, Sedgwick (1993, 5-6) noted that, ‘They all – religion, state, capital, ideology, domesticity, the discourses of power and legitimacy – line up with each other so neatly once a year’. The Government’s decision to keep this tradition going contributed to the UK having the worst ‘second wave’ of COVID-19 deaths relative to its population (Griffin 2020). As I wrote, ‘some cultural traditions have been prioritised while others have been cancelled... Normal modes of economic production were prioritised’ (Notes, September 20, 2020). I have wondered whether such behaviours or identities could be characterised as ‘risky’ and ‘reckless’, much as mine have been, in the form of a ‘reverse’ discourse (Foucault 1978, 101): ‘why shouldn’t a reverse discourse emerge in the context of COVID-19, where to go to church is immoral, to shop is pathological, and to occupy a pavement by walking hand-in-hand as a couple is deviant?’ (Notes, January 11, 2021).

In *Risk and Blame*, Douglas (1992) suggested that the modern term ‘at risk’ was as culturally meaningful as its pre-modern counterpart ‘in sin’. While discourses of ‘sin’ upheld the collective interests of community, she argued that discourses of ‘risk’ served individualist projects of the self. This modern discourse was invested in scientific rationalism in the form of an ability to calculate probabilities, objectively, seemingly free from bias. However, Douglas and Calvez (1990, 446) applied a more relativist, anthropological lens to HIV, noting that ‘only cultural theory’ can account for people’s ‘preferences’ to adopt or reject established methods of risk aversion. They constructed a typology of four cultures – centre, periphery, individualist and isolate – with different epistemes of risk, contested and consolidated by each. For those in the centre (normative) culture, defences against HIV were thought to be reinforced by ‘consolidation of the community, exclusion of outsiders, and repression of deviants’, seen as necessary to maintain health and order. Alongside migrants and working-class people, given that ‘homosexuals, prostitutes, and intravenous drug addicts are populations at risk inflames their exclusionary rhetoric’ towards the periphery, so that ‘risk aversion is part of its political defence against its own margins’ (Douglas and Calvez 1990, 458-60).

In the *Metro* piece (July 18, 2019), I was able to explore these themes further. For example, I drew attention to intersections between HIV stigma, racism and xenophobia (‘This “us” and “them” mentality continues to shape our politics, with figures such as Nigel Farage suggesting that HIV-positive people should be banned from coming to the UK’), alongside homophobia, biphobia, transphobia and sex work stigma (‘HIV has never been an exclusively “gay” issue... sex workers, trans women, and bisexual people have been demonised by association, or described as “vectors of transmission” into seemingly “respectable” communities’). Parallels with COVID-19 have emerged here, with the Home Office denying Farage’s claim that there is a ‘Covid crisis in Dover’ (Twitter, February 27, 2021). Another form of chauvinism has emerged around the UK (and other wealthy nations) hoarding COVID-19 vaccinations. For example, when I mentioned writing this paper to Matthew Hodson, the
Executive Director of NAM aidsmap, he said, ‘considering how poor we’ve been in universal treatment coverage, after 24 fricking years when we’ve been able to prevent death, I’m wary about thinking that a vaccine will roll out widely’ (Twitter, October 5, 2020). As with HIV, preventive treatment has become available, but the distribution of medicines is uneven, meaning that people (less privileged than Matthew and I) continue to die; researchers have also highlighted how COVID-19 has ‘exposed and amplified underlying inequalities in society’ and emphasised the need for more preventative public health strategies globally (Rimmer 2020).

Art, photography and finding my voice

Testing positive for HIV not only changed how I value research methods and social theory, but also artistic forms of expression which have sought to make sense of viral pandemics. Alongside providing a critique of normativity, the Metro piece was *queer* in both its arguments and aesthetics. While the BBC News interview included a series of photographs of Alex and I represented as a ‘normal’ couple (holding hands, sat at a picnic bench, sharing an ice-cream), Metro allowed for another form of self-expression through the performative embodiment of protest and gender non-conformity (Butler 2011). When the editor asked if they could ‘send one of our photographers out to take some pictures’ (Email, June 7, 2019), I asked them to meet me at London Pride, where I joined an HIV charity (Positively UK) to mark ‘the 50th anniversary of the Stonewall riots, where the LGBTQ rights movement was launched by sex workers, gender non-conformists, and trans women of colour, many of whom would become HIV-positive’ (Metro, July 18, 2019). I wore black knee-high boots, short shorts, and a crop top – with the phrase ‘CAN’T PASS IT ON’ written on my stomach in eyeliner – alongside pink eyeshadow, blue lipstick and a home-made ‘pearl’ necklace constructed with a repeating pattern of antiretroviral medications: pink (Triumeq), yellow (Isentress), blue (Truvada). In the same colours, I crafted a biohazard symbol which was pinned on my chest, something I later named the ‘Biopower Flower’ (Twitter, July 22, 2019). I also held a protest sign which read: ‘TRANS WOMEN + SEX WORKERS STARTED THIS’ (using colours of the trans and inclusive pride flags).

