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ABSTRACT

HIV/AIDS is known to have fundamentally transformed fields of biomedical research, the governance of health, and state–citizen relations. Based on research that was developed to analyze these transformations within HIV/AIDS activism at the European-level, we offer the term chrono-citizenship to describe the influence of time in constructs of citizenship. We argue that the temporal regime of biomedicine, or modes of governance that depend on biomedical understandings of time, have come to dominate HIV/AIDS narratives, policies and programs. Building on oral histories and three years of fieldwork in spaces of European-level networks and health-governing bodies, we suggest that citizenship in the field of HIV/AIDS has been defined through multiple, intersecting and, at times, antagonistic temporal regimes. To illustrate this, we expose the regime of loss, through which mourning, often denied space in the present, bears potential for new forms of subjectivity and community; the regime of sustainability, which centers the planning and surveillance of budgets over service provision in a climate unfriendly to human rights; and the regime of chronic crisis, in which persistence becomes a form of political agency against ongoing exclusion and disappointment. As we show, unearthing varied temporalities helps to denaturalize biomedical understandings of time, and invites a rethinking of the foundations needed to reach the 'end of AIDS' sought by civil society, UNAIDS and other health-governing bodies.

Introduction

On 18 March 2020, Portugal declared a 'state of emergency' over SARS-CoV-2, a new and deadly type of coronavirus. Two weeks later, the Portuguese government announced it would temporarily provide asylum seekers and migrants with pending residence-permit applications access to the country's social support and public healthcare structures. Short of granting them citizenship, this interim policy would 'unequivocally guarantee the rights of all foreign citizens,' the Portuguese Council of Ministers announced; their 'situation of regular permanence in National Territory,' however, would initially extend only until 30 June 2020 (Alberti & Cotovio, 2020). Guided above all by the temporal logics of public health, or what might be called a temporal regime of public health, the temporality set in motion by the state of emergency has thereby led to the renegotiation of the terms of accessing rights and recognition in the country, and infused state-subject relations with a remarkable temporal dimension.

Rather than restricting rights or conditionally excluding from protection (Agamben, 2005), the state of exception in this instance temporarily displaced the legal residence norms to exceptionally

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include the otherwise excluded into the rights afforded to citizens. The anticipated duration of public health emergency, in other words, came to determine the duration of social and political inclusion. We open with this account as it may be the most recent manifestation of what we have observed to be a central but often overlooked dimension of citizenship – namely, the ways in which time comes to play a decisive role in 'subject-making and being-made by power relations' (Ong et al., 1996, p. 737; c.f. Isin, 2009; Paparini & Rhodes, 2016; Rose, 2007; Young et al., 2019). To be distinguished from the taken-for-granted structuring influence of space in legal notions of citizenship as tied to the place of one's birth, residence or ancestral origins (Brubaker, 1992), this instance from Portugal illustrates how temporality can come to define the terms for accessing rights and entitlements. Extending beyond Portugal's top-down, government-imposed temporalization of citizenship for foreign nationals, we offer the term chrono-citizenship to capture how time is negotiated, mobilized and (re-)constituted in the enactment of citizenship – through processes of subjectification, collectivization and rights-claiming.

The temporal quality of citizenship became apparent to us during fieldwork on a different health crisis, HIV/AIDS, known to have fundamentally transformed fields of biomedical research, the governance of health, and state–citizen relations (Biehl, 2007; Epstein, 1996; Rose, 2007; Squire, 2013). As members of the 'Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health' (EUROPACH) research team focusing on European-level policy worlds, our fieldwork (2017–2019) took place in spaces of European-level networks engaged in policy responses to HIV/AIDS, such as at conferences, meetings or trainings. Research in personal, organisational and governmental archives, and 60 oral history interviews with actors selected to account for a tense, dense and multi-vocal field, served to document and contextualize activist engagements in shaping, negotiating and responding to HIV/AIDS policies from across the European region. Drawing from this material, we argue that citizenship in the field of HIV/AIDS has been defined through multiple, intersecting and at times antagonistic temporal regimes – illustrated using the regimes of biomedicine, loss, sustainability and chronic crisis. As we show, unearthing these temporalities helps to denaturalize the biomedical understandings of time that have come to dominate HIV/AIDS narratives, policies and programs (Sangaramoorthy, 2018), and provide a more nuanced understanding of the entangled temporalities through which citizenship is enacted in the field.

Citizenship and temporality

Beyond its common understanding as a legal status, citizenship has been reframed in the social sciences and humanities to include practices and narratives of social, cultural and economic inclusion and exclusion, often described through the lens of subjectification, belonging and participation. Scholars have noted that citizenship processes have become less constrained by traditional purveyors of rights and entitlements (e.g. the state, nation, city), and emerge through the claiming of rights as part of social and political struggle and not just membership into a predefined polity (Isin, 2009; Rose, 2007). In the realm of health, such acts of citizenship have been increasingly theorized in relation to the compelled uptake and deployment of biomedical technologies and epistemologies as they subsume, reshape or compete with the logics of social, economic and political institutions. Biological citizenship is the most widely used term (Petryna, 2002; Rose & Novas, 2005), but related concepts include therapeutic (Nguyen, 2010), biopolitical (Epstein, 2007), pharmaceutical (Biehl, 2007), patient (Paparini & Rhodes, 2016) and HIV (Young et al., 2019) citizenship. Taken together, these concepts account for the growing influence of the biomedical sciences and biopharmaceutical treatments as part of a biopolitical form of governance – 'a system of claims and ethical projects that arise out of the conjugation of techniques used to govern populations and manage individual bodies' (Nguyen, 2005, p. 126).

