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COMMENT



Stigmatisation and resistance processes: Reflections on the field of HIV research and an agenda for contemporary stigma studies

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ABSTRACT

Stigmatisation processes constitute key barriers to effectively addressing the HIV pandemic. In this article, we provide a critical overview of this field's current state of the art, highlighting some key emerging issues that merit greater research attention in the future to ensure that contemporary research on stigmatisation and resistance processes continues to engage with changing social and political circumstances. We look at how resistance to stigma has developed in the context of HIV and highlight some of the most important programmatic strategies that have emerged over the history of the pandemic. We present the key concepts of 'moral panics' and 'necropolitics', and we articulate them in relation to new global phenomena that deepen the processes of stigmatisation. Moreover, we identify an agenda for investigation which merits greater attention in future research, intervention, and advocacy: 1) changing political environments, neoliberalism, growing political polarisation, and the rise of political extremism; 2) the rise of the information age, technological change, and social media; and 3) rebuilding civil society and governmental responses to stigma.

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Introduction

Although we now recognise that stigma processes related to health conditions are as old as human history, it was only in 1963 that Erving Goffman's classic book, *Stigma: Notes on the Management of Spoiled Identity* (Goffman, 1963) established stigma as a key category for social analysis. While Goffman did not explicitly refer to stigmatisation as a social process, we will use the phrase 'social processes of stigmatisation' in this article to refer to how any specific attribute, whether of an individual or group, is stigmatised in society (Maluwa et al., 2002; Parker & Aggleton, 2003).

Stigma is not just the presence or absence of an attribute in itself but is also its identification through social relations in specific geographic spaces. Stigmatisation processes operate in the individuals' daily lives and are experienced in the concrete and practical exercise of relationships between socially marked people and other people in territorial places with a peculiar history and geography. In this sense, the lens of the other (or others) and the spaces they inhabit are fundamental to the stigmatisation processes. Therefore, no physical or moral attribute is ontologically laudatory or even insulting, as this classification would always depend on the labelling of another

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individual or group in a specific context of power and domination. These processes are procedures for producing and maintaining power in social relations, as they separate people and groups socially labelled as 'dangerous' or 'disposable' from those called 'normal' with the aim of domination, whether physical, economic, or symbolic.

Our perception is that the production of studies related to stigma and health can be located in three general moments. Although we recognise that Goffman launched the concept of stigma on a sociological basis, the first phase of studies in the field of health was influenced by social psychology, emphasising individual and behavioural aspects. In a second moment, we can observe a growing focus on social aspects, influenced by structuralist sociology to think about stigma as a social process based on and produced by social structures that also produce social inequalities.

In this approach, stigma could be understood as social processes mediated by notions of power and domination that social actors implement in the daily life of social spaces to legitimise the status of domination of those in a position of hegemony, and as a social process linked to competition for power, the legitimisation of hierarchy, and the production and reproduction of structural inequalities mobilised by social, cultural, political, and economic forces that create and reinforce processes of social exclusion in different contexts (Parker & Aggleton, 2003). Monteiro et al. classified these two first moments as research approaches: 'individual' and 'social', respectively (Monteiro & Villela, 2013b, p. 72).

In a third moment, much work on stigma processes has emphasised aspects of the intersectionality of social markers of difference. In that regard, stigmatisation processes must also consider that people or groups are stigmatised based on different markers of social difference, such as gender identity, sexual orientation, race, skin colour, ethnicity, social class, and gender (and others). Stigmatisation processes also interact with other indicators of social difference (e.g. race, gender, and social class), making it necessary to understand the process of stigmatisation not only from the perspective of a specific social attribute, but also from an intersectional perspective (Couto et al., 2024; França et al., 2024; Jackson-Best & Edwards, 2018; Logie et al., 2022; Monteiro et al., 2013; Turan et al., 2019; Villa-Rueda et al., 2022).

In the context of these studies, there is probably no single global health issue that has generated as much concern about stigma and discrimination as is the case with the HIV and AIDS pandemic over more than four decades now. Furthermore, it had become clear to almost all the key actors involved in responding to HIV and AIDS, both locally and globally, that stigma (and discrimination resulting from stigma) should be seen as one of the key barriers to effectively addressing the pandemic. For example, stigmatisation processes affect individuals and their intersubjective relationships, limiting the adoption of preventive practices as well as impacting programmatic dimensions, thus hindering access to prevention, treatment, and care (Babel et al., 2021; Chimoyi et al., 2021; Mgbako et al., 2022), affecting several dimensions of the lives of people living with HIV, such as socialisation, workspaces, and the establishment of affective-sexual bonds (Chimoyi et al., 2021; Cruz et al., 2021).

