

Ending the HIV Epidemic

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FROM THE EDITOR

Epidemic Familiarity

Olivia S. Kates, MD

For the generation of infectious diseases physicians who have become my teachers, mentors, and friends, the early years of the HIV pandemic had a monumental influence on their lives. Many were drawn to the field to confront unprecedented challenges in medicine, public health, and justice that first emerged in the medical literature in the spring of 1981.¹ Ethical challenges were numerous, with political figures refusing to acknowledge the ongoing crisis, physicians afraid to treat patients with HIV, and policymakers neglecting and othering patients or members of the public at risk, including children. Such responses occurred amidst mainstream explicit homophobia, sex negativity, economic conservatism, and limited scientific understanding of the virus and its transmission, such that consistently effective interventions were unavailable until 15 years after the first reported cases.²

Decades later, much seems to have changed. In October 2019, the US Department of Health and Human Services launched Ending the HIV Epidemic: A Plan for America. This 4-part program has been thoughtfully designed to leverage decades of advances in HIV testing, treatment, and prevention to reduce virus transmission by at least 90% by 2030.³

This issue of the *AMA Journal of Ethics* explores justice and equity, tensions between **individual and public health priorities**, and competing narratives about how to understand ongoing ethical questions. Both the nature and the scope of ethical challenges related to HIV have evolved over time; the purpose of this theme issue is to illuminate how these evolutions have played out during the Ending the HIV Epidemic program. During the planning of this theme issue in early February 2020, days before recognition of the global dissemination of COVID-19, we asked about the AIDS pandemic: *What does it mean to bring a devastating pandemic, which has preoccupied public consciousness and poignantly drawn attention to structural inequity, to a just end?*

The COVID-19 pandemic has **raised familiar questions** but on an accelerated timeline. Calls for swift, scientifically informed government responses to patients' and communities' needs and vulnerabilities; nondiscriminatory narratives about SARS-CoV-2's origins; equitable resource allocation; transparency in intervention development and delivery; and simple acknowledgement of the stakes echo calls from decades ago about HIV. Health professionals and citizens whose earlier lives were shaped by HIV awareness face new political obstacles,⁴ social and cultural division, and unabashed expressions of

White supremacy that undermine our individual and collective capacity for healing. Those new to health care practice have been told that COVID-19, like AIDS for their predecessors, will be unmatched and career defining.

Experts in infectious diseases, public health, ethics, and justice who have contributed to this issue of the *AMA Journal of Ethics* have done so under extraordinary circumstances. They have been treating hundreds of their own patients who are afraid of, diagnosed with, or dying of a terrifying new disease that could be mitigated substantially through behavioral modification and empowered public health institutions. They have been raising their voices in opposition to racial and **ethnic inequities in health**, police brutality, and deeply entrenched, pervasive racism. These dimensions of the contemporary pandemic context demand our attention if we are to think more powerfully about and respond more effectively to communicable diseases now and in the future. Each time we respond to a new outbreak, the actions, interventions, or sacrifices that we ask of ourselves individually and collectively influence others across space and time. Contagion evokes intense emotions, such as fear (particularly racialized fear), which can too easily be exaggerated and misdirected toward persons (particularly persons with minoritized identities) rather than diseases. And infectious diseases, unlike causes of heart disease or chronic lung disease or cancer, can emerge suddenly and evolve quickly. While there is cause for hope, it remains to be seen whether Ending the HIV Epidemic will achieve its goal of reducing HIV infections in the United States and, if it does, whether it will last. It also remains to be seen whether transmission reduction can be achieved internationally in places where the burden of HIV infection is higher and the resources available to prevent it and respond to it are often fewer. And, as we have already seen with COVID-19, new outbreaks and new retellings of pandemic stories will begin before this one ends.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

Should Needlestick Protocols Influence Documentation or Disclosure of a Patient's HIV Status?

Shaoli Chaudhuri, MD, MPH, Raaka Kumbhakar, MD, and Ellen Morrison, MD, MPH

Abstract

Heightened privacy and confidentiality stakes around HIV have resulted in unique anonymity and nondisclosure policies and practices. This commentary on an occupational exposure case considers benchmarks in the evolution of HIV testing. Persistent stigma continues to exacerbate ethical complexities and ambiguities clinicians face in an “end the epidemic” era.

