NOTES FROM THE FIELD

How Do We Balance Tensions Between COVID-19 Public Health Responses and Stigma Mitigation? Learning from HIV Research

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We are not being invaded. The body is not a battlefield. The ill are neither unavoidable casualties nor the enemy. We—medicine, society—are not authorized to fight back by any means whatever. – Sontag (1 p. 180)

Sontag’s quotation above from ‘AIDS and its metaphors’ [1] reminds us to expose, and disengage from, constructions of illness that propagate fear. We are called to address the fear of COVID-19 by correcting misinformation [2, 3]. While misinformation is indeed a driver of fear and stigma, other underlying facilitators produce stigma [4, 5] and need to be considered in stigma mitigation. HIV research and an understanding of the historical construction of illness can be leveraged to mitigate COVID-19 stigma. COVID-19 public health responses—essential for prevention and containment [6, 7]—also have the potential to exacerbate stigma [8]. We outline four tensions between COVID-19 containment and stigma mitigation, and offer possible ways forward.

How We Approach Illness Matters

There is a long history of othering in conceptualizing illness, whereby the sick are separated from the healthy [9]. Responses to illnesses are shaped by their unpredictability and perceived contagion [10]. Illnesses have been constructed as both evil predators and personal responsibilities, contributing to social rejection [1, 10]. Jones [11] described historical examples of how responses to epidemics unfold. At first there may be a lack of recognition of the seriousness of the problem, followed by public responses that are grounded in moralistic and mechanistic interpretations. This could be followed by government actions, such as quarantine, that can exacerbate power imbalances between civilians and the state. Who and what is respected in a society become clear in an epidemic [11].

Social reactions to ‘plagues’ reveal the perception that the illness originates elsewhere [1, 10, 11]. Blaming a foreign other for epidemics is commonplace throughout history. Sontag described “a link between imagining disease and imagining foreignness…illness is a species of invasion” (1 p. 48). Military metaphors—including such terms as targets and fighting—frame illnesses as society’s invasive, wicked infiltrators that spur paranoia and command social order, and in turn can exacerbate pre-existing social inequities [1, 10, 12]. Medical education constructs the body as a battlefield that requires us to strengthen our defense system [12].

Tensions Between Stigma Mitigation and COVID-19 Public Health Responses

Historical and current approaches to illness—including HIV—can inform COVID-19 stigma reduction. Tensions between stigma mitigation and COVID-19 containment emerge regarding: physical distancing, travel restrictions, misinformation, and engaging affected communities.

First, othering can result in social distancing through reduced interaction with stigmatized persons [13]. Yet to slow the spread of COVID-19, it is necessary to practice public health recommended physical distancing—avoiding close contact and maintaining 1 m distance from others [7]. While an integral component of containment [6, 7], how can we ensure that physical distancing does not exacerbate othering, avoidance, and mistreatment toward persons associated with COVID-19? Stigma-reduction messaging can carefully reflect the evolving patterns of COVID-19 risk to
foster empathy while simultaneously transforming physical distancing into a normal and sustained practice until the pandemic is over. While there are no direct parallels to HIV with physical distancing, HIV has long contended with the tension between negotiating intimacy and physical connection in a pandemic. The 1983 publication “How to have sex in an epidemic: One approach” explored care, love, and intimacy as reasons for safer sex motivation [14]. Pleasure (not only fear of HIV infection) is key to engaging in HIV preventive practices [15, 16]. Similarly, UNAIDS [8] and WHO [3] suggest that building connections via kindness and caring (rather than simply fear of COVID-19 infection) can motivate uptake of non-stigmatizing physical distancing.

COVID-19 travel bans, lockdowns, and movement restrictions are being implemented across dozens of countries. Movement bans and quarantines are often legally enforced, for instance by military and municipal police. These approaches help with COVID-19 containment and allow greater responsiveness to overstretched health systems. Yet COVID-19 travel restrictions may also facilitate stigma and xenophobia by reproducing the social construction of illness as a foreign invasion, in turn reinforcing social hierarchies and power inequities [1, 10]—at times through authoritarian means [11]. Enforcement of travel bans, movement restrictions, and quarantines may disproportionately affect already stigmatized persons, including homeless persons [17], persons who are incarcerated [18], migrants and refugees [19], undocumented immigrants [20], and racial minorities [8]. There are global media reports of arrests for COVID-19 transmission [21–25]. Travel bans also exist for HIV: 48 countries currently maintain travel restrictions for people with HIV, reflecting the pervasiveness and persistence of social control measures that perpetuate stigma [26]. HIV transmission has been criminalized [27] in 72 countries [28]: such policies are not evidence-based and harm the health and human rights of people with HIV [29, 30]. Lesbian, gay, bisexual and transgender (LGBT) persons, sex workers, and people who use drugs, experience criminalization that reduces access to employment, housing, and healthcare, and exacerbates risks for violence and practices that elevate HIV exposure [31–34]. As an alternative approach, COVID-19 travel bans and quarantine could include anti-stigma and anti-xenophobia public messaging and training of legal authorities [4, 35]. Furthermore, UNAIDS recommends that in lieu of criminalization for breaching COVID-19 public health policies, approaches should focus on empowering and strengthening communities to support persons to protect their own and one other’s health [8].