In some places, the discriminatory approach towards people living with HIV is evident even in the physical structures of health services, with two separate windows for drug delivery, one for people living with HIV and another for other customers (Nyblade et al., 2019). Stigmatisation processes have also affected prevention, such as pre-exposure prophylaxis (PrEP) access (Magno et al., 2019b; Silva-Brandao & Ianni, 2022) and HIV testing (Cota & Cruz, 2021; Freitas et al., 2023; Krueger et al., 2016; Pinheiro-Junior et al., 2016).

Although increasing stigmatisation has been extensively documented over the past decade, it is also important to note that there is room for resistance. Foucault highlights the fact that power relations are productive, and whenever there is a power relationship, there is the possibility of resistance (Foucault, 2013). Taking this thesis into account, we could say that the experience of stigmatisation, which is permeated by intense power relations between individuals, families, strangers, institutions, etc., always produces resistance, which co-exists with power (Magno et al., 2018a). In this sense, it is clear that resistance movements to stigmatisation processes are generated through

the individual and collective struggles of people living with HIV and LGBTQIA + people, which occur in scenarios of both everyday micropolitics and macropolitics (Kadri & Schweickardt, 2015), through the establishment of non-governmental organisations (NGOs) and other civil society organisations (CSOs), and in advocacy for sex education and HIV prevention methods and services (Almeida et al., 2021).

Furthermore, while the continued importance of the fight against stigma has been highlighted in the programmes of international organisations confronting the pandemic (UNAIDS, 2023), this goal has increasingly been separated from the key biomedical indicators. Stigma has been given a secondary status as creating an ‘environment limiting access or utilization of HIV services’ (UNAIDS, 2021, p. 10). Although these agencies have launched campaigns and set goals to combat stigma and discrimination over the past two decades, these measures have yet to be accompanied by creating accurate indicators to assess countries’ progress. In the absence of a broader understanding of how stigma and discrimination operate to create vulnerability, and without clear indicators of success beyond access to health services, agencies such as UNAIDS have been able to do little more than make vague claims of generalised success but without providing any real evidence of what ‘success’ might truly mean in practice (UNAIDS, 2022).

In this article, we build on the important record of work carried out over the past two decades (the 2000s and the 2010s), including our own previous work in this area (Parker, 2012, 2024; Parker & Aggleton, 2003), in order to highlight some key emerging issues that merit greater research attention in the future to ensure that contemporary research on stigma processes continues to engage with changing social and political circumstances. Our goal is not to offer an exhaustive or systematic review of the field of HIV and AIDS-related stigma and discrimination research, but rather to provide a kind of ‘history of the present’ (Bevir, 2008; Garland, 2014) – a critical overview of the current state of the art of the field as it exists today, highlighting both some of the most important accomplishments to date as well as some of the key challenges that must be addressed in the future. In highlighting key findings as well as continuing challenges, we will draw heavily on work carried out in Brazil (Magno et al., 2018a, 2018b; Parker et al., 2016), as well as in other parts of Latin America, but we will also include research and findings from other regions, precisely because issues related to stigma and discrimination have been so widespread and continue to constitute one of the key priorities that must be confronted in order to address the global epidemic.

The future is today: An agenda for contemporary stigma studies

The HIV pandemic has persisted among us for more than 40 years, and the release of Goffman’s seminal book on stigma was 60 years ago (Goffman, 1963). The world has changed in profound ways over this period, but despite the significant volume of research carried out on stigma during this time, the impact of many of these changes on stigma has received less attention than it deserves. It underlines the importance of broadening research, intervention, advocacy approaches, and of drawing on interdisciplinary social science methods in order to more effectively engage with structural and environmental factors in situations of rapid social change. Approaches such as comparative case study methods (Collier, 1993), comparative historical analysis (Lange, 2012; Mahoney & Rueschemeyer, 2003), the extended-case method (Burawoy, 2009, 2016), and situational analysis (Van-Velsen, 1979) all offer important possibilities for investigating the kinds of changing contextual factors that have been identified as crucial in stigma processes.

In keeping with this emphasis on engaging with the broader structural and environmental factors that shape stigma and discrimination, we would particularly like to emphasise the potential usefulness of a number of key concepts that might be helpful to us. The first concept that we think is worth emphasising is the idea of ‘moral panics’, introduced almost exactly a decade after the original Goffman’s book on stigma, in a highly influential book by South African-British-Israeli sociologist, Cohen (1972), and later adapted for analysis of HIV and AIDS and related issues in the mid-1980s (even before stigma had been widely used to examine AIDS-related issues) by Weeks

(1985) and Watney (1987). Cohen had used the concept of moral panics to describe when ‘a condition, episode, person or group of persons emerges to become defined as a threat to societal values and interests’ (Cohen, 1972, p. 1), and authors such as Weeks and Watney used it during the 1980s to analyse extreme conservative stigmatisation of both practices and communities that were seen as wilfully causing HIV transmission through their non-normative sexual and drug-using behaviours. But it largely disappeared from social research on stigma during the 1990s and the 2000s.