Case

J is a general surgery resident on call for the trauma service. When responding to a call about a patient of unknown identity with multiple gunshot wounds, J sustains an accidental needlestick injury with a contaminated, large-bore, hollow needle. J follows employee health guidelines for occupational exposure to blood-borne pathogens and requests postexposure prophylaxis to minimize risk of HIV infection. The “source” patient remains unconscious in an intensive care unit and their identity is not known. Based on regulations in J's state of licensure, the patient's blood can be drawn and anonymously tested for HIV. J is informed that the test result is positive. In keeping with state law, the test result is not included in the patient's health record and J is instructed not to disclose the result to the patient unless the patient consents to testing.

A week later, the patient regains consciousness. Although J doesn't typically do so, J emphasized to the patient the importance of obtaining a routine, confidential HIV test. The patient refuses testing, stating, “I don't have AIDS.” J believes it is a dereliction of duty not to disclose the patient's HIV status; J reveals to the patient that, because of a needlestick accident, an anonymous HIV test was performed without consent. The patient becomes upset. J responds by clarifying that this is standard protocol for a needlestick accident, offers the patient confidential HIV testing and, if needed, treatment and counseling. J leaves the patient's room so the patient can quietly consider their options.

About to change service assignment, J asks a fellow general surgery resident, L, to take over the patient's care. L is aware of J's needlestick and J's initiating postexposure prophylaxis. J tells L, “If you develop a rapport with this patient, please counsel them to

get tested. Or at least counsel them to use condoms.” J worries that, if the patient does not consent to an HIV test, other clinicians will not know that this patient has HIV and the patient will not receive necessary care.

Commentary

In the world of public health, HIV has perhaps been unique in its spread, pathogenicity, and long-standing impact. Infection is a biological event, but complex political, economic, and social dynamics often result from it. The deadly AIDS crisis of the 1980s and 1990s was characterized by a dearth of treatment options and the disease’s initial appearance in marginalized patient populations, particularly in persons who inject drugs (PWID) and men who have sex with men (MSM). Gay rights advocates feared further stigmatization and became vocal lobbyists against widespread testing.^{1,2} The term *HIV exceptionalism* arose during the early epidemic,^{1,2,3} and HIV exceptionalism manifested as a set of policies defining HIV as fundamentally different from other diseases. The rationale was to protect patients’ rights and maintain their privacy and anonymity, as well as to protect patients from discrimination, especially given that those most at risk (eg, MSM, PWID, sex workers) were *already stigmatized* and vulnerable. Civil rights groups and public health officials alike opposed HIV test reporting for this reason, as well as out of concern that patients would refuse testing or counseling if reporting were mandatory.³ As demonstrated in J’s case, although HIV is now treatable, ethical dilemmas arising from treating HIV as exceptional remain.

HIV Testing Policies

Nationwide, there is significant variability among laws and policies regarding HIV testing. These include whether and when testing is confidential and whether *testing is routine* for all patients unless they opt-out and actively consent to not be tested or whether testing is not done routinely for all patients, such that patients must actively opt-in and consent to testing. Such policies vary by state with respect to (1) whether testing without consent is permitted, (2) who has the authority to order HIV testing without consent, (3) how test results are officially documented, and (4) how a patient is informed. In New York State, for example, informed consent is required though it is possible to opt-out; in Washington State, laws requiring both opt-in and opt-out have been repealed.^{4,5,6} As of 2012, 36 states had some legal framework for occupational exposure cases, in which patients are tested for HIV without their consent (colloquially referred to in clinical settings as “unconsented” cases).⁷

Professional societies and government agencies have also put forth recommendations regarding HIV testing. The American Medical Association states that physicians should test patients for HIV without their consent “only in limited cases in which the harms to individual autonomy are offset by significant benefits to known third parties, such as testing to protect occupationally exposed health care professionals or patients.”⁸ The Centers for Disease Control and Prevention (CDC) recommends only that a person whose bodily fluids might be a source of an occupational exposure be tested for HIV without their consent.⁹ With regard to HIV screening, the CDC states that HIV testing should not be done without consent.⁹ Additionally, written informed consent for HIV testing was common until 2006, when the CDC also recommended routine opt-out testing.^{9,10}

