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Living through and with the global HIV/AIDS pandemic: Distinct ‘pandemic practices’ and temporalities

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ABSTRACT

In this study, we expand on the newly devised sociological concept of pandemic practices that emerged during the COVID-19 outbreak by applying it to the HIV/AIDS pandemic. The analytical heuristic of pandemic practices distinguishes between four kinds of practices: (i) primary practices that encompass the public’s direct response to the pandemic, (ii) responsive practices that encompass altered routines and social interactions, (iii) adaptive practices that encompass more elusive organisational and legal legacies and (iv) meta-practices that produce particular narratives about the pandemic dynamics that might lead to lasting socio-cultural behavioural changes. In this paper we probe further into the notion of meta-practices. The results show that the prolonged nature of the HIV/AIDS pandemic combined with the widespread stigmatisation of vulnerable groups has led to distinct social practices that fragment along socio-economic lines both internally in countries but also between high-income and low-income countries. As the COVID-19 pandemic becomes increasingly endemic, lessons learned from HIV/AIDS expose the dangers of similar fragmentations where parts of the population return to normal but where many others continue to suffer not only from adverse health outcomes but also social exclusion and stigmatisation. Thus, we argue that attention to pandemic practices, and how they produce and reinforce underlying socio-economic vulnerabilities would strengthen long-term pandemic responses.

1. Introduction

Many scholars in the field of social and health sciences have increasingly argued for the importance of understanding how slow-onset phenomena result in new and continuously changing socio-cultural practices as societies and people react to factors like new data, political scandals, secondary effects, and wider meta-narratives (Boin et al., 2021; Yamori and Goltz, 2021; Staube-Delgado, 2019; Viens and Littmann, 2015). Overall, COVID-19, as a totalising phenomenon, has resulted in a number of interesting analytical innovations revolving around socio-cultural practices as well as the lived experience of pandemics. One of these is the analytical notion of ‘pandemic practices’, which refers to the various types of social practices that emerge or change throughout pandemics (Werron and Ringel, 2020).

A starting assumption in this study is that the temporal, epidemiological and vulnerability dynamics of pandemics and global health crises shape the nature of social practices and the ways in which narratives evolve. This, in turn, shapes how health threats become ‘real’ from a

socio-cultural perspective. Generally, diseases and epidemics are inherently temporal processes, although they are characterised by very different manifestation dynamics depending on their nature. Hence, our goal here is to reflect on the consequences of pandemic temporalities and vulnerabilities by applying and expanding the concept of pandemic practices, which has been devised in the context of the COVID-19 pandemic, to a very different and more ‘mature’ pandemic case, the HIV/AIDS pandemic.¹ As publications in this journal also suggest, important insights may be gleaned from applying the lessons learnt from pandemics and previous disease outbreaks to the case of COVID-19 and vice versa (Barnes, 2021; Sobol et al., 2020). Comparing COVID-19 and HIV/AIDS by engaging the notion pandemic practices, we will illuminate how differences in temporalities and vulnerabilities produce distinct social practices, a notion that carries important theoretical and practical implications.

Theoretically, we argue that the notion of pandemic practices can be fruitfully elaborated on by illustrating how it fits into pandemics of different temporal and epidemiological natures. Therefore, one of the

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¹ Although some actors, such as the WHO, categorises HIV/AIDS as a ‘global epidemic’ we have chosen the label of pandemic in this paper.

primary theoretical contributions of this study stems from expanding on the concept of pandemic practices temporally to allow for an inquiry into the distinct meta-practices that emerged from our analysis of the HIV/AIDS pandemic. We herein emphasise two new meta-practices: (i) one based on judicial or normative legacies and how they produce specific political narratives over time and (ii) one based on how new pandemic practices (e.g. COVID-19) displace and interact with already existing pandemic practices (e.g. HIV/AIDS).

Practically, the comparative analysis highlights how distinct temporalities and vulnerabilities produce different pandemic practices both over time and across pandemics. The most pronounced practical relevance of this study lies not so much in concrete policy recommendations as in highlighting the potential of the analytical heuristic for systematic comparisons across different health emergencies. This, in turn, can shed light on differences and similarities and also, importantly, map future pathways for the current ongoing pandemic of COVID-19. One very likely pathway is that while many people are already back to living their normal lives permeated by a decreasing number of COVID-19 pandemic practices, many others will likely carry the burden of not only adverse health outcomes but also social practices of stigmatisation and exclusion for years to come. A main argument in this study, rooted in the analysis of the HIV/AIDS pandemic practices, is that medical solutions are insufficient to effectively stifle some of these adverse pandemic practices. Overall, the analysis of pandemic practices underlines the benefits of applying more holistic social science perspectives to longer term pandemic responses and their socio-cultural legacies.

There are however a number of important differences between COVID-19 and the HIV/AIDS pandemic. One such difference is primarily temporal: the HIV/AIDS pandemic has lasted for five decades now. This pandemic has passed through a series of critical paradigm shifts, in which it has transitioned from initially being considered an untreatable infection to an infection that can be kept in check with medication, including prophylactic treatments. We therefore argue that the analytical notion of pandemic practices can become more widely applicable if it is adjusted to fit pandemics of a temporal nature different than that of the COVID-19 crisis. It can also be observed that the HIV/AIDS pandemic manifests very differently in the social sense. Since its onset, HIV/AIDS has disproportionately affected already stigmatised subgroups (Logie and Turan, 2020). Similarly, advances in treatment and prevention have not been equally distributed across the world, leaving a very unevenly distributed HIV/AIDS burden across regions (UNAIDS, 2021). Therefore, the presence of HIV/AIDS is unequally perceived within and between countries, depending on the social determinants of risk and global inequities in healthcare. COVID-19, on the other hand, was experienced as a totalising phenomenon for everybody, as news of the virus, mitigative measures, testing regimes and anxiety were more widespread. In other words, these health threats differ not only in their temporal aspects, but also in how indiscriminately they shape social practices and cultural responses within populations.