However, with the rise of extreme right-wing politics during the 2010s and into the 2020s, we have seen an explosion of organised campaigns targeting abortion, anti-gender campaigns, attacks on services for transgender, book-banning of LGBTQI+ publications, and similar morally-based attacks. Because of the organised and systematic nature of these attacks, we argue that stigma is being weaponized and deployed in dangerous new ways. A focus on moral panics should be revived and brought back to the centre of analysis in stigma research on HIV (Monteiro & Villela, 2019). We argue that it can help us to better understand the intentional use of stigma and discrimination in the present political climate, and the chilling effect that such campaigns are having concerning HIV-related programmes and policies.

In addition to reviving a focus on moral panics and the weaponization of stigma and discrimination in the troubled political times that we live in today, a second conceptual innovation that we want to call attention to is the potential utility of Achille Mbembe’s notion of ‘necropolitics’ (Mbembe, 2003; Mbembe, 2019). Focusing on the use of social and political power to determine why and how some people must die while others can live, Mbembe argues that ‘under the conditions of necropower, the lines between resistance and suicide, sacrifice and redemption, martyrdom and freedom are blurred’ (Mbembe, 2003, p. 40). In a sense, Mbembe’s notion of necropower intertwines with Foucault’s conceptualisation of biopower, making it possible to more fully capture not only how power regulates life, but how it also creates ‘*death-worlds*’: ‘forms of social existence in which vast populations are subjected to living conditions that confer upon them the status of the *living dead*’ (Mbembe, 2019, p. 92).

This focus on necropower has proven to be an effective conceptual tool for thinking about issues related to the impact of racism, gender power, sexual oppression and related forms of social exclusion and marginalisation (Haritaworn et al., 2014; Perera & Pugliese, 2021). We think that it can be linked in productive ways to theories of intersectionality, which has been a major focus of research and analysis on stigmatisation processes over more than a decade now (Bowleg, 2012; Logie et al., 2022; Turan et al., 2019). It can be especially useful in helping to shift our emphasis from the social determinants of health to the political determinants of health, which can in turn open up new possibilities for intervention (Dawes, 2020; Gore & Parker, 2019). It can also help us to better understand how stigma and discrimination can infiltrate and invade ‘the responses of governments, of the intergovernmental system, and the globalised neoliberal capitalist system more broadly’, transforming the social and political determinants of health into the social and political determinants of *death*, and appropriating racism, gender oppression, sexual stigma and discrimination and class oppression as the ‘drivers’ of official policies and programmes in ways that can only be addressed through political resistance and activism (Lee et al., 2022, p. 789; Parker & Aggleton, 2024, pp. 129–130).

Moral panics and necropolitics provide conceptual frameworks that focus attention on how social and political power is used, often intentionally, for purposes of control. They determine how some people must live and some must die. Drawing on such frameworks might help us to identify a broader range of issues and topics for investigation as well as amplify the methodological approaches that we draw on, especially by giving greater attention to interpretive approaches to power and politics (Bevir & Blakely, 2018).

Drawing on such diverse conceptual frameworks and social research methodologies could potentially help to revitalise the field of stigma studies, especially in relation to HIV and AIDS, and would make it possible to more effectively investigate some of the changing structural and environmental factors that we think may currently be impacting stigma processes in relation to the pandemic. With these conceptual and methodological considerations in mind, in the remainder

of this Commentary, we would like to call attention to at least three key clusters of issues and factors that we think may have especially serious consequences for HIV-related stigma and discrimination, and that therefore merit increased research attention: (1) changing political environments, neoliberalism, growing political polarisation, and the rise of political extremism; (2) the rise of the information age, technological change, and social media; and (3) rebuilding civil society and governmental responses to stigma. While space limitations make it impossible to discuss these clusters in detail, we nonetheless want to briefly outline why we think these areas merit serious attention (and how today they contrast with earlier phases in response to the global epidemic).

Thus, the concepts of ‘moral panic’ and ‘necropolitics’ can help to understand better how stigmatisation processes are (re)produced in contemporary social interactions, which are marked by an expansion in the use of social networks, increasing technological transformation, and strengthening of far-right movements with the aim not only of controlling populations but of exterminating them subjectively or concretely. They can also help us to better understand processes of collective resistance to stigmatisation and discrimination and the key role that civil society organisations, as well as progressive governmental policies, can have in rebuilding the fight against stigmatisation processes that have lost some of their energy recently in the face of extreme conservative campaigns and movements in many countries.

Changing political environments, neoliberalism, growing political polarisation, and the rise of political extremism

The HIV pandemic has always been one of the most highly politicised global health issues (Piot et al., 2007). However, the political environment shaping responses to the pandemic has changed in different ways over time. Beginning in the 1980s, the generally conservative environment in many countries led to serious delays in responding to HIV and AIDS precisely because of stigmatising views related to affected communities and populations (The Panos Institute, 1990). Over time, especially beginning in the 1990s, however, more progressive political climates opened up social and cultural spaces for addressing the pandemic, creating a global social movement in response to HIV and AIDS, and ultimately for a massive scale-up of the AIDS response in the 2000s.