Anonymity and Nondisclosure

Generally speaking, patients in the United States can access anonymous HIV testing, whereby patients’ names and personal information are not collected, at select testing

sites; this policy encourages individuals to seek testing without fear of disclosure.¹¹ (Confidential testing, in which test results are entered in a patient's health record, is standard.) Anonymous testing in occupational exposure cases is less straightforward: results are deidentified, but testing is done without a patient's consent. In the case above, in which a patient is unable to consent due to being unconscious and has no available surrogate, New York State's (and many other states') laws allow deidentified testing in occupational exposure cases.^{7,12,13}

This particular case highlights that whether a diagnosis is disclosed to a patient depends on whether that patient consented to testing, and this practice is unique to HIV. Patients have a right to know their own test results. But this case poses a more nuanced question about a patient's right *not* to know. Does this right also exist? If so, how does it interface with clinicians' rights and safety, the rights and safety of those whom a patient might expose to HIV, and a patient's decision-making capacity?

Risks and Perspectives

From an ethics standpoint, we can approach possible harms and pitfalls of nonconsensual HIV testing by looking at risks to and perspectives of various actors. Allowance of deidentified testing after occupational exposure protects health care workers from risk, expense, and unnecessary postexposure prophylaxis (PEP), although current PEP regimens are much better tolerated than previous ones. J's primary motivations include their personal level of risk (and risk to any partners) and their duty to the patient and others. J feels obligated to ensure that the patient is knowingly tested for HIV and can receive care. J also wishes to protect others from future exposure and infection. Using a clinical bioethical framework, one might conclude that J's actions were motivated by principles of beneficence and nonmaleficence. In many diseases—and, one might argue, more so in HIV—harms of knowing one's diagnosis should be weighed against potential harms to oneself and the public of not knowing. In some cases, like this one, HIV test results can be excluded from a patient's health record. But in this case, although test results are technically excluded from the patient's record, the clinician knows the patient's HIV status and is concerned about risk of harm to the patient whose access to care is delayed by the patient not knowing and exposure risk to individuals who could be infected by the patient.

From the patient's perspective, being tested without consent is a violation of autonomy. After awakening, the patient had capacity to consent to or refuse **disclosure of test results**. Although J's inclination is to ensure that a diagnosis leads to treatment, J's disclosure—or even intimation—of the patient's status might lead the patient to feel mistrust or that their privacy and autonomy have been violated. In our case, even J's suggestion to a colleague that the colleague be more assertive in efforts to have the patient tested implies a positive result.

In cases like this one, a balance must be struck between patient autonomy and a physician's urge to offer care they believe is in that patient's best interest. Patients have a right to balance their assessment of possible negative outcomes of learning they are HIV positive (eg, depression, social stigma, possible intimate partner violence) against benefits of early detection and intervention. Clinicians must provide accurate information so that patients can make informed decisions. J appropriately asked the patient to consider HIV testing. But, legally, patients with decision-making capacity may refuse testing and care, and J cannot force the patient to pursue either of those options or to permit disclosure of their serostatus in their health record.

Public Health and Equity

This case has public health implications for patient rights regarding HIV testing. Whereas advocates and various institutions for many years stressed an individual rights-based approach to testing, the 2006 CDC recommendations for universal HIV screening for pregnant women marked a shift toward public health.¹⁴ In the case, an untested, uninformed patient risks infecting others. Indeed, one study showed that individuals with HIV who are unaware of their status engage in roughly twice as many high-risk behaviors with any partner as individuals with HIV who are aware of their status.¹⁵ Other public health implications include the ways that HIV disproportionately affects people of color.¹⁶ An argument for maintaining HIV exceptionalism might be that communities of color are already so distrustful of health care that violating their right not to know could further marginalize these communities' members and exacerbate existing health inequity.