Benton et al. (2017) have argued that 'conceptions of time and temporality configure and reflect power relations in global health' (p. 454), thereby rendering temporal regimes central to understanding notions of difference, health and the self. With the concept 'temporal regimes,' we refer to

provisional and situated modes of governance that are dependent on shared understandings of time, experiences in time and orientations to time (Poell, 2020). Rather than universal and stable social and political realities, the temporality of a given temporal regime is induced from the contingent and contested production of time in everyday practices, a process often referred to as temporalization (Munn, 1992; Ringel, 2016). As forms of governance that are defined above all through shared but variable modes of temporalization, temporal regimes can coexist and interact in a field of analysis, introducing antagonistic, stabilizing or crosscutting temporal orientations that shape understandings of the past, perceptions of the present and visions of the future (Appadurai, 2013; Bryant & Knight, 2019). The defining qualities of citizenship are hence importantly shaped by the strategies mobilized to enact, enforce and negotiate the temporal regimes of a given field.

In the literature on biological citizenship, researchers have well accounted for the shifting temporalities of biomedical technologies and biomedical understandings of illness in shaping the terms for accessing rights, gaining recognition and enacting responsibility (Nguyen, 2005, 2010; Squire, 2013). Rose and Novas (2005) suggest that biological citizenship operates above all within a 'political economy of hope': 'Biology is no longer blind destiny, or even a foreseen but implacable fate. It is knowable, mutable, improvable, eminently manipulable. Of course, the other side of hope is undoubtedly anxiety, fear and even dread at what one's biological future, or that of those who one cares for, might hold' (p. 442). Within this literature, the temporalities of hope and fear in the realm of health are fundamentally linked with the developments, advancements and circulation of biopharmaceutical technologies, such as via biomedical forms of prevention, treatment or vaccination (Biehl, 2007; Nguyen, 2010). However, given that rights-claims in the realm of health extend beyond access to biomedical technologies, there is a pressing need in social science research on health and citizenship to explore hope, fear and other modes of temporalization that do not revolve around the field of biomedicine.

Derived from our fieldwork, the temporal regimes of loss, sustainability and chronic crisis underscore that biomedicine is not the only temporal structuring force in fields of health care and activism. As modes of governance, these entangled regimes highlight the under-appreciated and variable influence of time and temporality in contemporary forms of citizenship. To provide a conceptual framework for theorizing these regimes as indicative of particular citizenship dynamics, we offer the term 'chrono-citizenship' to capture the role of time and temporalities in shaping and enacting forms of subjectivity, collectivity, and claim-making. Here, we borrow from the Greek prefix *Khrono-*, meaning time, to denote citizenship claims and constructs of and in relation to time (Freeman, 2010). In the field of HIV, the relevance of time in constructions of the self, claim-making and belonging has been most often analyzed through the temporalities of clinical trials, adherence to medications and treatment activism – often interrogating the implicated biomedical logics and practices (Epstein, 1996; Nguyen, 2010; Rosengarten, 2017; Young et al., 2019). Inspired by this literature, we expose below selected temporal regimes that are further out of sync with the biomedical approaches that dominate contemporary HIV/AIDS policies in Europe.

Temporal regime of biomedicine

Narratives about the past 40 years of the HIV/AIDS epidemic introduce turning points that reveal shared temporal rhythms and markers in accounts of history, and privilege or naturalize certain operating logics over others. In particular, a dominant narrative has emerged about a transition from 'death sentence to chronic disease management', as per a WHO-Europe publication title (Matic et al., 2006), thereby centering a perceived shift in the temporality of life as an indicator of the epidemic's transition in time. Pivotal in this narrative is the 1996 advent of highly active antiretroviral therapy, and a subsequent decline in AIDS-related deaths and AIDS diagnoses in the European region (Matic, 2006, p. 9). For those with access, the emergence of effective antiretroviral therapy (ARV) allowed for the prolongation of life among people living with HIV, thereby reconfiguring infection with the virus from a terminal to chronic condition. Understood generally as the continuity of biological illness over

the course of an incurable disease, the notion 'chronic' here is embedded in what Sangaramoorthy (2018) describes as 'biomedical notions of time' (p. 2; Smith-Morris, 2010). Based on this shift from the life-altering influence of ARVs, Dannecker (2002, pp. 61–62) coined a distinction between 'old' and 'new' AIDS – between a linking of AIDS with death to its linking with continued life.

Also framed within a temporal regime of biomedicine, transnational health-governing bodies increasingly began in 2010 to anticipate the 'end of AIDS' (Kenworthy et al., 2018). Most recognized in this project has been a 2014 initiative developed by the United Nations Joint Program on HIV/AIDS (UNAIDS) promising a 'fast-track' commitment to end AIDS worldwide by the year 2030. This program was dependent on achieving a set of goals by 2020: 90% of all people living with HIV know their HIV status; 90% of all people with diagnosed HIV infection receive sustained ARVs; and 90% of all people receiving ARVs achieve viral suppression. As is apparent already in the program's title, '90-90-90: An ambitious treatment target to help end the AIDS epidemic', the economy of hope upon which this vision for the future rests is dictated above all by the norms of biomedicine (Sangaramoorthy, 2018).