But since the early 2010s, the political landscape that made possible more effective responses to HIV and the stigma that it generated has increasingly given way to growing political polarisation, the rupture of liberal democracies, and the rise of extreme right-wing movements (Carothers & O’Donohue, 2019; Castells, 2018; Parker, 2024). In countries as diverse as Brazil, India, Russia, and the USA, extreme right-wing populist authoritarian politicians have made many of the populations most affected by HIV and AIDS, and in some cases, the AIDS response itself, objects of scorn, stigma, social exclusion and marginalisation (Cueto & Lopes, 2022; Daniels, 2019; Gener, 2023; Sharma, 2015; Yasaveev, 2020).

Additionally, attention should also be given to the more amorphous but nonetheless growing impact of campaigns organised by right-wing forces and movements that may often be independent of the State (though frequently working in collaboration with government agencies when populist politicians or right-wing political parties control the machinery of the State). Specific right-wing campaigns such as the anti-gender movements, for example, have targeted key sexual and reproductive health and rights issues (such as feminism and abortion rights, transgender rights, and LGBTQI+ issues more broadly) both through national and transnational campaigns in ways that can clearly impact HIV-related stigma and discrimination (Fassin, 2020; Kuhar & Paternotte, 2017; Murray, 2022). Taken together, these various trends related to populist authoritarian political movements, political polarisation, and right-wing extremism on the rise around the world clearly have the potential to make a serious (and largely negative) impact on stigma processes that merits urgent research attention.

In this context, we also draw attention to the deepening of neoliberal dynamics that create new rationalities (e.g. the conception of a *homo economicus* as a kind of self-entrepreneur, providing his

own capital and means of production and, therefore, source of income) and structure the conduct of subjects not only from an economic and material point of view but also from a social, subjective, and affective perspective (Foucault, 2010). This phenomenon has been more intense since the global economic crisis of 2008 and, even more recently, the advent of the COVID-19 pandemic, which promoted intense changes in global political-legal and socio-economic dynamics. New labour relations (e.g. ‘uberization’ which is a worldwide phenomenon of deregulation and precariousness of work through digital platforms [Davis & Sinha, 2021; Kaye-Essien, 2020]) and the destruction or weakening of democratic institutions, human rights, and collective organisations have all fed into an intensification of stigmatisation in many countries.

In addition, these neoliberal dynamics produced new ways of living in the world, new types of social relations and subjectivities based on generalised competition, the fragility of increasingly ‘virtualized’ social relations, and the conception of the individual as ‘an enterprise’ (Dardot & Laval, 2017, p. 3). As neoliberalism becomes hegemonic, there is increasing stigmatisation of groups that do not fit the criteria of a neoliberal society – i.e. the unemployed, immigrants, the poor, etc., who are perceived as people who ‘use a disproportionate share of welfare resources’ (Lamont, 2018, p. 424). With the emergence of digital platforms and apps to search for sexual partnerships (Chow et al., 2016; Simões, 2018) and the engagement of the State in the organisation of prevention responses, we have observed an increasing emphasis on individual biomedical measures at the same time that we have seen a weakening of the collective responses of the groups most affected by the pandemic (Aggleton & Parker, 2015). These phenomena have all become more ominous with the global rise not just of far-right movements but, even more menacingly, of far-right governments.

Research on HIV has, in general, been slow to respond to how changing political contexts impact the pandemic, and work focusing on stigma and discrimination is no exception. Gradually, however, studies have begun to investigate the experience of stigma and discrimination within extreme right-wing political environments – and occasionally to make connections between specific politicians, political environments, and policy arenas and the ways in which they may impact the experience of stigma and discrimination. In Brazil, for example, despite the historical record of social mobilisation and institutional success in responding to the Brazilian epidemic, a study conducted among people living with HIV from seven capitals in 2019, during the first year of the Bolsonaro government, showed that 41.0% of the interviewees were aware of discriminatory comments about their serological status in the family, 19.6% had lost a source of income or job, and 17% had been excluded from social activities owing to their HIV positive status (UNAIDS, 2019). It was an extreme right-wing government that encouraged stigma and discrimination, led by a populist authoritarian politician who became famous for his discriminatory rhetoric and what we might describe as (mis)government that openly stigmatised people living with HIV as well as LGBTQIA+ people (Cueto & Lopes, 2022; Malta, 2018; Paiva et al., 2021).