The rest of this article is structured as follows. Section 2 elaborates on the analytical framework of this article, which is centred on the heuristic of pandemic practices. In this section, we focus on outlining the four levels of abstraction in which pandemic practices play out. Section 3 provides an overview of HIV/AIDS, where our aim is to provide a brief overview of the key attributes of this pandemic, which are of relevance to the points raised throughout the article. Section 4 serves as a reflection on how the notion of pandemic practices as a heuristic, initially coined for analysing the COVID-19 pandemic (including a focus on living through and with the pandemic), can produce new insights when applied to the HIV/AIDS pandemic, a global health crisis with very different temporal and social characteristics. Our aim is thus to expand the concept of pandemic practices beyond its original focus on COVID-19, emphasising temporal and social dimensions. Finally, Section 5 succinctly presents the main points and issues raised in this article, including wider potential applications of the analytical notion.

2. Pandemic practices and the lived experience of pandemics

COVID-19 has been recognised as a global pandemic for the better part of two years at the time of writing, with global recovery remaining elusive. This state of affairs has triggered an unprecedented surge in research in all fields, as people are trying to make sense of the unfolding events as they occur, in various ways (Odone et al., 2020). In 2020 alone, more than 63,000 academic articles with COVID-19 in their titles were published in the National Library of Medicine. Coincidentally, this number is larger than that of all scientific articles published in the database over the last 40 years with AIDS in their titles (around 62,000 articles). Generally speaking, most of the articles on COVID-19 are directly related to the SARS-CoV-2 virus, including studies on its structure, how it is transmitted, the effectiveness of non-pharmaceutical interventions, models of its future spread, effective treatments for COVID-19 and vaccine development.

Policy responses and crisis management aspects have also been extensively studied (cf. Boin et al., 2021; Dunlop et al., 2020). Other individuals have instead strived to make sense of the crisis as it unfolded, noting the importance of studying the history and social practices as they are being formed and continuously (re)negotiated. In one such effort to make sense of the slowly developing but rapidly changing course of events ‘emerging before [their] very eyes’, sociologists Tobias Werron and Leopold Ringel (2020, p. 56) performed an experiment in creative sociological theorising centred on the notions of ‘living through the COVID-19 pandemic’ and ‘pandemic practices’. They noted that ‘viral epidemics such as SARS-CoV-2/COVID-19 have a genuinely ‘eventful’ character’ as ‘they are temporal by definition’ (p. 56). Moreover, noting the impossibility of arriving at a definitive sociology of the crisis as it unfolded, they also discussed the importance of theorising its unfolding, citing the work of Sewell (1996), and argued that although many of its effects may be temporary in nature, some responses to the unfolding events may lead to structural transformations.

One advantage of employing a practice-based research design to contemporary crises is that it allows studying socio-cultural practices that are ‘established, reproduced, connected, disconnected, institutionalised, and deinstitutionalised in the course of the pandemic’ (Werron and Ringel, 2020, p. 56). Such practices solicit attention to sense-making and meaning-making processes, as witnessed in new or altered activities that people engage in and supported (or upended) by dominant narratives and changes within these (for more details on practice theory, see: Rouse, 2007; Nicolini, 2016). Moreover, the insights gained from practice scholarship also underline the notion that practices interact and might morph into new kinds of practices (Reckwitz, 2002). Hence, and as Werron and Ringel (2020) argue, nuanced analyses of pandemic practices need to be sensitive to the different levels of abstraction at which they occur, as well as their different direct and indirect manifestations and whether they are novel practices or adjusted or abandoned practices. We also noted that practices vary in the way in which they become institutionalised. In light of this context, Werron and Ringel (2020, p. 57) define pandemic practices as ‘(i) social practices that (ii) emerge and/or continue during the COVID-19 pandemic, are (iii) related in some way or another to the discovery and spread of [disease agents], and (iv) can connect to each other in the course of the ... pandemic’. It should be noted here that health threats should in some way be totalising (at least within a certain community) to be able to exist as a socio-cultural phenomenon. The authors thus note that ‘this conceptualisation refers to all kinds of practices that transform [the threat] into a social phenomenon’, in a way that renders it real in the form of actions, ways of thinking and narratives/counter-narratives. As the pandemic cannot be experienced or observed directly (or by ‘the naked eye’), it is made real as a social phenomenon through studying its virological properties and its spread among populations—knowledge that cannot be produced or scientifically refuted by laypeople. The crisis is therefore to some extent upheld by trust, although not universally shared, as witnessed by those denying the existence of COVID-19 either

in its entirety or as a threat that justifies societal response—similar to how the value of money is sustained by trust and only depends on the trust of the majority for being ‘real’ as a social phenomenon. More specifically, Werron and Ringel (2020) identify three basic kinds of pandemic practices and an intersecting meta-type augmenting the nature of the three:

1. *Primary pandemic practices*: Practices falling into this category are those that relate directly to the nature of the crisis, including direct responses to it (e.g. mitigation). These include those practices related to understanding the scientific basis as well as direct reactions to this information. Primary pandemic practices are mainly upheld and awarded legitimacy (or enforced) by public health agencies and experts, but they later become self-sustaining as the crisis becomes a socio-cultural phenomenon. In the times of COVID-19, these practices include being tested, wearing masks, applying social distancing, and getting vaccinated.
2. *Responsive pandemic practices*: Practices falling into this category are those that relate to altered routines and social behaviours resulting from the new regime imposed by the altered state of affairs. Examples during COVID-19 include changing the nature of various interactions, such as working from home, going for walks, shopping online, digital teaching, home schooling, producing cultural artefacts, engaging in activism, adopting new or altered ways of recreation or actively resisting change. Some responsive practices can in this way be thought of as reinforcing or amplifying primary pandemic practices (such as showing a vaccine certificate to partake in an activity), whilst other response practices may seem to delegitimise or exercise a negative influence on primary practices.
3. *Adaptive pandemic practices*: Practices falling into this category are those that may be considered practices more distant from the actual health problem in question and that in hindsight may be challenging to trace back to the original event. Examples are new innovations or technological and organisational or even legal developments that occur as part of primary and response practices, such as increased digitalisation of work life, changes of pandemic laws and changes to the economy (e.g. changes to patterns of online shopping demand).
4. *Pandemic meta-practices*: Practices falling into this category include relationships and narratives that emerge and serve both to uphold the crisis while it is ongoing and to shape the way in which it produces lasting changes to society, cultures and sub-cultures. These include narratives regarding a pandemic’s future and aftermath as well as the changes to frameworks and practices that help shape the ontology and epistemology of the COVID-19 pandemic.

Given the above information, we argue that these pandemic practices serve as a useful heuristic for studying not only COVID-19, but also a number of other pandemics and health threats, including HIV/AIDS. By presenting pandemic practices as a novel approach for the analysis of pandemics, Werron and Ringel imply a focus that goes beyond COVID-19, although no attempt has been made to apply the concept to other pandemics or health crises as of now. As we have noted, the HIV/AIDS pandemic is both similar to- and different from the COVID-19 pandemic. It could be argued that HIV/AIDS is not experienced as a totalising socio-cultural phenomenon like COVID-19 for the majority of the world’s population, as its impact and risk profile are highly skewed towards particular at-risk populations and geographical regions. Yet, the presence of the HIV/AIDS pandemic is definitely totalising for people who are part of high-prevalence communities, whether they belong to sub-groups within a low-prevalence context or to sub-groups within a generally high-prevalence context. In other words, the degree to which the pandemic is experienced as totalising is likely to be shaped by targeted public health messaging and other targeted measures that shape the lived experience of pandemics. Moreover, the HIV/AIDS pandemic has lasted for decades and is not likely to end anytime soon, although the United Nations has set a goal for it to end by 2030, a goal that remains

elusive as key 2020 milestones have not yet been reached (UNAIDS, 2020).

3. HIV/AIDS: An overview

In general, an estimated 40 million people are currently living with HIV worldwide (UNAIDS, 2021). The HIV/AIDS pandemic is often erroneously perceived as a historical period that has occurred in the 1980s as AIDS-related deaths in the United States peaked in 1995. However, at the global level, up to a million people may have died from AIDS in 2019 alone, with more conservative estimates showing a global toll of around 600,000, down from an all-time high of just over three million in 2004 (ibid.). Notably, in countries with a low overall prevalence, there is also a considerable variation. For example, according to the Joint United Nations Programme on HIV/AIDS (UNAIDS), it is estimated that sex workers, people who inject drugs (PWID) and men who have sex with men (MSM) face a relative risk of HIV infection that is up to 22 times higher than that among the general population (UNAIDS, 2019). Within these groups, in turn, the risk is also shaped by the socio-economic status and varies among racial and ethnic groups. In other words, the HIV/AIDS pandemic continues to threaten both life and wellbeing although it is highly unequally distributed within and between countries.

One UNAIDS initiative aims to accelerate the progress and end the global pandemic by 2030, although many issues must still be overcome (UNAIDS, 2020). At the global level, many countries were close to reaching the first 2020 milestone of increased testing so that more people living with HIV can know their status and have access to reliable information. However, only about 60% of those living with HIV currently have access to treatment (target 2 in the initiative), to the extent that they have become ‘undetectable’ (target 3 in the initiative). Thus, it can be concluded that this trajectory will not result in an end for the HIV/AIDS pandemic by 2030 unless the efforts are scaled up.

At present, the HIV/AIDS pandemic is in many ways a creeping crisis borne out of stigma and inequality. Within many countries, the risk of infection is unevenly distributed among the population. Both infection risk and barriers to treatment are strongly shaped by social factors, including homophobia, racism, classism and lack of services for PWID and sex workers. In many ways, national and global responses to the HIV/AIDS pandemic have triggered wide cultural effects as the nature of the pandemic required a radical re-examination of stigma-related barriers to testing and treatment. The HIV/AIDS pandemic has forced humans to radically re-think stigma and social barriers to information, testing and treatment. Moreover, decades of work have gone into removing stigma-related barriers to addressing the crisis.

The uneven burden of the HIV/AIDS pandemic has become even more evident at the global level, wherein the lack of insurance and the inability to afford lifelong treatment continue to claim lives. While an estimated 12,000 AIDS-related deaths have been recorded in Western and Central Europe and North America in 2019, the pandemic claimed an estimated 18 million, 3.5 million and 1.5 million lives in Sub-Saharan Africa, Asia and Latin America, respectively (UNAIDS, 2021). Hence, although new HIV infections and especially AIDS-related deaths are decreasing, the HIV/AIDS pandemic will remain with us at least throughout the first half of the century.

HIV infects its hosts mainly through sexual intercourse or through pierced skin. Many information campaigns aim to curb the spread of the virus, as also seen in the case of COVID-19, through both pharmaceutical (preventive and suppressive medication) and non-pharmaceutical (altered behaviours) interventions. Although the HIV/AIDS pandemic has arguably not been experienced as a totalising phenomenon for the world’s population as a whole, it has certainly been experienced as a totalising phenomenon for some populations. Among MSM, for example, the presence of the pandemic is experienced more intensely, in a cultural sense, than for most countries’ populations at large. The same is true for other at-risk populations, such as sex workers or PWID. Moreover,

among countries, the presence of the HIV/AIDS pandemic varies considerably depending on the severity of ongoing epidemics. As such, claiming that the presence of the HIV/AIDS pandemic is only minimally felt in the 21st century means ignoring its uneven impact and the unevenness in the extent to which it is felt as a totalising phenomenon, or a phenomenon that shapes (even if only minimally) daily lives and actions of sub-communities that are heavily targeted by public health responses to it.