Entwined with the 'end of AIDS' narrative are now two overlapping sets of actors, policies and programs that are similarly built around the expanded availability of bio-pharmaceuticals. The first, U = U (Undetectable = Untransmittable), is a collaborative project between activists, civil society and, at times, care-providers and government bodies that seeks to reduce the stigma of living with HIV by stressing that the virus cannot be transmitted to sexual partners if made undetectable in the bloodstream, typically as a result of adherence to a bio-pharmaceutical regimen. Illustrating a multiplicity of biomedical notions of time – e.g. continual and punctual, approaching infection both pre- and post-exposure – the second phenomenon concerns ongoing or event-based use of bio-pharmaceutics as a form of HIV prevention known as pre-exposure prophylaxis (PrEP). A rich literature has emerged exploring the varied, complex and unpredictable citizenship dynamics that have taken shape around the introduction of these biopharmaceuticals, especially focusing on the emergent subject constructs and forms of responsibility to the self and society (Paparini & Rhodes, 2016; Young et al., 2019).

The dominant biomedical narrative thus centers three temporal shifts that form a linear trajectory of progress: the epidemiological crisis of a deadly virus, now relegated to the past; the ongoing management of a persistent illness, qualified as chronic; and the sought after 'end of AIDS' future, fundamentally dependent on the promises of bio-pharmaceuticals. The selected markings of time in this narrative account for certain processes and lived experiences that reveal and also hide from view particular dynamics of citizenship. Together, they expose how biomedicine comes to structure and mark chrono-citizenship as centered around the (non)availability of treatments and adherence to medications. The temporal regime of biomedicine came to produce what Biehl (2007) has termed patient-citizens – responsibilized and adherent bio-pharmaceutical subjects, thus overshadowing the plurality of lived experiences and non-biomedically-centered engagements with HIV/AIDS evidenced across Europe. As the next sections show, accounting for alternative temporal regimes in the landscape of HIV/AIDS activism allows for relativizing this narrative and adding complexity to our understanding of citizenship in relation to the epidemic in the region.

Temporal regime of loss

Simon Watney's home is a living archive of remnants from his years of engagement with HIV in and out of the UK. During the sporadic breaks over the course of our interview, he worked to retrieve saved digitized information so that it might be used for our research. Destined to move homes, his health fragile and his belongings with friends, he was unable to access, in the moment, materials stored on his hard drive. He had donated much of his belongings to a UK-based archive, but lamented that the materials sat unsorted, and thus unavailable for interested users. Like so many, he was saddened that the remnants of his relations, organizational attachments, and remarkable life as an activist and caregiver might be lost forever. The potential loss of his personal archive, hauntings

of a bygone era, would erase, it seemed, or further repress, the overwhelming experiences of loss that he carries with him. This double meaning of loss – of past friends, lovers and peers, but also of a fitting outlet for engaging with loss in the present and future – was a common theme among long-term activists in our fieldwork.

Robin Gorna, former member of the UK-based HIV/AIDS charity, Terrence Higgins Trust, and, later, HIV/AIDS-policy coordinator at the European Commission, described the entanglements of loss and activism in the early years of the epidemic:

> it was very normal to be going to one or two or three or four funerals a week […] We would have buses that would turn up and bus us all out […] maybe one or two people would elect to stay behind to keep things going because of course we knew that you had to maintain a service even in the loss […] I had a very remarkable fast track to understanding things that sometimes people only start to learn and think about in their 50s […] I think it certainly has made me personally much more focused on what really matters, and very intolerant of people who tell me things are urgent when they're not about people dying.

Energies in the everyday rhythms of HIV-activists thus oscillated between care-provision and mourning – between possibilities of hope for the future, and a reality of unfolding loss in the present. Against the biomedical narrative of progress in the face of a public health emergency, another notion of urgency took shape around this loss of lives, and the types of communities that were simultaneously built-up, fortified, undone and rendered impossible as a result of that loss. '[M]ourning on such a constant and protracted scale,' wrote Watney in one of his many publications, 'constitutes a completely transformative personal experience, after which one will never again be the person one was "before"' (Watney, 2000, p. 217). Indeed, not just a preliminary stage in a transition to effective medication, shared experiences of loss among those who survived were narrated to have importantly impacted interviewees' senses of self and community, and forever changed what counts as urgent in the temporality of life.

The urgency of loss brought about by the often slow and unpleasant deaths of friends, lovers and community members translated into collectivizing practices that included self-help groups, palliative care work and buddying services (Brown, 1997). For those diagnosed with AIDS, anticipating and planning for death became a strategy for taming the horrors of a shortened future: Brian West, for example, long-time survivor of the European AIDS Treatment Group (EATG), described participating in a 'paint-your-own-coffin' session as part of community support he referred to as 'end-of-life focused.' Through the forms of subjectivity and collectivities that emerged around accompanying, responding to or anticipating death and loss, shared experiences of fear, care and mourning came to delineate a particular politics of belonging that exceeded the norms and services of the state. Faced with stigma or rejection from parents and care-professionals, chosen or community family members of persons dying often took up roles as care providers. Denaturalizing and thereby decentering biologized notions of reproduction so privileged in the rights of marriage, care and inheritance, the temporal regime of loss thus further expanded and strengthened pre-existing social and political modes of kinship through mourning and palliative care practices (Weston, 1997).