Similar processes have also occurred in other regions of the planet. The USA, for example, was also the scene of the advance of the extreme right with the advent of Trumpism in the USA in 2016, reinforcing and legitimising several ideas that were racist, sexist, Islamophobic, xenophobic, and stigmatising against various minorities (Silva, 2019). This has also been the case in Turkey, which experienced unprecedented levels of human rights violations and discrimination of specific groups after a coup attempt in the country in 2016 (Avinçan et al., 2023), and in Uganda, where the parliament (with strong popular support) broadened the scope of the legal criminalisation and punishments against homosexuals in 2023 (Dasandi & Erez, 2023). These examples show how the State apparatus can actively produce and institutionalise stigmatisation processes in democratic or dictatorial societies.

But if what must be understood as ‘State-sponsored stigma and discrimination’ has clearly been on the rise over the course of the past decade in many diverse countries around the world, both researchers and activists have also been able to respond in important ways. Brazil offers an important example of the ways in which social research can respond to challenges posed by conservative, populist, and authoritarian politics. Following the election of Bolsonaro in late-2018, the impact of

the Bolsonaro government's policies (and Bolsonaro's stigmatising public statements [see Borba, 2021]) over the course of his government from 2019 to the end of 2022 was well documented in social research as well as in the mainstream news media. It was also because of the ways in which Bolsonaro, and the broader political movement that he both represented and led, channelled, and deployed stigma and discrimination for political purposes and gains, that Brazilian researchers increasingly sought to explore new ways of theorising stigma in order to capture these political dimensions. While they have continued to draw on important theoretical frameworks such as intersectionality, they have also revived interest in the kinds of more explicitly political frameworks such as moral panic as a kind of political mechanism used to produce and reproduce inequalities and structural violence (Monteiro & Villela, 2019), and on necropolitics as a way of conceptualising the role of authoritarian neoliberalism in shaping the re-emergence of AIDS-related stigma as a kind of 'necropolitical instrument' (Cazeiro et al., 2021, p. 5363; see, also, Ferreira & Cordeiro, 2022; and da Silva, 2022).

This shift of focus to the political contexts that shape both stigma and resistance processes was also especially visible in the ways in which academic researchers, AIDS activists, and investigative journalists in Brazil responded to the collective nightmare of the Bolsonaro government, providing key examples of ways in which it is possible to push back and create sites of resistance. A number of examples are worth highlighting precisely because they may provide inspiration for similar work developed in other locations confronting comparable political challenges. Among other things, researchers, activists, and journalists documented the various ways in which the extreme right-wing government chipped away at Brazil's once pioneering AIDS programme, downgrading its institutional status by merging it with other chronic conditions within the administrative structure of the Ministry of Health, straightjacketing and censoring its once high-profile and prevention and sexuality education campaigns, and discontinuing on-going outreach to sexual minority youth through social media platforms (Agostini et al., 2019; Parker, 2019b; Pinheiro et al., 2022).

It is important to highlight that this growing emphasis on political contexts does not represent a major paradigm shift from the primary emphasis of stigma theory that has been consolidated in recent decades. It continues to focus on power and inequality as the key factors that underlie the deployment of stigma, prejudice, and discrimination (Link & Phelan, 2001; Maluwa et al., 2002; Parker & Aggleton, 2003). It also extends recent understandings of intersectionality as a crucial part of the dynamics of stigma processes (Bowleg, 2012; Logie et al., 2022). But it does represent a subtle shift of emphasis from a broad focus on the social determinants of health to a narrower examination of the political determinants of health. It thus identifies politics and political processes as meaningful sites for intervention. It is precisely because of this that we view this shift as an important area that merits increased attention in the future.

The rise of the information age, technological change, and social media

A second key area of change in recent decades that potentially has an important impact on stigma processes and that has evolved especially rapidly during recent decades is what has been described as the development of 'the information age' (Castells, 2010), with a shift that has intensified over the past four decades from an industrial mode of development to an informational mode of development. Structured through networks making possible a constant flow of information, the informational society depends on constant technological change that mediates the relations between social actors, with technological innovations creating new forms of social polarisation and social exclusion. These new forms of exclusion and polarisation have been analysed as the 'black holes of informational capitalism' affecting whole continents (such as sub-Saharan Africa) as well as impoverished communities in the societies of the global North (Castells, 2010), and these are precisely the zones that are most affected by the HIV globally. The digital communications technologies that have shaped this information age were not even imagined, or were

only present in works of fiction, at the time when HIV and AIDS first emerged. In this sense, it is necessary to understand better the role of these new forms of communication, such as the internet, computers, smartphones, and social media and other digital platforms that have made possible both the rapid spread of ideas and a range of actions that reinforce stigma and discrimination.