4. Applying the notion of pandemic practices in the context of HIV/AIDS

From the perspective of social theory, it can be argued that these epistemological factors have also shaped how the phenomenon exists socio-culturally. While the disease was initially perceived as an untreatable condition, it is now considered manageable given the access many people currently have to anti-retrovirals. One implication of this is that treatment later became available for some people who received what would have been a terminal diagnosis at that time in the 1980s. The phenomenological aspect of first having received a terminal diagnosis and later discovering that the disease is manageable has popularly been referred to as the Lazarus Effect (Rasmussen and Richey, 2012; Thompson, 2003), signalling a sense of resurrection experienced by previously terminal patients. However, the experience of the Lazarus Effect gave rise to its own ontological crises, as extensive preparation had been undertaken by some individuals as part of end-of-life preparations—preparations that were no longer relevant as life went on.

Similarly, the HIV/AIDS pandemic has given rise to a number of subgroup labels and identities over its long timespan. Social analyses from when the disease was considered terminal gave rise to smaller sub-cultures of deadly intimacy (e.g. García-Iglesias, 2020; Palm, 2019), in which the risk of terminal illness was actively defied and resisted (and current identities form around living ‘positively’). Voices from the other end of the spectrum actively promoted abstinence (Underhill et al., 2007; Santelli et al., 2013). Social attitudes towards HIV diagnoses were particularly re-negotiated once the infection was perceived as manageable with anti-retrovirals. New pharmaceutical innovations in preventive (prophylactic) HIV medications have yet again served to re-negotiate the socio-cultural presence of HIV in at-risk communities (Young et al., 2019; Auerbach and Hoppe, 2015). However, it is worth noting how the unequal global progress on ending the HIV/AIDS pandemic also means that the way that pharmaceutical innovations shape social practices varies greatly across contexts.

The degree to which populations experience the presence of the HIV/AIDS pandemic as a totalising phenomenon also varies greatly between populations within a country as well as between countries. At-risk populations who have been exposed to HIV/AIDS information campaigns for a lifetime may experience the presence of this pandemic much more than the population at large, and they may engage in decision-making and prevention practices that the population at large are generally oblivious to. A significant variation has also been observed between countries, as some countries have HIV prevalence rates reaching up to 20% while others exhibit HIV prevalence rates of 0.1% or even lower. Moreover, within low-prevalence countries, the prevalence among at-risk populations may be significantly higher than that among the population at large, shaping the practices among the members of at-risk populations. These practices may centre around preventing, limiting or treating the infection itself (primary practices), manifesting as new or changed routines and behaviours (responsive practices), some of which produce deeper cultural effects (adaptive practices). The practices may also shape ways of making sense of the phenomenon, the narratives around it and the global mechanisms or targets aimed at rendering the crisis governable in the epistemological sense (meta-practices).

4.1. Primary practices

In general, the direct responses to crises depend largely on their distinct traits, which vary considerably from one crisis to another (or, in the case of pandemics, from one contagion to another), although many similarities may also be observed. This is particularly true for crises of the same type, such as between pandemics. Infectious disease response generally focusses on limiting, treating, and managing contagion and infections through both pharmaceutical and non-pharmaceutical interventions. Some infectious diseases are perceived as neglected, showing that there is no clear relationship between severity and attention. The nature of the responses to contagion is, thus, shaped by various factors, such as the speed of development, influenceability (related to the perceived speed of termination) and how vulnerability is distributed in a social determinants of health (risk) sense.

Initially, the emergence of HIV/AIDS resulted in very few primary practices because of the neglected nature of the disease. The current cultural legacy of the pandemic is arguably shaped by its initial framing as an epidemic that mainly threatened stigmatised groups, particularly MSM, PWID and sex workers. The initial status of HIV infection as a terminal diagnosis gave rise to distinct primary practices both among people who had been infected with HIV and among concerned individuals at large, including activists. As with COVID-19, the practice of being tested for HIV only became routine at more advanced stages during the pandemic. Early on, HIV infection was shrouded in mystery and was highly stigmatised, and little information was communicated through official channels, limiting the level of awareness of the problem, with stigma being a major barrier. As noted by Werron and Ringel (2020), primary pandemic practices play a key role in rendering a pandemic real in the form of knowledge production and dissemination and health responses, as the unfolding events are not visible to the naked eye. In general, primary practices can be grouped into four categories: (i) practices aimed at improving the depth of knowledge or scientific basis, (ii) practices undertaken by people who are or believe they are infected, (iii) practices undertaken by people who consider themselves at a risk in general and (iv) direct efforts by concerned individuals to elevate the issue to a crisis status on the policy agenda. These practices naturally respond to new developments in both science and culture and vary from one context to another.

As with COVID-19, one important category of primary practices is the efforts to improve the state of knowledge on the unfolding events. These practices refer to enhancing ‘the evidence’, for example, studying the virus, initially attributing the symptoms of AIDS to HIV, monitoring the spread of the virus among a population, defining ‘key populations’ for interventions, advancing treatment and prevention. This information, in turn, forms the basis for non-pharmaceutical interventions, such as communicating the promotion of certain behaviours and discouraging others. Such efforts have continually faced obstacles owing to the stigmatised nature of HIV/AIDS, for example, the collaboration with or even the facilitation of safer practices amongst individuals who partake in activities that have been or continue to be criminalised in many countries.