Through the lens of loss, particular moments reveal themselves as turning points in the terms that dictate what it means to be a person worthy of recognition. Paramount among them may have been the conviction that one lives a life worth living, and thus also a life worthy of mourning (Butler, 2020). Erin O'Mara, communications officer of the European Network of People who Use Drugs, described realizing that her own life, and the lives of her community members, were not constructed as worthy of the commemoration afforded to others, even as experienced by herself and her peers. This occurred during the much-valued mourning ceremony of yet another gay male friend who had died of AIDS-related complications. Talking to another friend whose husband, a person who injected drugs, had also died of AIDS-related illnesses but whose death had gone all but unacknowledged, made her realize that she had not even considered commemorating the death of her friends who used drugs. Turning a newly acknowledged sense of grief into a possibility for grievance (Love, 2007, p. 151), O'Mara then got involved in drug users' rights activism. As such, a new relationship with lives

past became a political act and form of militant grieving (Butler, 2020, p. 106; cf. Crimp, 1989). Forging a new appreciation of loss – a hitherto un-acknowledged ethical obligation to her peers – and an affiliated sense of self and community, this event thus provoked, for O'Mara, a recognition and reconfiguration of what Butler (2020) terms the 'unequal distribution of grievability' (p. 59).

Awareness of the grievability of life when faced with a heightened possibility of loss has brought for some a new appreciation for the present. Halberstam (2005) qualifies this 'constantly diminishing future' and 'new emphasis on the here, the present, the now' as 'queer time' (p. 2). For Watney, the equation of AIDS with death was what brought such important meaning to the Denver Principles, a 1983 proclamation of rights authored by 'people with AIDS' demanding their involvement in relevant decision-making processes (PWA Coalition, 1987). 'It was a remarkably enabling conference,' he said, referencing the event introducing the principles, 'which launched the idea that AIDS didn't have to be a death sentence and that one could live with a strong identity, a primary social identity.' For Watney, the impact of the statement – a forceful condemnation of the framing of 'people with AIDS' as victims and patients, terms seen to relegate them to defeat, helplessness and dependence – is best embodied in the last of the proclaimed rights of 'people with AIDS': the right 'to die – and to LIVE – in dignity' (ibidem, p. 149). Grover (1987, p. 26) locates this declaration as a first step in a shift towards becoming people *living* with AIDS – with tense in *present continuous*. Emerging as a contrast to the dominant specter of death, the Denver Principles thus provoked, as part of a temporal regime of loss, precisely what the advent of ARVs was said to do in the biomedical regime outlined above – it came to distinguish between a linking of AIDS with death to its linking with continued life.

Life here is not what follows from effective medication; it is, instead, recognition that one is alive in the present continuous. Watney (2000) refers to something similar when he wrote of the 'meaningfulness of life,' which he sees to risk eroding if the dead are left unattended – 'without testimony' (p. 22). But testimony to and by whom? Corinna Gekeler, former member of the AIDS Coalition to Unleash Power (ACT UP) Europe, suggested in our interview that 'long-term survivors don't want to hear from other long-term survivors how hard it was.' Even in current programming on aging with HIV, 'it's such an itchy thing,' she told us, referring to the memories and suffering of long-term survivors. Stephen Dressler, co-founder of the EATG, told us 'sometimes you don't know where to go with all your memories or impressions, losses, grief.' Haunted by the past, these long-time activists carry lost lives with them but struggle to find space for engaging with the past's continuity in a present so oriented towards a biomedicalized future. Love (2007) suggests that to fully engage with loss, one must come to terms with what she calls, simply, the 'temporality' of grief (p. 151). Rather than leaving the past behind, longed for in all instances may be space for melancholia: an 'ongoing and open relationship with the past – bringing its ghosts and specters, its flaring and fleeting images into the present' (Eng & Kazanjian, 2003, p. 4). The temporal regime of loss thus exposes a need for policy and practice to account for entanglements with, rather than divisions from, the past in the present and future.

Temporal regime of sustainability

In 2017, the first Eastern Europe and Central Asia conference took place on harm reduction (HR), a non-moralizing approach to minimizing the negative health impacts of drug use (c.f. Faust and Struzik, both in this issue). Hosted by the Eurasian Harm Reduction Network (EHRN – later EHRA for Association), the conference focused on how to continue services made possible by an international health financing mechanism, the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), which had planned to soon leave the region. Many local organizations were dependent on the Global Fund for the provision of HR services, and, facing hostility from state governments, were under threat of closure, thereby provoking a renewed sense of crisis among many at the conference. Unlike with biomedicine and loss, the temporal register of crisis under the regime of sustainability, referring to the temporality that determines the continuity of services, programs and organizations (EHRA, 2018), has thus come to revolve more around the rhythms of funding streams than around

lost lives or the advent of bio-pharmaceuticals. As such, the logics that determine funding eligibility and duration become among the logics that regulate temporal shifts in and out of states of crisis.

One such logic became apparent at a panel in which representatives from four previously funded countries reported on the states of their HR services after the Fund's withdrawal. Nearly all such programs had vanished in three of the countries, which the speakers explained as following from a lack of political will, international pressure and advocacy training. Conclusions drawn from these unsuccessful transitions, it was hoped, would allow for the extended duration of services for others, and so they extracted lessons-learned for the organizational and governmental representatives in attendance. A Global Fund advisor also explained their approach to sustaining programs after withdrawal. Crucial, he said, is that countries have time to plan for future transition processes, now 'integrated into the DNA of grants' through performance frameworks and budgets. Recent changes to eligibility criteria meant that the organizations from eight countries in attendance became ineligible for funding, whereas those in two previously-funded countries became eligible again due to spikes in HIV. This latter shift was 'bittersweet', the speaker explained, because these organizations can now revitalize their services if they demonstrate that they will not end up in the same position three years later.