The impact of new forms of communication, and especially of social media, in contributing to the intensification of political polarisation in ways that both feed into and are also produced by authoritarian populist politics has now been clearly documented (Kubin & von Sikorski, 2021; Tucker et al., 2018). Social research has also begun to be carried out, focusing on the interconnections between extreme right-wing politics, social media platforms, and stigma in relation to demonised cultural categories and social groups (Silva, 2019; Zhuravskaya et al., 2020). These processes have fed into moral panics and the deployment of stigma and discrimination into a range of health conditions and crises, with a veritable boom in relation to COVID-19 (Bhanot et al., 2020; Islam et al., 2020). Again, research carried out in Brazil in the wake of Bolsonaro's election has been both extensive and rich in this regard (Belin & Rizzotto, 2021; Machado & Miskolci, 2019; Recuero et al., 2021), especially in relation to stigma processes related to the COVID-19 crisis, but also in relation to HIV and AIDS and non-normative genders and sexualities (Cueto & Lopes, 2022; Ferreira & Cordeiro, 2022; Parker, 2019b). But there is still much to be done to investigate and understand the pathways that are travelled between the extremist politicians, state-sponsored discrimination, technological dissemination, and the experience of stigma at the grassroots on the part of affected communities and populations.

On the other hand, it is also important to understand how these media can be used to cope with and resist stigma. There is already a large and rapidly growing literature related to social media, stigma and mental illness, but comparatively little has been done to explore social media in relation to HIV-related stigma (Garett et al., 2016; Hutchinson, 2022). In some places, an increasing number of people living with HIV join the world wide web through social media to reveal their serological status, publicise their medication routines, and combat stigma (Agência Aids, 2023; Brandelli Costa et al., 2022; Friedland et al., 2020). They often do this in ways that take into account aspects of the intersectionality of HIV and AIDS-related stigma with other markers of social difference (e.g. race, gender, sexual orientation, gender identity, etc.) (Scheim & Bauer, 2019). The role of information technology, information flows, and digital platforms in the production and reproduction of HIV-related stigma processes, and as sites for possible intervention in order to combat stigma and discrimination in relation to the pandemic – and the relationship between informational technologies and the political processes described above – thus constitutes another important area for both research and intervention in the future.

Recent studies carried out in Brazil offer examples of the intersection of information technology, social media, and activist responses to HIV and AIDS that we think merit further attention. Melo and colleagues (Melo et al., 2020, p. 1), for example, developed what they described as a 'virtual ethnography' of a closed Facebook group made up of people living with HIV. Through the analysis of the 'posts' made by the members of the group, they were able to examine the ways in which this virtual community served as a kind of contemporary version of earlier 'in-person' support groups, and documented the ways in which stigma continued to exist for participants (concretely expressed in fear of rejection and social abandonment, situations where prejudice and discrimination were recounted, and so on) rather than being reduced because of access to treatment as had been hoped in many discourses on the possible shift of HIV to chronic-but-manageable status (Damascano et al., 2019; Melo et al., 2020).

In research carried out by Duque and Seffner (Duque & Seffner, 2022), a similar approach to 'online ethnography' was developed to investigate three HIV and AIDS-focused YouTube channels created by young Brazilian men who are both openly HIV positive and gay. They found that the channels serve as 'pedagogical devices' that allow channel users to situate their own experience of HIV within the broader history of the struggle against the pandemic and to work through

their experience of stigma in a way that makes living with HIV a kind of ‘second closet’ – one that involves constructing knowledge about being HIV seropositive, just as their ‘first closet’ involved constructing understandings about sexuality and being gay (Duque & Seffner, 2022, p. 95). Both studies demonstrate the possibilities for methodological innovation as well as the importance of understanding how the experience of stigma is articulated in relation to the history of responses to HIV and AIDS.

Finally, in one of the most innovative studies that we have seen, Oliveira and Simões have combined in-person and virtual ethnographic approaches with a kind of ‘partial autoethnography’ or ‘I-witnessing’ (Geertz, 1988; Parker, 2019a) in order to examine the experience of the Loka de Effavir-enz Collective, a group of multiracial (but predominantly black) young people, both cisgender and transgender, living with HIV that emerged in the 2010s in Brazil (Oliveira & Simões, 2023). They ‘show how the members of Loka articulate themselves as subjects crossed by the HIV/AIDS stigma, claiming the exercise of their sexualities and identities marked by gender, race, and class’ (Oliveira & Simões, 2023, p. 117). These young people also use social networks such as Facebook as a virtual point of departure for then moving into physical spaces of social mobilisation, producing ‘new forms of HIV/AIDS activism’ (Oliveira & Simões, 2023, p. 124). They question the biomedicalization of the policy response to the pandemic as well as unrealistic promises of ‘the end of AIDS’ while simultaneously building a new ‘network of care based on the construction of safe relationships’ (Oliveira & Simões, 2023, p. 125). This study is especially worth highlighting because of its explicit and courageous articulation of the lead investigator’s own experience of stigma: while much research and analysis of HIV and AIDS stigma and discrimination has been carried out by investigators who have themselves experienced its impact, rarely has this been discussed so openly and thoughtfully as in this research.