Constructing this outfit took considerable time, thought and effort, alongside months of dieting so that I would have a flat enough stomach to write on legibly, and feel comfortable displaying my midriff. I read warnings about wearing practical shoes, but ‘nothing quite prepared me for the agony of six hours of stop-start walking through central London in high heels’ (Notes, July 8, 2019). Yet I was pleased that the effort was well received by others. For example, when the Metro piece was published, one aspect of my outfit caught the eye of Andrew Keates, a theatre director, who posted:

Andrew:  Totally relate to @Max_Morris as someone else living with #HIV. Max – please can you share your artwork on your t-shirt? Definitely going to have one made up for myself.
Justin Dorey, a graphic designer, responded with his interpretation of the Biopower Flower, noting that he was ‘struck by the design’ (see Figure 1).

While Foucault’s (1976, 136) concept inspired the rhyming name, whereby antiretrovirals represent a shift from ‘power of life and death’ to ‘life-administering power’, the icon was stylised following a tradition of HIV-positive, queer art. For example, the flower motif used to represent the biohazard symbol was influenced by Robert Mapplethorpe’s photography; the same week that I seroconverted, I had visited an exhibition in Los Angeles: ‘Having an amazing day in LA seeing lots of controversial erotic art, including… Mapplethorpe at the Getty’ (Twitter, May 13, 2016). Noting historical associations between floral and homoerotic imagery, Schultz (1998, 88) noted that ‘[Mapplethorpe’s] flowers become potent signs of gay sexuality standing at the end of a long tradition’. Perhaps less thoughtfully,
my interpretation focused on the photographer’s playful use of light and juxtaposition: ‘This was one of my favourite prints... the shadow cast by the flower looks like the devil’ (Instagram, May 13, 2016). This playfulness was also a theme of artworks by Keith Haring and Derek Jarman, who inspired the use of bright pink, yellow and blue which (mis)matched the pastel shades of my antiretroviral necklace. The use of primary colours was also a feature of Jarman’s (1993) final works, including ‘Ataxia – Aids is Fun’ and ‘Blue’, autoethnographic accounts of the artist’s HIV-related disabilities (a neurological condition and partial blindness, respectively).

As with HIV (e.g. the 1987 tombstone advert), visual imagery has been a part of the UK Government’s discourses of blame, shame and responsibility in relation to the transmission of SARS-CoV-2. For example, the ‘Look him/her in the eyes’ campaigns have sought to individualise the ‘Risk’ and (following/bending of) ‘Rules’, rather than acknowledging its political ‘failure to control the coronavirus pandemic, coupled with widening inequality over the past decade’ which has contributed to the UK’s world-beating death-rate (Griffin 2020). Given that viruses are not restricted by the political construct of borders, any effective response must consider the health of humanity as a collective rather than relying on the individual logic of neoliberalism.

Discussion

This paper has sought to complicate the simplistic binaries which construct the politics of health (guilt/innocence, progress/regression, individualism/collectivism) as reproduced by media discourses. Drawing on excerpts from my digital diary – scattered conversations, posts on social media, and other reflections – I have drawn attention to the (bio)power of art and literature, metaphor and photography, as a way to make sense of pandemics. Joining HIV organisations such as NAT and THT, some newspapers reported that ‘Covid-19 crisis raises hopes of end to UK transmission of HIV’ (The Guardian, May 13, 2020). As I have argued, such claims do not reflect the complexity of global health inequalities, nor the far-reaching and long-lasting consequences these events will have on the political economy of normativity.

Alongside talking to other positive people who are visible in the media, there is a rich history of artistic and conceptual work from the ‘start’ of the HIV pandemic, which has helped me to think through the ‘start’ of the COVID-19 pandemic. For example, Foucault’s concepts of biopower and normative judgement were formed – in part – through consideration of how modern societies responded to pandemics. He described how quarantine measures were adopted during the seventeenth century, making a distinction between ‘the leper’ and ‘the plague’. The former led to the ‘separation’ of affected individuals, the latter created ‘segmentations’ of entire communities, which he described as ‘the great confinement on the one hand; the correct training on the other’ (Foucault 1977, 198). An interesting parallel could be drawn between responses to HIV and COVID-19, where the former was associated with individual ‘risky’ behaviours and/or identities (gay men, sex workers, people who use drugs,
etc.), the latter has confined most of us to home for the better part of the past year to ‘Protect the NHS’ (National Health Service) and ‘Save Lives’.

Borrowing Foucault’s scepticism towards biopower, this paper has drawn on creative and qualitative methods to understand the significance of dominant discourses of sexuality and health. It has demonstrated the value of autoethnography for complicating and extending analyses of media. However, as Ellis (2007) and Ettore (2017) have argued, autoethnographers must be cautious in how we represent others for ethical reasons. This paper may be interpreted as constructing its own ‘monsters’, such as ‘the professor’, or indeed normative families (‘zombies’, as I called them). However, this would be a misreading, not least because the goal of this paper has been to deconstruct simplistic discourses of blame, shame, fault and guilt at the individual level. This speaks to the wider politics of respectability and responsibility which seems to contort all discussions of pandemics, both past and present.

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