The temporal regime of sustainability governs through the temporal logics that determine an ability to continue organizational existence over time. In our field, multi-stakeholder conferences condense chrono-citizenship arrangements in which a variety of actors collectively negotiate the shifting rhythms and norms of funding bodies and cycles. Depending on their interests, participants work to lengthen the duration of life-prolonging programs otherwise neglected, denied or criminalized by state governments, or they assess the strategies and promise of such lengthening efforts against the shifting interests and goals of funders. As the aforementioned presentations make apparent, a loss of funding can risk a loss of services, organizations and the existence or quality of HR projects, thereby linking the temporal regimes of sustainability, loss and biomedicine. However, rather than pharmaceutical regimens, chrono-citizens under the temporal regime of sustainability are compelled to adhere to the demands of funding bodies, which entails the pre-formulation and ongoing assessment of performance frameworks through application, reporting and evaluation processes (Morfit, 2011). Community organizations and service providers are forced to adjust to the shifting logics of transnationally-operating funding bodies, which are governed by an amalgam of remarkably unstable rationalizing logics, such as the global market, public health and political will (Biehl, 2007; Nguyen, 2010). Unlike with the other regimes, as we have seen, a loss of lives in such a contingent and dynamic environment can mean, paradoxically, a return to the seeming safety-net of funding.

The thin line between funding as a safety-net and impediment became apparent in our interview with EHRA Director, Ganna Dovbakh, who observed that the Global Fund came to stifle innovation and flexibility in Ukraine, also a key Global Fund beneficiary:

> They needed to make it like an industry – so boutique and tiny and specific projects need to be national-wide, similar, like a franchise […] I was part of all of this and I know the logic why we did this. We needed to make this accountable and that's why we introduced the indicators and we are understanding what people are getting and all of these very complicated systems […] But at the same time, we lost this creativity and flexibility of the package, flexibility of response.

Whether as a safety-net or an impediment, the possibilities for the future under the temporal regime of sustainability are thus shaped above all by the past and its imagined futures – by the pre-defined interests of funders and agreed-upon promises of funding recipients – rather than the possibilities and challenges as they unfold in the present. Not just repressive or constraining, these funding implications have clearly led to new responsibilities for civil society actors, but also to the creation of adapting strategies and possible modes of resistance. Ivan Varentsov, advocacy advisor of EHRA and member of the Andrey Rylkov Foundation for Health and Social Justice, a Russian NGO in the field of HR and drug policy, told us about how the Foundation, deprived of Global Fund and state resources, dropped its office and board of directors, relying instead on virtual meetings or casual settings.

Donations through online fundraisers could thus be funneled directly to services. 'When you don't have money,' he told us, 'you don't need to write all these crazy reports and explain to all these people why and what and how you do.'

The temporal regime of sustainability has further entailed the reconfiguration of subject constructs, and the production of new types of advocacy – as illustrated by Alexandra Volgina, co-founder of the grass-roots, street-activist group from Russia, FrontAIDS, and current employee of the Global Network of People Living with HIV. Asked about the most pressing future direction for activism, Volgina told us that it is no longer time for 'rights rhetoric' in a political climate hostile to the human-rights paradigm; hope for the future is instead in 'budget advocacy.' Defined by EHRA (2018) as 'strategic activities to influence government decisions on allocating and implementing public health budgets and the provision of services, and to enhance the transparency and accountability of government institutions/service providers' (p. 16), budget advocacy has also been pushed to the center of the Association's policy agenda. The strategy relies on 'budget data', analytical know-how and a set of best practices to foster civil society engagements in the management of funder budgets.

The regime of sustainability has thus produced a landscape in which the budget, grasped as a vector for determining health priorities, is seen as a key policy document for shaping the social and political conditions of health. Less about adherence to treatment, chrono-citizenship under the regime of sustainability relies upon an economical advocate equipped with the data and skills necessary to calculate costs for the future, and manage expenses in the unfolding of service provision, treatment acquisition and other HIV-related programs. The budget domain has become among few chrono-citizenship spaces in which implicated actors – focused on maintaining services in an unfavorable social and political climate – can exercise agency, influence and solidarity. If neoliberalism encourages the responsibilization of individuals and collectivities over issues otherwise managed by government agencies (Rose, 2007, pp. 63–64), the temporal regime of sustainability has become one of the guiding chrono-citizenship rationalities under neoliberalism in the European region. Faced with withdrawing or absent welfare states, and a lack of political will to support HIV-related projects and rights-based interventions, activist and community groups are compelled to provide HIV prevention services with the support of transnational funding mechanisms rather than state governments. With the centering of budget activism, this dependence on external funding redirects the focus of activist groups to securing the maintenance of their work – cyclically open to the threat of extinction or the short-term promise of extension.

Taken together, these terms of citizenship reflect and (re-)produce a divided horizon of the future: in the short-term, the future is thickened with predefined calculations, conditions and commitments, and, in the long-term, it is so thinned of certainty or possibility as to hardly be imaginable at all. The issue here is thus not just to make more money available for HIV/AIDS-related work, but rather to account in policy and programming for the possibilities and limitations of the temporal regime of sustainability – e.g. to fold the contingencies of the present and unimaginability of the (long-term) future into the strategies for sustaining effective HIV-related services where they are under threat but continue to be needed.

Temporal regime of chronic crisis

In 2012, as Greece was in the midst of a financial crisis and responding to an emerging HIV epidemic among people who use drugs, hundreds of women in Athens were forcibly tested for HIV (Kloka, 2014). Alleged to be sex workers and many of them using drugs, those women who tested positive were charged with 'illicit prostitution' and 'repeated intentional grievous bodily harm.' To understand how such blatant rights violations could occur in an EU-country signatory to numerous human-rights conventions, we visited Athens in 2018 to interview the women and representatives of groups that mobilized to provide them with legal, social and psychological support. While these interviewees described the events as exceptional, this exception was continuous with the women's exceptional conditions of existence: They were 'easy targets,' we were

repeatedly told, due to their ongoing states of precariousness and exclusion. Faced with persistent poverty, social neglect and police harassment, these women did 'not stand as people,' one informant relayed; they did not count 'as citizens.'