Rebuilding civil society and governmental responses to stigma

Finally, greater attention to rapidly changing legal and policy environments constitutes a third important focus for both research and intervention in relation to HIV and AIDS-related stigma processes. Even though there is widespread agreement both among researchers as well as among civil society actors and activists, that stigma and discrimination are among the greatest barriers to effective responses to the global epidemic, for more than a decade now stigma and discrimination, like other social factors associated with HIV and AIDS, seem to have largely fallen off the list of indicators of success defined by global AIDS policymakers such as UNAIDS. A focus on ‘Zero Discrimination’, which was a central goal of the 2011–2015 strategic plan (UNAIDS, 2011), has given way to other exclusively biomedical markers of success, more or less coinciding with unfounded promises of the end of AIDS (Kenworthy et al., 2018; Parker, 2024). While lip-service is occasionally paid to the need to address stigma and discrimination, concrete programmatic initiatives aimed at reducing stigma and/or discrimination have largely disappeared, and there is little evidence that monitoring the incidence of stigma is a priority.

But in spite of these recent challenges, there are still important windows of opportunity for refocusing attention on stigmatisation and resistance processes within the law and policy arena, as well as an urgent need to seek to resurrect and reconstruct a focus on stigma and discrimination both on the part of governmental HIV and AIDS programmes as well as on the part of civil society organisations (CSOs). Research and analysis in relation to stigma and discrimination, if linked in meaningful ways to advocacy, can potentially feed into this in important ways if we consciously focus on this goal. Comparative analysis of legal and policy environments might offer an opportunity for re-examining progress (or lack of it) in relation to stigma and discrimination internationally (Kavanagh et al., 2020; Torres et al., 2017). Resources exist, such as The People Living with HIV Stigma Index, originally developed in 2008 by the Global Network of People Living with HIV (GNP+) in partnership with the International Community of Women Living with HIV (ICW), the International Planned Parenthood Federation (IPPF) and UNAIDS (GNP+, 2008), and regularly

updated since that time, has used in over 100 countries and provides an exceptional source of baseline data (Ferguson et al., 2022; Friedland et al., 2020).

Furthermore, it is also essential to analyse laws and regulations in countries that protect or criminalise people living with HIV, and to document the ways in which advances in science and technology related to HIV can result in new forms of stigmatisation (Chen, 2016; Csete et al., 2023; Hoppe et al., 2022). And precisely because the rise of extreme right-wing social and political movements described above has frequently led to both increasing levels of stigma and discrimination as well as the dismantling of existing governmental HIV and AIDS programmes, there is also an urgent need to explore ways in which academic researchers together with civil society activists and organisations might work together to revive the kinds of monitoring and documentation efforts related to incidents of stigmatisation and discrimination that were especially important very early in the pandemic in order to call public (and media) attention to stigma processes related to HIV and AIDS (Sabatier, 1988; The Panos Institute, 1990). But just as was the case early on in the mobilisation of the HIV response, progress in this regard will clearly require both advocacy and intersectoral dialogue aimed at bringing stigma back as a priority not only for governmental programmes but also for NGOs and CSOs.

In addition to documenting the incidence of stigma and discrimination, it is especially important to monitor qualitative stigma through studies that listen to people's experiences of stigmatisation, and that foster solidarity by making that experience understandable to others (Arias-Colmenero et al., 2020; Souza et al., 2021). Many of the Brazilian studies mentioned above in relation to examining the impact of technological innovations and social media provide important examples of the ways in which in-depth qualitative research can be used to both document nuances in the experience of stigma and discrimination as well as the way in which people living with HIV and affected communities experience and resist stigma, prejudice, and discrimination. And both NGOs and academic organisations have played important roles in seeking to translate research findings and to ensure that they reach not only academic audiences but wider publics.

Two recent examples of effects to translate research findings and make them available to wider audiences include the publication two books of stories based on oral-history interviews exploring stigma and discrimination. The first is a book titled *E se fosse com você: Histórias vividas de estigma e discriminação em 40 anos de HIV/AIDS* [And if it happened with you?: Stories of living with stigma and discrimination in 40 years of HIV/AIDS], produced by the *Associação Brasileira Interdisciplinar de AIDS* (ABIA) (<https://abi aids.org.br/e-se-fosse-com-voce/35266>) for dissemination among the population generally and for use in training and capacity building primarily with HGOs, CBOs and public health professionals (Souza et al., 2023; Souza & Pereira, 2021). The second is a book titled *Zero discriminação: Contos sobre histórias de vidas e as epidemias de hiv* [Zero discrimination: Short stories about the life histories and HIV epidemics], produced as part of a Massive Open On-line Course on 'Zero Discrimination – hiv and aids', developed in partnership by the Universidade Federal do Rio Grande do Sul (UFRGS) and the Instituto Federal do Rio Grande do Sul (IFRS) (Dantas & Aguiar, 2021), together with the Brazilian National Council for Scientific and Technological Development (In Portuguese: *Conselho Nacional de Desenvolvimento Científico e Tecnológico – CNPq*) research group on Health, Environment and Development and the LGBTI + Health Thematic Group of the *Associação Brasileira de Saúde Coletiva* (ABRASCO) (Gonçalves et al., 2021).