Individuals who were or thought they were infected, in turn, were generally provided with a terminal diagnosis prior to the emergence of effective anti-viral therapies. Such ‘existential slaps’ (Coyle, 2004) produce very different primary behaviours at different stages but oftentimes involve preparing for life coming to an end (e.g. cashing in life insurance, drawing up a will or doing what one loves the most, in addition to a long process of emotional processing). Another common primary practice in the context of terminal illness is to pursue possible life-prolonging treatments or alternative treatments or, as was only possible in the latter half of the 1980s, to participate in trial experiments on potential anti-retrovirals and life-extending drugs. Stigma, in turn, gave rise to practices aimed at not displaying symptoms of AIDS. The first anti-retroviral was approved in 1987, but its coverage remained limited. For individuals who have received a terminal diagnosis, as we

noted, the discovery of a drug and the renewed hope for survival resulted in an existential crisis in its own right. With life insurance having to be paid back (many had accumulated debt) and end-of-life preparations having to be cancelled, pharmaceutical interventions radically affected such practices. Hence, it can be concluded that the advent of new and continuously improving prophylactic medicines continues to change the social landscape of HIV/AIDS.

As awareness of HIV/AIDS surged, the increasing social presence of the pandemic shaped practices with increasing intensity. For example, it can be observed that primary practices in the context of the unfolding events have an identity-forming element, which gives rise to and strengthens responsive practices and their durability. Such responses range from actively refusing to take precautionary measures at one end of the continuum to extensively disrupting previous practices in others (which may or may not become a central part of one's identity). Both responses, in a sense, relate back to the pandemic as long as it exists consciously in the public imagination, thus rendering both resistance and compliance and everything in between as pandemic practices, at least to some extent. This, in turn, hinges on the issue salience of the health problem in question.

Central to rendering the pandemic real and producing responses to it is not only the pursuit of science and other forms of knowledge production. Elevating issues onto the policy agenda requires effort and more than just knowledge. Overall, activism and engagement by civil society played a key role in elevating the status of the emerging HIV/AIDS pandemic to a crisis status in the United States in the mid/late 1980s, as well as later in elevating it onto the global agenda. In general, the active social amplification of scientific information on the part of concerned individuals (encompassing HIV-positive individuals, members of 'key populations' and individuals who are part of the population at large) increases the level of perceived acuteness, which in turn shapes the extent to which the phenomenon is experienced as totalising (and for whom). This notion, in turn, gives rise to a diverse set of responsive practices.

HIV/AIDS campaigns have mainly targeted specific populations rather than the whole population. One exception is countries with higher prevalence, although also here advice is often tailored to specific groups who are perceived as drivers of the pandemic. The stigma that is often associated with HIV/AIDS signifies that a major brunt of primary practices have focussed on efforts to reach those at risk or infected. In other words, one set of practices, centred on enhancing awareness and changing values, have given rise to other sets of pandemic practices, centred on seeking information, being tested and receiving treatment or using preventive treatment regimens. While the pharmaceutical aspect of HIV/AIDS is clear, where searches for new and better drugs, improved tests and prophylactic treatments have been central, a major brunt of the practices associated with HIV/AIDS are also targeted at changing socio-cultural aspects through information, policy change and more direct interventions for at-risk populations. Since HIV infects its hosts primarily through sexual intercourse and through pierced skin, interventions have been aimed at changing the practices associated with sex, how medical or dental procedures are carried out, practices related to injecting drug use and occupational hazards in the health sector.

4.2. Responsive practices

Among at-risk populations in particular, actions such as requesting or discussing the HIV status or safer sex have become commonplace, at least in contexts in which risk behaviours are not highly stigmatised or criminalised. However, similar to every social practice, this also produces counter-practices, as interventionist approaches are also associated with contestation. Medical doctors have been criticised for not understanding safer sex preferences and choices on the grounds that people care about more than only their health. There have also been accounts of HIV infection and AIDS symptoms having been rendered a form of desire and identity (García-Iglesias, 2020; Dean, 2009).

Individuals who believe that they are frequently exposed or may have been exposed undergo prophylactic or post-exposure treatment (taking pre-exposure prophylaxis (PrEP) or post-exposure prophylaxis (PEP)), a responsive practice that for many augments how they experience the presence of the HIV/AIDS pandemic.

Some researchers have expressed concerns that the emergence of PrEP, a regimen that prevents HIV infection in HIV-negative individuals, increases the risk-taking behaviour as a response (Montaño et al., 2018; da Silva-Brandao and Ianni, 2020). There have also been reports that testing for HIV and other sexually transmitted infections (STIs) is performed routinely in many contexts, although policymakers have pointed out the difficulty of reaching those who identify outside target communities (for example, if the behaviour that increases HIV exposure (such as homosexuality, sex work or injecting drug use) is also criminalised). Generally speaking, the way in which the presence of HIV/AIDS impacts such practices is in this way also shaped by identity. Defying the advice of health authorities is also considered a response and forms identities and communities as a form of feedback or resistance. Hence, the analytical notion of pandemic practices would benefit from increased attention to how they are formed as well further theorisation around how public health interventions become contested, as well as how resisting them forms communities that engage in so-called 'deviant behaviour'.

The risk of HIV also lies at the centre of political discourses on the legal status of drug use. Proponents of harm reduction policies argue that supplying clean needles and syringes can help reduce the risk of HIV and other infections in PWID. The message underpinning the harm reduction strategy is that, given the opportunity, injecting drug use can be made less risky if a basic set of practices are made more readily available. Similarly, reaching out to sex workers to promote safer sex would, in socio-legal contexts that criminalise sex work, give rise to difficult contradictions between the desire to promote public health and the desire not to endorse illegal practices.