Crisis is not a singular event here, but rather an ongoing experience (Vigh, 2008). Chronic conditions of crisis for some persons thus make them more vulnerable to a loss of rights and protections. As such, chronic crises and trajectories of regress and backlash undermine the temporality of progress as portrayed through the temporal regime of biomedicine. Regarding older Black women in the US, Sangaramoorthy (2018) similarly suggested that the 'hope signaled by the "end of AIDS" discourse and its logic of chronicity obscures the sense of protracted uncertainty and precarious life conditions experienced by those who have lived and continue to live in the shadows of the epidemic' (p. 14). As for the arrested women in Athens, living 'in the shadows' came to translate into ongoing vulnerability to the spread of the virus and structural violence of the state. The temporal regime of chronic crisis – the temporality of existing within constraints on life under enduring conditions of instability and precarity (Butler, 2020) – captures precisely this ongoing-ness of intersecting forms of vulnerability.

In addition to those interviewed in Athens, several other European-level activists framed their engagements around groups existing in continuous states of crisis. For these persons, primarily embedded in intersecting communities of sex workers, migrants and people who use drugs, HIV was just one among a variety of factors shaping ongoing vulnerabilities. Existing at the intersections of persecution, illegality and poverty, these group representatives told of activist strategies focused on the management of everyday survival within a landscape of everlasting precarity and insecurity – seen to enhance vulnerability to HIV. As such, there was consensus that HIV activists should not prioritize risk-reduction behaviors and bio-pharmaceutical medications; yet-to-be-achieved structural changes are also necessitated, we were told, to enable a shift from the chronic conditions of crisis that forever contribute to the spread and impact of illness. Rather than an end-of-AIDS future, hope here becomes a yearning for crisis as exception rather than ongoing context (Vigh, 2008).

As a key contributor to their conditions of crisis, sex workers in Europe are often framed as vectors of HIV transmission – part of a broader political response to the epidemic entailing the amplification of pre-existing structures of surveillance and repression. Niki Adams, spokesperson for the English Collective of Prostitutes, told us that the police upped the abuse of sex workers as part of a 'witch hunt' meant to curb the spread of the virus upon its emergence. 'The violence against sex workers on the street increased in particular, and also in premises [...] on the grounds of HIV and AIDS.' Ruth Morgan Thomas, coordinator of the Global Network of Sex Work Projects and co-founder of SCOT-PEP, a sex worker-led organization in Scotland, told us of SCOT-PEP's intentional de-centering of the behavioristic model of prevention exemplified through condom promotion, but also through mandated HIV testing: 'I think it took people a while [...] to get their head out of that space and [...] looking at sex workers as a whole human being.' Rather than a primarily biomedicalized subject, this whole-human-being approach to understanding the subjects of HIV prevention grasps them within the intersecting social, economic and political conditions that produce vulnerability: as per Morgan Thomas, 'the lack of access to health insurance, to pensions, to banking, to all of the things that everybody else takes for granted.'

For Morgan Thomas, interventions aimed at reducing HIV must also engage with the factors contributing to the constant state of crisis underlying vulnerability to poor health. For all sex worker activists we interviewed, the most pressing example has been the criminalization of sex work, a policy they have sought to overturn with only limited success. A condensed moment of hope for Morgan Thomas was the publication of the 2009 UNAIDS *Guidance Note on HIV and Sex Work* on which she worked successfully to include the decriminalization of sex work as recommended precondition for reducing sex workers' vulnerability to HIV. Minimizing the negative impact of HIV was thus entwined with working to undo repressive policies predating the epidemic. Pushing for decriminalization here became, in other words, a chrono-citizenship strategy that penetrated a crisis of the moment to intervene in the ongoing crisis of criminalization.

Despite these efforts, the criminalization of sex work in Europe is on the rise rather than decreasing (Jahnsen & Wagenaar, 2018). As part of the temporality of chronic crisis, we thus observe that the condensed sense of hope made possible through achievements in advocacy at the transnational level do not necessarily translate into structural shifts in the realities of sex workers' lives. Certain moments of hope, it might be said, feel more hopeful than others, and the ultimate ephemerality of hope in its most condensed form – its short-lived existence, typically ending in disappointment – can come to threaten the insistent endurance of hope at all as it defines activism under chronic crisis. In emphasizing the risk of losing hope entirely – or, as she calls it, 'the binding that fantasy has allowed' (p. 48) – Berlant (2011) well illustrates the dramatic threat to the present that comes with such ongoing failures of hopeful longing even beyond the seemingly inevitable continuation of the same. A guiding question for the activist subject produced out of the conditions of chronic crisis is thus not about sustaining funding, but about how to sustain hope in the face of ongoing exclusion and disappointment.

Given that chronic conditions of crisis – marked by poverty, violence and murder, also contributors to HIV vulnerability – constitute the everyday for many sex workers in Europe, Luca Stevenson, coordinator of the International Committee on the Rights of Sex Workers in Europe, expressed disappointment that HIV-specific bodies had not taken a firm stance against criminalization. 'It's not that they exclude sex workers, but they don't include us either,' he told us. Due to their far-reaching influence in the region, Stevenson joined EATG in 2018 to enhance the inclusion of sex workers' needs in the group's advocacy and programs, especially with respect to (de-)criminalization. Faced with the disappointments that accompany hope in this temporal regime, Stevenson thus adopted what Appadurai (2013) has termed 'a disciplined dialogue between the pressures of catastrophe and the disciplines of patience' (p. 127) – negotiating the ongoing urgency of crisis with an active process of waiting. Rather than a passive and static condition, waiting in this context becomes an agential form of engagement with potential political allies in an unfavorable political environment.