Both books take great care to document significant diversity in relation to genders, sexualities, racial and ethnic identities, and social classes, highlighting cross-cutting dimensions of stigma and discrimination in spite of the diversity of communities and populations impacted. And both focus on translating aspects of experience documented through research on stigma and discrimination in ways intended to generate both understanding and solidarity on the part of readers who may otherwise have little or no direct experience of HIV and AIDS and its consequences for those it impacts. They are clearly intended to open up possibilities for dialogue and consciousness-raising, very much in the dialogical tradition of Latin American popular education associated with thinkers

such as Paulo Freire – a tradition that has inspired much work on both treatment literacy and prevention literacy related to HIV and AIDS (Colvin & Robins, 2009; Parker et al., 2016).

Indeed, the issue of dialogue is perhaps especially important to emphasise in relation trying to bring stigma and discrimination back as a central priority for both civil society and governmental programmes in response to HIV and AIDS. Although recognition of the importance of addressing stigma and discrimination has always existed over the history of the pandemic, it is striking how concrete programmes focusing on these issues have tended to disappear over the course of the past decade – and how this has intersected, during exactly the same period, with growing conservatism and authoritarianism, increasing political polarisation, diminishing financial resources for the fight against HIV and AIDS, and the rise of competing priorities. The history of the response to the pandemic over more than four decades now gives us reason to believe that effectively confronting such challenges will depend heavily on our ability to engage in cross-sectoral dialogue and to build analysis/advocacy alliances, with the constant participation of the communities most affected by HIV and AIDS, in order to bring the fight against stigma and discrimination back to the centre of the response to the pandemic, but in ways that will respond to the changing circumstances of the contemporary world (Parker, 2024).

Final remarks

More than 40 years have passed since the emerging HIV pandemic called new attention to stigma as a key issue in the field of global public health. Unfortunately, many issues related to stigma and discrimination have shown great continuity and should continue to be an ongoing focus of research attention today and in the future. However, other aspects related to contextual factors associated with stigma processes have changed with time, just as new considerations have emerged in the rapidly changing world that we inhabit, and it is important for social research on stigma processes to continue to evolve as well in order to continue to engage with contemporary social and political conditions.

We are living in a new era of speed in the propagation of information, the advancement of technologies increasingly aimed at exploring the individual as an entrepreneur of himself/herself and solely responsible for his/her future, and the emergence of populist and extremist leaders that have caused a split in the social fabric. These phenomena may explain the deepening of stigmatisation processes against people living with HIV in many countries. However, if, on the one hand, these technologies have been used to spread stigma, discrimination, and hatred, on the other hand, they have also helped communities to produce articulation and resistance because stigmatisation processes are not closed, sealed, and doomed to oppress individuals without resistance. Resistance is intrinsic to any power relationship and can be as powerful as oppression. Therefore, despite calling attention to the negative effects of stigma, we highlight acts of individual and collective resistance that can change the correlations of force, as exemplified by the confrontation of civil society organisations against HIV and AIDS, just as we highlight the importance of pushing ourselves to continue to confront the changing circumstances that shape stigma processes both in the present and in the future.

In this sense, we draw attention to the need for a research agenda on the processes of stigmatisation and resistance related to HIV and AIDS that takes into account the sociocultural transformations that have occurred in the last two decades, such as the deepening of neoliberalism, growing political polarisation, the rise of political extremism, and the consequent weakening of intersubjective relationships and community responses. We argue that the concepts of ‘moral panic’ and ‘necropolitics’ can be useful in planning empirical studies that analyse the explicit and subtle mechanisms of how power is related to stigmatisation processes. Focusing on the intersubjective production of moral panics can offer key insights into the ways in which stigma and discrimination are deployed with the aim of controlling bodies (and pleasures), as in Foucault’s notion of bio-power. In much the same way, focusing on necropolitics, grounded in Mbembe’s notion of

necropower, can help us to explore the ways in which stigma and discrimination operate through racism, gender inequalities, sexual oppression and economic exclusion to also discard or destroy bodies that are seen as disposable because they are not part of the profitable logic of the neoliberal market. While control and elimination may seem to be very different strategies for the exercise of power in the contemporary moment, we are convinced that there are important ways in which stigmatisation and resistance processes have essential roles to play in relation to both. Research focusing on greater understanding of both these strategies should be an urgent priority in the fields of HIV and AIDS as well as global health more broadly.

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