4.3. Adaptive practices

Generally, it is safe to say that the emergence of HIV/AIDS has changed sex forever (which is in itself a meta-level claim). While HIV/AIDS can be understood as a slow-onset global pandemic, it can also be understood as a series of interacting epidemics (McInnes, 2016). This is because, after all, the way the disease shapes lived experiences depends on the context, both geographical and otherwise. Regardless of whether HIV/AIDS is perceived as a global pandemic or a series of epidemics, it is clear that it also exists as a cultural phenomenon. Notably, the growing activism in the Global North in the 1980s, in conjunction with the high-profile AIDS-related deaths among celebrities, helped spark awareness towards the disease and also gave rise to its cultural existence. In the attempt to trace its origins mainly to communities that were already marginalised before the emergence of the disease, it took considerable efforts and the deaths of high-profile celebrities to really raise the salience of the disease on the political agenda. More recently, it has been argued that the response to HIV/AIDS later became disproportionate, overshadowing non-communicable diseases with far greater disease burdens (Kenworthy et al., 2017).

It can also be observed that the identity-forming potential of personal HIV status may shape the legacy of the pandemic over the long term. Although the (elusive) goal of ending AIDS is pursued and considered by many experts to be a tangible goal within reach, given sufficient funding and political will, it is still probable that identity categories such as 'poz' may continue to exist as cultural artefacts even when the disease fades out of public consciousness. While the cultural impact of a potential vaccine or durable cure remains unknown, we expect that the onset dynamics of the HIV/AIDS pandemic will continue to shift as new pharmaceutical regimes are developed, in the same way that anti-retroviral therapy (ART) and PrEP have changed HIV/AIDS-related practices.

Within the policy sphere, it can be observed that a dedicated Millennium Development Goal (MDG) for HIV/AIDS was an important driver of issue salience towards the year 2015. The replacement of the MDGs with the Sustainable Development Goals (SDGs) in 2015 is arguably indicative of a decreased concern towards HIV/AIDS as a global phenomenon, which is possibly attributable to falling mortality rates and scaling up of treatment. Such developments may backfire, however, as such re-definition of HIV from a deadly disease to a manageable condition ultimately shapes practices that facilitate prevention, such as safer sex practices, funding, and services. Hence, the concept of pandemic practices should in this way also consider how dragged out and protracted pandemics and health crises are shaped by the general ebbs and flows of issue salience cycles (Downs, 1972).

4.4. Meta-practices

The first type of meta-practice identified by Werron and Ringel focusses on the role of data visualisation, communication strategies and data aggregation in rendering an elusive phenomenon like a pandemic real in the public imagination. In the case of COVID-19, notions such as ‘flattening the curve’ were implemented in anticipation of surging cases based on sophisticated modelling of the future evolution of the unfolding events. In the case of HIV/AIDS, the process was considerably slower because of how the virus spreads and who it was most prevalent in. Hence, HIV/AIDS is considered an example of how difficult it can be to initially render unfolding events real when the personal sense of risk among the population at large remains minimal. Once HIV/AIDS was recognised as an emergency in many of the world’s largest cities, meta-narratives generally focussed on key populations and not on all populations. Data visualisation has never been as pervasive and totalising as for the COVID-19 pandemic, with daily case and death numbers reported in many of the world’s most read newspapers.

The second type of meta-practice concerns narratives that bring previously established practices into question. For COVID-19, some clear examples include the role of hand hygiene and wearing face masks, as well as numerous less well-prevalent narratives concerning, for example, the future of traveling, sustainability transitions and austerity-related budget cuts for hospitals, as well as discourses on global inequities in health and elsewhere. While some of these factors are also recognisable in discourses and policy on HIV/AIDS, several aspects are also distinct. For example, HIV/AIDS has brought a different set of previous practices into question (instead of washing hands, wearing gloves and wearing masks, the narratives focus on how societies could have been so careless about exchanging body fluids in medical and non-medical settings). Condom use, abstinence, circumcision and, more recently, taking PrEP have become politicised. Discrimination and stigma have also become very much a barrier to lowering the prevalence of HIV, as underground cultures cannot be easily reached in prevention programmes. Hence, HIV/AIDS in many ways gave rise to discussions surrounding the negative effects of stigmatising homosexuality, injecting drug use and sex work.

The third type of meta-practice concerns symbolic practices of socio-culturally institutionalising the event as an ‘Event’. At this point in time it remains elusive how COVID-19 will evolve or whether it will become a pandemic that cannot readily be pinned in time, much like HIV/AIDS. This most likely depends on how societies worldwide will manage the transition from a pandemic to an endemic situation, discursively speaking. It also depends on global institutions, for example, whether there will be a UN decade, a World COVID-19 day, a coloured ribbon or the likes, all of which seem questionable given the high salience of the issue. In the case of HIV/AIDS, people are already familiar with red ribbons and World AIDS Day which mainly serve to increase the salience of the issue. Many consumers have displayed their support for the cause by purchasing Product Red™ products in support of the Global Fund. As with COVID-19, however, the efforts aimed at spatio-temporally locating a site and time for a global AIDS crisis remain an arbitrary

exercise given the pervasiveness of the disease as a social issue in strained healthcare systems and environments of waning trust in pharmaceutical quick fixes that remain infeasible for many, even in parts of the developed world (see Table 1).