Although J would ideally educate the patient on the importance of knowing their status and on the fact that HIV is a treatable disease, J should respect the patient's wishes. J must first attempt to understand why the patient is refusing disclosure before jumping to conclusions or forcing unwanted information on them. Disclosure of status could heighten mistrust between patient and clinician, thus precluding the patient from engagement in care.

A New Era

HIV stigma persists. In the era of "end the epidemic," the framework for testing and results disclosure needs to shift to take into account the factors that allow HIV exceptionalism to persist—namely, the laws and policies concerning testing and the structural biases that have been discussed. Although some who seek an end to HIV exceptionalism maintain that there is no longer anything inherently exceptional about HIV,^{2,9} the continued high global disease burden of AIDS and the increasing prevalence of HIV internationally demand a new approach.^{17,18} HIV continues to disproportionately affect individuals and communities already stigmatized by their minority status.¹⁶ The intersection of multiple diverse lived experiences and social disadvantages might not be overcome by simple interventions such as HIV counseling. But perhaps clinicians can help mitigate stigma and improve HIV tracking and treatment by educating patients, building trusting relationships with and offering support for patients, and expressing solidarity with those seeking an end to systemic violence that undermines patients' health status or access to health care.

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Should Clinicians Respond if Patient HIV Denial Could Exacerbate Racial Health Inequities?

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Abstract

This commentary examines the appropriateness of a clinician's deceiving a patient who will not discuss lifesaving therapy through the lens of solidarity, a key professional ethical value. Clinicians' awareness of social determinants of many patients' increased vulnerability to HIV infection is needed to promote equitable HIV intervention outcomes at both individual and community levels.

To claim one AMA PRA Category 1 Credit™ for the CME activity associated with this article, you must do the following: (1) read this article in its entirety, (2) answer at least 80 percent of the quiz questions correctly, and (3) complete an evaluation. The quiz, evaluation, and form for claiming AMA PRA Category 1 Credit™ are available through the [AMA Ed Hub™](#).

Case

M is a 56-year-old Black man with human immunodeficiency virus (HIV) who is hospitalized with failure to thrive and dyspnea. Prior to hospitalization, M did not have an infectious disease or a primary care physician, and he was not taking antiretroviral therapy (ART). In the past 20 years, when physicians have tried to speak to M about his HIV diagnosis and benefits of ART, he has said, "I don't have HIV," or "I don't talk about that."

M has a CD4+ count of 3 cells/μL. He is diagnosed with *Pneumocystis jirovecii* pneumonia, norovirus diarrhea, and acquired immune deficiency syndrome (AIDS) wasting syndrome. During hospitalization, his relationships with clinicians worsen; if a clinician mentions HIV, M breaks eye contact, becomes silent, and interacts minimally.

An infectious disease specialist, Dr D, visits M to talk about his pneumonia. M consents to antibiotics to treat this infection and appears interested in strengthening his immune system "in other ways," as Dr D suggests. Dr D continues to use M's positive response as an opportunity to motivate M to take ART and is tempted to give M ART without saying it is HIV treatment. She is worried about deceiving M, taking unfair advantage of his lower health literacy, and upsetting him if he discovers that "immunity booster pills" are actually ART. Since low engagement with health care and worse health outcomes are prevalent in some communities of color and sometimes accompanied by

misinformation about HIV, Dr D is encouraged by M's engagement. She considers whether it might be best to get him to take ART, even unknowingly, to save his life.

Commentary

HIV disproportionately afflicts marginalized populations, but not through intrinsic biological susceptibility. Homophobia, drug use criminalization, inequitable access to HIV testing and treatment, and racism in sexual network formation contribute to HIV disparities.^{1,2} Clinician awareness of these and other **social determinants** of vulnerability to HIV infection is key to promoting equity in HIV outcomes. Combined with empathy, awareness of these factors can motivate education and testing in high-risk populations and focus funding and program development efforts in vulnerable communities.