Governed by a fluctuating sense of hope in a present of enduring threat and disappointment, claim-making under this regime may also include what Butler (2020) calls 'persistence': insisting on one's presence in the face of ongoing exclusion. Morgan Thomas describes the activist subject emerging in the regime of chronic crisis 'an absolute survivor' – persons 'with amazing strategies for coping with the bullshit that society bangs on us.' She hence applauds their ability 'to step one foot in front of the other every day and to challenge society as we do.' This visual of stepping forward within political and social conditions of stasis, continuity or even regress offers a counter-temporality to the biomedical 'end of AIDS' narrative. Rather than invested in a future envisioned as inevitable success, Morgan Thomas emphasized the unfolding conditions of the present: 'we should start celebrating that fierceness that's within each and every one of us.' Policy sensitive to the temporal regime of chronic crisis would thus direct attention to the strategies for existing within these unfolding conditions of the present – defined by enduring precarity and disappointment, combined with remarkably persistent gestures of hope as survival. It would necessitate engagement with the multiple structures that produce crisis as chronic, futures as diminished and the present as ongoing struggle.

Back to the future: the end of AIDS?

This paper has offered new perspectives into thinking about the role of time in processes of subjectification, collectivization and claim-making. Shifting the lens from space to time in analyses of citizenship, it introduced the notion chrono-citizenship to describe citizenship constructs of and in relation to time. To this end, it explored enactments of citizenship – extracted from oral histories and fieldwork on European-level HIV/AIDS activism – through the temporal regimes of biomedicine, loss, sustainability and chronic crisis. Given the growing influence of health on the reconfiguration of citizenship globally, the HIV/AIDS epidemic offers a revelatory and timely field of study. Within this field, the literature on biological citizenship has focused primarily on the social and

political dimensions of biomedicalized phenomena. This theoretical framing risks unwittingly re-centering biomedically-inflected notions of the self, community and belonging. Our analysis of how time is mobilized in citizenship offers one route for relativizing this tendency and adding complexity to contemporary understandings of citizenship – an approach that might be put to use in other areas of research as well.

Applied to the field of HIV/AIDS, this attention to temporality exposes that biomedical under-standings of time have come to structure global HIV/AIDS narratives, policies and programs. Especially with regards to the proposed 'end of AIDS' future, it is essential that we consider some of the epidemic's alternate temporalities to imagine what it might truly mean to approach such a goal. In particular, the three analyzed temporal regimes have exposed how social, economic and political preconditions can stifle or open possibilities for change: through loss, an engagement with the past that continues often unacknowledged in the present; through sustainability, a finance-dependent mode of continuity in which a divided future is open over and again to extinction or extension; and through chronic crisis, in which ongoing vulnerability, precarity and disappointment are met with persistence, active waiting and enduring hope. Taken together, these analyses point to the importance of thinking in terms of multiple rather than singular understandings of time in the conceptualization of policy, and accounting for entanglements of (bio)medical, social, economic and political conditions rather than prioritizing one over the others.

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References

Agamben, G. (2005). *State of exception*. University of Chicago Press.
Alberti, M., & Cotovio, V. (2020, March 30). *Portugal gives migrants and asylum-seekers full citizenship rights during coronavirus outbreak*. CNN. https://edition.cnn.com/2020/03/30/europe/portugal-migrants-citizenship-rights-coronavirus-intl/index.html
Appadurai, A. (2013). *The future as a cultural fact. Essays on the global condition*. Verso.
Benton, A., Sangaramoorthy, T., & Kalofonos, I. (2017). Temporality and positive living in the age of HIV/AIDS -A multi-sited ethnography. *Current Anthropology*, *58*(4), 454–476. https://doi.org/10.1086/692825
Berlant, L. (2011). *Cruel optimism*. Duke University Press.
Biehl, J. (2007). *Will to live: AIDS therapies and the politics of survival*. Princeton University Press.
Brown, M. (1997). *RePlacing citizenship: AIDS activism & radical democracy*. The Guilford Press.
Brubaker, R. (1992). *Citizenship and nationhood in France and Germany*. Harvard University Press.
Bryant, R., & Knight, D. (2019). *The anthropology of the future*. Cambridge University Press.

Butler, J. (2020). *The force of non-violence: An ethico-political bind*. Verso.

Coalition, P. W. A. (1987). PWA Coalition Portfolio. *October*, 43, 3–16. https://doi.org/10.2307/3397570

Crimp, D. (1989). Mourning and Militancy. *October*, 51, 3–18. https://doi.org/10.2307/778889

Dannecker, M. (2002). Erosion der HIV-Prävention. [The Erosion of HIV Prevention]. *Zeitschrift für Sexualforschung*, 15(1), 58–64.

EHRA. (2018). *Budget advocacy: A guide for community activists*. EHRA. https://harmreductioneurasia.org/wp-content/uploads/2018/11/EACB_AdvocacyGuide_book_20181017_web.pdf

Eng, D. L., & Kazanjian, D. (2003). Introduction: Mourning remains. In D. L. Eng & D. Kazanjian (Eds.), *Loss. The politics of mourning* (1–28). University of California Press.

Epstein, S. (1996). *Impure science: AIDS, activism, and the politics of knowledge*. University of California Press.

Epstein, S. (2007). *Inclusion: The politics of difference in medical research*. University of Chicago Press.