The fourth type of meta-narrative refers to the way in which global health crises manifest in the global-local (‘glocal’) policy sphere (Rubin, 2019). Bureaucratic responses are generally believed to long outlast the crises that they are designed to handle. COVID-19 gave rise to a number of techno-scientific practices of measurement and counting, such as counting cases, counting the global death toll, scoring countries and producing indexes and statistical theories. The existence of the pandemic ‘in the numbers’ is considered to be essential for constructing its social presence since few people observe it with their own eyes. At the time of writing this article, it remains unclear how such meta-narratives will change with the transition to an endemic phase. In either case, a whole machinery has been activated, producing statistical practices that will be institutionalised and will persist. Narratives of winners and losers between countries and regions are commonly observed in reports and the news media. The learning process will give rise to notions of ‘precedent’ and ‘model responses’, based on seemingly simple statistical proofs but shrouded in difficult normative contradictions and priorities.

In the context of HIV/AIDS also, the proper way in which to approach best practices remains contested. Key populations engaged in

Table 1
Temporal, vulnerability and social aspects of the COVID-19 and HIV/AIDS pandemics.

	COVID-19	HIV/AIDS
Temporal dynamics	Framed as an event to be overcome (whether natural or through vaccinations). Often clearly framed in ‘pre’ and ‘post’ pandemic terms, although eradication remains an elusive goal.	Institutionalised as a condition of life for a vulnerable population, which can be alleviated through social and medical practices. Notions of ‘pre’ and ‘post’ pandemic have broken down because of the protracted nature of the pandemic.
Vulnerability dynamics	Vulnerabilities highly correlated with age across different socio-economic contexts. Global pandemic with huge repercussions for countries in all regions and across different income groups. Limited stigmatisation of particular social groups.	Initially, vulnerabilities were highly correlated with sexual orientation and drug use. Currently, however, vulnerabilities are increasingly correlated with health inequities and poverty. Key populations vulnerable to HIV/AIDS remain stigmatised and even criminalised in many regions.
Social practices	Generated a very diverse set of non-pharmaceutical and later pharmaceutical responses. There are hardly two countries with the same types of prevention measures. Evidence bases and policy responses remain highly contested (e.g. whether to focus on hand hygiene or mask wearing). A strong focus on restrictions, quarantine, travel bans, vaccine passports and documentation. Legacy remains unknown at the time of writing this article.	Generated a very diverse set of non-pharmaceutical and later pharmaceutical responses. New medical innovations have changed the cultural manifestation of the disease (risk) as a result of ART first and then PrEP later. Evidence base less politicised after the initial decade. Countries respond in similar ways in terms of their HIV prevention strategy, although stigmatisation and criminalisation of at-risk groups oftentimes remain a barrier. Few, if any, bans have been implemented as a result of the HIV/AIDS pandemic. Mixed legacy in terms of underpinning arguments in favour of liberal policies in some contexts whilst underpinning discriminatory policies in other contexts.

the 'fight' against HIV/AIDS remain criminalised in many regions. It can also be observed that a considerable global policy apparatus exists for the management of HIV/AIDS as a global health crisis, with UNAIDS being just one prominent example. Still, the fact that HIV/AIDS had an MDG of its own but no SDG to boot is also suggestive of the role of issue salience cycles. If AIDS were to become a condition of the past as a result of successful eradication, it will still remain uncertain how bureaucracies created to manage the disease would respond. It is worth noting that the aftermath of protracted slow-onset crises is not exactly a well-studied topic partly due to the limited number of examples of successfully 'closed' global-agenda issues (HIV/AIDS is a relatively peculiar issue in the global health sphere due to the vast institutional context built around the issue). In this article, we have also hinted at a potential fifth and sixth meta-practice that emerged as a result of our reflections on the HIV/AIDS pandemic, a pandemic with a considerably longer temporal horizon.

The fifth meta-practice that we consider based on the HIV/AIDS case is the ways in which pandemics and pandemic practices may produce normative, policy and judicial legacies. Despite being somewhat related to adaptive practices, these types of meta-practices are more difficult to discern because of their elusive nature. While we have surely found cases of normative legacies of pandemics or court rulings, policy changes or reform processes that are more or less directly traceable to a particular health crisis or problem, we may also imagine that smaller and cumulative changes to cultural values and social norms are more difficult to pinpoint. Still, such incremental changes will ultimately lead to new policy stances, moral landscapes, new attitudes and new demands for rights, among other changes. The HIV/AIDS pandemic is a case in point.

One of the most durable legacies of such a pandemic is likely to be the role that it has played in justifying various practices of decriminalisation and legalisation of previously illicit or highly stigmatised social practices. HIV/AIDS prevention narratives have paved the way forward for the decriminalisation of sex work, homosexuality, injecting drug use and sparked other emancipatory effects in many countries in the name of public health. Moreover, the so-called 'harm reduction strategy', and advocacy for supplying PWID with clean needles and legal protection, for example, is also founded on the assumption that it ultimately also serves public health aims as it may reduce the prevalence of HIV/AIDS in these populations (as well as of course considerations of individual rights and health ethics).

At the same time, HIV/AIDS continues to be stigmatised, making it particularly difficult for different groups to embrace prevention medicine like PrEP out of concerns of being associated with elevated HIV/AIDS risk. Court rulings have also set a precedent in cases of future emergent diseases. One example is the fact that intentionally infecting people with HIV has been criminalised and that the practices that we have previously mentioned, such as intentionally pursuing HIV infection or intentionally compromising condoms (stealth), have been addressed in legal systems. However, we also notice a backlash here as some countries initially pursued a public health approach to at-risk populations but have since turned to increasingly persecute a number of these populations and, thus, contribute to pushing them underground, which in turn changed the tide for HIV/AIDS prevention efforts in some contexts.