Third, it is necessary to address misinformation and lack of awareness regarding COVID-19—but not sufficient. Stigma mitigation also needs to tackle facilitators such as social inequities [4], including racism and xenophobia. Public health strategies that improve access to COVID-19 testing and employment sick leave benefits have the potential to reduce stigma. Yet addressing underlying social inequities and healthcare access require long-term investment in transforming values, laws, and policies. The tension therefore emerges between the immediate—and faster—work of providing information in the midst of the COVID-19 pandemic and the need for long-term investment in reducing social inequities. Stigma-reduction strategies for HIV and other health issues have largely targeted intrapersonal and interpersonal dimensions, far fewer have addressed structural factors such as legal issues, policies, and rights [36]. Interventions should address both drivers (knowledge, misinformation) and facilitators (health policies, institutional practices) [37]. We know from an extensive body of HIV-related stigma research that multiple stigma dimensions can negatively impact health practices and outcomes [5]. COVID-19 stigma mitigation can therefore consider enacted stigma—acts of discrimination and mistreatment, felt-normative stigma—demeaning community norms and values, internalized stigma—the ways that persons accept negative perspectives toward a group(s) they may belong to, and anticipated stigma—concerns that one will experience future discrimination and bias [5]. We have seen international financing for HIV decline [38], threatening the global ambition to end the pandemic. This is not unique to HIV: the United Nations Population Fund also reported significant funding shortfalls for humanitarian relief in 2019 [39]. We need to act now to harness political investment in challenging the social inequities that exacerbate COVID-19’s impact on marginalized communities—such as refugees [19] and undocumented immigrants [20]—rather than waiting for the pandemic to subside when there may be a decreased sense of commitment, urgency, and momentum.

Fourth, we need to engage persons most affected by COVID-19 in developing stigma mitigation strategies, yet they may experience social and health disparities that present barriers to research participation. Lived experiences of COVID-19 and other intersecting stigmas [4, 5, 40] can inform contextually specific and stigma-informed public health approaches. For instance, gendered roles as family caregivers and front-line healthcare workers may elevate women’s exposure to COVID-19 [41], requiring a gender-based analysis of social and health impacts of public health measures such as quarantine. Past pandemics such as Ebola reduced women’s access to maternal and child health services [42], abortion [43], and reduced uptake of HIV services [44]. Social disparities are associated with health disparities. Persons experiencing stigma, such as people newly diagnosed with HIV [45] and LGBT persons [46], are disproportionately impacted by depression. Although research is nascent, the stress from COVID-19 stigma may have analogous mental health impacts [47, 48], including on healthcare providers [49, 50]. Strategies therefore need
to factor in multiple health conditions and social identities to understand and reduce COVID-19 stigma. A syndemics approach could be useful in mapping the ways that social inequities contribute to the production of multiple interacting health issues, including COVID-19 [51]. Creative, web-based, and community-engaged strategies can aim to reduce participation barriers to involve persons most impacted by COVID-19 stigma in research and program development (e.g., addressing access barriers posed by COVID-19 caregiving and/or healthcare provider roles, quarantine, mental health challenges). We need more information to reduce COVID-19 stigma—multi-level strategies can address underlying stigma drivers and facilitators [4]. Public health actors can challenge military metaphors and other stigmatizing language in public health messaging and media [1, 10, 12]. Applying an intersectional lens [4, 40] can improve understanding of the ways that COVID-19 stigma intersects with gender, race, immigration status, housing security, and health status, among other identities. Balancing tensions between stigma mitigation and COVID-19 prevention and containment can inform immediate and long-term strategies to build empathy and social justice in current and future pandemics.

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Compliance with Ethical Standards

Conflict of interest The authors have no conflicts of interest to declare.

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