Freeman, E. (2010). *Time bindes: Qeer temporalities, queer histories*. Duke University Press.

Grover, J. Z. (1987). AIDS: Keywords. October, 43, 17–30. https://doi.org/10.2307/3397563

Halberstam, J. (2005). *In a queer time and place: Transgender bodies, subcultural lives*. NYU Press.

Isin, E. (2009). Citizenship in flux: The figure of the activist citizen. *Subjectivity*, 29, 367–388. https://doi.org/10.1057/sub.2009.25

Jahnsen, S. O., & Wagenaar, H. (Eds.). (2018). *Assessing prostitution policies in Europe*. Routledge.

Kenworthy, N., Thomann, M., & Parker, R. (2018). From a global crisis to the 'end of AIDS': New epidemics of signification. *Global Public Health*, 13(8), 960–971. https://doi.org/10.1080/17441692.2017.1365373

Kloka, M. (2014). The HIV epidemic among injecting drug users in Greece during the economic crisis. *Drug Policy Dialogue in South Eastern Europe*, (4), 1–10. https://www.diogenis.info/cms/files/2015/11/Briefing_Paper_No_4_HIV_2014_doc.pdf

Love, H. (2007). *Feeling backward loss and the politics of queer history*. Harvard University Press.

Matic, S. (2006). Twenty-Five Years of HIV/AIDS in Europe. In S. Matic, J. V. Lazarus, & M. C. Donoghoe (Eds.), *HIV/AIDS in Europe. Moving from death sentence to chronic disease management* (pp. 1–14). WHO-Europe.

Matic, S., Lazarus, J. V., & Donoghoe, M. C. (2006). *HIV/AIDS in Europe. Moving from death sentence to chronic disease management*. WHO-Europe.

Morfit, N. S. (2011). 'AIDS is Money': How donor preferences reconfigure local realities. *World Development*, 39(1), 64–76. https://doi.org/10.1016/j.worlddev.2010.09.003

Munn, N. D. (1992). The cultural anthropology of time: A critical essay. *Annual Review of Anthropology*, 21, 93–123. 1 https://doi.org/10.1146/annurev.an.21.100192.000521

Nguyen, V.-K. (2005). Antiretroviral globalism, biopolitics, and the therapeutic citizenship. In A. Ong & S. Collier (Eds.), *Global assemblages: Technology, politics, and ethics as anthropological problems* (pp. 124–144). Blackwell Publishing.

Nguyen, V.-K. (2010). *The republic of therapy: Triage and sovereignty in West Africa's time of AIDS*. Duke University Press.

Ong, A., Dominguez, V. R., Friedman, J., Schiller, N. G., Stolcke, V., & Ying, H. (1996). Cultural citizenship as subject-making. *Current Anthropology*, 37(5), 737–762. https://doi.org/10.1086/204560

Paparini, S., & Rhodes, T. (2016). The biopolitics of engagement and the HIV cascade of care: A synthesis of the literature on patient citizenship and antiretroviral therapy. *Critical Public Health*, 26(5), 501–517.

Petryna, A. (2002). *Life exposed: Biological citizens after chernobyl*. Princeton University Press.

Poell, T. (2020). Social media, temporality, and the legitimacy of protest. *Social Movement Studies*, 19(5-6), 609–624. https://doi.org/10.1080/14742837.2019.1605287.

Ringel, F. (2016). Beyond temporality: Notes on the anthropology of time from a shrinking fieldsite. *Anthropological Theory*, 16(4), 390–412. https://doi.org/10.1177/1463499616659971

Rose, N., & Novas, C. (2005). Biological citizenship. In A. Ong & S. Collier (Eds.), *Global assemblages: Technology, politics, and ethics as anthropological problems* (pp. 439–463). Blackwell Publishing.

Rose, N. (2007). *The politics of life itself: Biomedicine, power and subjectivity in the twenty-first century*. Princeton University Press.

Rosengarten, R. (2017). Pluralities of action, a lure for speculative thought. In A. Wilkie, M. Savransky, & M. Rosengarten (Eds.), *Speculative research. The lure of possible futures* (pp. 71–83). Routledge.

Sangaramoorthy, T. (2018). Chronicity, Crisis, and the 'End of AIDS. *Global Public Health*, 13(8). 982–996. https://doi.org/10.1080/17441692.2018.1423701

Smith-Morris, C. (2010). The chronicity of life, the acuteness of diagnosis. In L. Manderson & C. Smith-Morris (Eds.), *Chronic conditions, fluid states* (pp. 21–37). Rutgers University Press.

Squire, C. (2013). *Living with HIV and ARVs: Three-letter Lives*. Palgrave Macmillan.

UNAIDS. (2009). *Guidance Note on HIV and sex work*. UNAIDS. https://www.unaids.org/sites/default/files/sub_landing/files/JC2306_UNAIDS-guidance-note-HIV-sex-work_en.pdf

Vigh, H. (2008). Crisis and chronicity: Anthropological perspectives on continuous conflict and decline. *Ethnos: Journal of Anthropology*, 73(1), 5–24. https://doi.org/10.1080/00141840801927509

Watney, S. (2000). *Imagine hope. AIDS and gay identity*. Routledge.

Weston, K. (1997). *Families we choose: Lesbians, gays, kinship*. Columbia University Press.

Young, I., Davis, M., Flowers, P., & McDaid, L. M.(2019). Navigating HIV citizenship: Identities, risks and biological citizenship in the treatment as prevention era. *Health, Risk & Society*, 21(1–2), 1–16. https://doi.org/10.1080/13698575.2019.1572869