Sixth, global pandemics do not exist or advance in isolation; they compete for space on already crowded political agendas and battle for attention on distracted minds among the populace. Just as the emergence of COVID-19 did not end all other health crises, so too did the HIV/AIDS crisis not become the only or even the main cause of death at the global level. Epidemics of quite different socio-temporal characteristics continue to unfold, whether it be the so-called obesity epidemic, lifestyle disease epidemics or antimicrobial resistance (AMR). A number of meta-narratives on these interactions may be found in the scientific literature and popular media. For example, a number of viewpoint articles have pointed out the existence and non-existence of connections

between COVID-19's attention surge and a negative impact on HIV/AIDS prevention and treatment (e.g. Jiang et al., 2020; Brown et al., 2021). Similarly, we have also found a number of articles on the inter-connections between various seemingly 'more acute' health crises and the ways in which disproportionate attention to these displaces the pressing issue of AMR, which will cause more deaths over the long term (Hsu, 2020; Getahun et al., 2020).

In other words, pandemics do not simply emerge, persist or end; they interact and produce synergies or competitions for attention, funding and care. The more COVID-19 is practised, socially speaking, the less HIV/AIDS is practised. Just as the news media have reported on record low levels of cancer screenings during COVID-19, with potentially devastating long-term consequences, HIV/AIDS has also waned from public attention as a result of the surge in issue attention being awarded to COVID-19. Future research building on the concept of pandemic practices should, thus, also consider how various pandemics, epidemics and health crises or other mega-issues on the agenda interact for better or worse.

5. Concluding remarks

By engaging a pandemic with quite different temporal, virological and epidemiological traits from those of COVID-19, in this study, we engaged the concept of pandemic practices with the purpose of reflecting on how the concept may be applied to pandemics with a different set of traits. Engaging the concept of pandemic practices in the context of HIV/AIDS yielded a number of interesting insights and lessons learned. In terms of primary practices, the HIV/AIDS pandemic has been re-defined a number of times, which has also shaped how the disease exists socio-culturally. For example, when HIV was re-cast as a manageable condition and no longer as constituting a death sentence, the primary practices changed accordingly. Incentives for prevention were altered and the way in which at-risk populations behave also changed, with certain socio-cultural effects. Later, the emergence of prophylactic treatments further changed the lived experience of HIV risk and the affective stance towards the prospect of HIV infection. However, as for responsive practices, the picture is more complex. When HIV infection was considered a death sentence, a sense of apathy in some cases gave rise to a culture of embracing risks in some sub-communities.

In general, the identity-forming nature of disease seems to play a significant role in shaping how people engage in responsive practices. In the case of adaptive practices, it can be observed that the HIV/AIDS pandemic has left a significant impact on the policy world, popular culture, development funding and many other sectors. Moreover, the fact that HIV/AIDS is inherently a pandemic of inequality renders it ignorable or a non-issue in some contexts but still a deadly disease in other contexts in which care remains inaccessible or unaffordable. The normative legacy of HIV/AIDS has underpinned efforts to decriminalise or even legalise previously criminalised or stigmatised practices based on arguments that reaching populations that are forced underground has become a public health problem in its own right. In this sense, in many parts of the world, HIV/AIDS is both a stigmatised disease and a disease that has played an emancipatory role, at least in some contexts (HIV/AIDS is also in many cases used as a justification for stigmatising or discriminating against certain populations).

Theoretically, this study offers two additional forms of meta-practices. One of these focusses on the way in which pandemics leave legal, policy and normative legacies. We argue that the HIV/AIDS pandemic has galvanised support for certain emancipatory reforms for at-risk populations in some contexts while justifying stigma in other contexts. The second meta-practice introduced in this study focusses on the temporal aspect and the way in which crises with different temporal dynamics co-exist and interact on the horizon. In general, pandemics never occur in isolation, and the emergence of new health crises displaces the attention, funding and efforts at preventing and minimising pre-existing health challenges. For example, the emergence of COVID-19

has displaced the attention to HIV/AIDS programming as well as to anti-microbial resistance.

Applying the concept of pandemic practices to other types of epidemics and health crises may, thus, produce other interesting insights as practices are to some extent shaped by virological traits and policy responses to disease, some of which are overlooked and some of which become totalising. Concretely, applying the heuristic of pandemic practices to HIV/AIDS also offers some lessons for the COVID-19 pandemic. While the COVID-19 pandemic is still portrayed as a focussed event (with a clear before and after), the pandemic practices, while changing over time, will often have longer-term ramifications. In particular, our analysis of the HIV/AIDS pandemic raises some concerns regarding adverse academic practices that appear to be replicated in the current COVID-19 pandemic.

Just as with HIV/AIDS, many people might be able to go back to living their normal lives largely unhampered by most pandemic practices, while others will continue to suffer from adverse health outcomes, stigmatisation, exclusion and even criminalisation. This can already be observed in many high-income countries, where unvaccinated individuals, primarily from ethnic minorities and rural areas, not only bear the brunt of hospitalisations and fatalities but also are increasingly socially and politically stigmatised. The opposition to- or support for vaccines and masking appears already to have taken on identity-forming nature for many. Hence, our analysis cautions against a likely rift between high-income countries, where most pandemic practices might gradually fade out of direct consciousness, and low-income countries, where much more pronounced pandemic practices might continue to adversely influence the livelihoods of vulnerable sections of the population. Importantly, these practices in many low-income countries are not only shaped by the COVID-19 pandemic but also influenced by many other epidemic manifestations, such as HIV/AIDS, Ebola, tuberculosis, and malaria. Further research will be needed on the co-existence of multiple health emergencies and problems as well as on how these interact to form complex cultural responses. Thus, solutions are needed to address not only the pandemic itself (as an important health issue to be resolved), but also the more diverse pandemic practices (both nationally and globally) that have materialised (as social issues).

Author's contribution

Reidar Staube-Delgado formulated the idea, structured the manuscript and wrote the initial draft and implemented the final edits. Olivier Rubin assisted with the idea formation stage and conceptualizing the theoretical contribution of the paper and wrote the second draft.

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