Clinician Awareness

Awareness of patients' social vulnerability to HIV infection can enable clinicians to have good conversations with individual patients about reducing their risk of infection.³ A clinician who knows that HIV infection prevalence is higher in populations with specific sexual behaviors, for example, can take a more complete sexual history of a specific patient, which can better position that clinician to help that patient reduce their risk of HIV infection or transmission. But awareness of a patient's social vulnerability to HIV infection can also fuel discrimination and stigma.⁴ Men who have sex with men, people who inject drugs, and other groups with higher-than-average HIV infection risk are among those who experience **discrimination from clinicians**, which might affect HIV medication adherence or utilization of HIV primary care.^{4,5,6} Even well-meaning clinicians who would never intentionally discriminate might assume that demographics are the most important determinant of an individual patient's risk. Clinicians who are aware that HIV infection prevalence is higher in patients from a given sociodemographic group might mistakenly infer, for example, more than they should about a specific patient's mindset, behaviors, or risk profile on the basis of such demographics. If patients respond to this kind of error in reasoning by feeling stigmatized, they are likely to feel alienated from family and friends, employers, community leaders, and clinicians from whom they could seek help.⁷

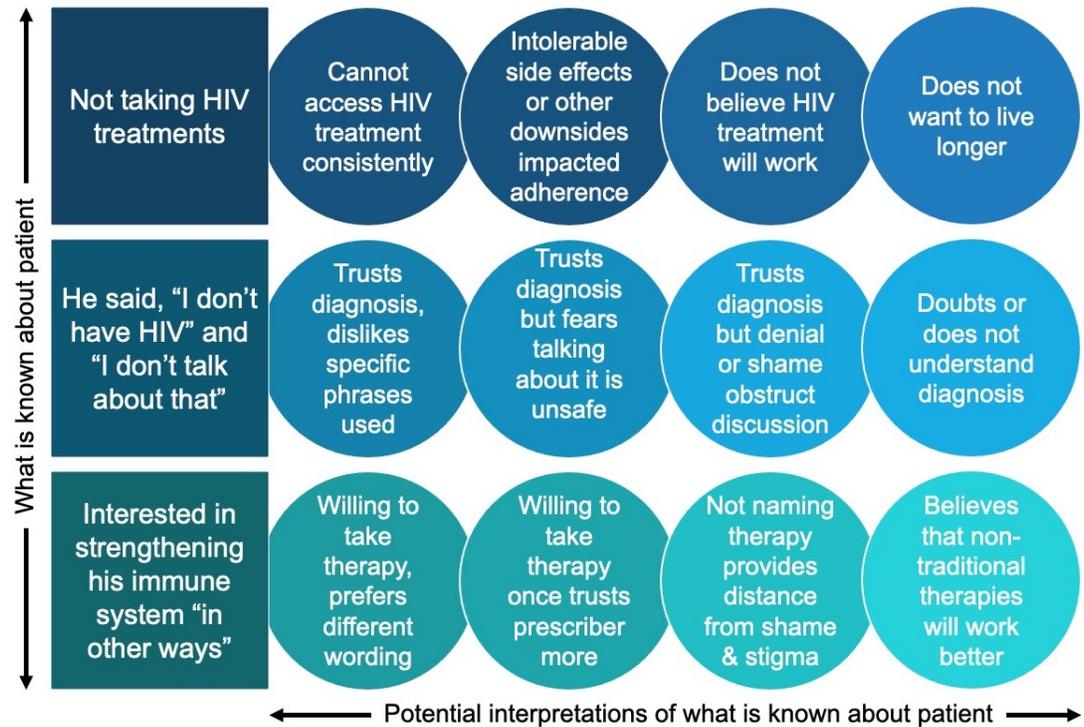
Clinicians also need to cultivate awareness that patients can respond to HIV stigma with reluctance to discussing either their risk behaviors or their infection status,⁸ perhaps out of fear of loss of employment, loss of insurance, suffering abuse, or being ostracized. Others respond to HIV stigma by internalizing it and might come to believe that they do not deserve care.⁹ Even patients who have unrestricted access to health care could, for instance, stop seeking health care if they expect a clinician to treat them poorly.^{10,11} In response to social or internalized stigma, people with HIV tend to develop coping mechanisms, including denial, which can exacerbate how they feel psychologically and physically. Indeed, HIV diagnosis has been associated with poorer self-reported health outcomes as well as lower engagement in care, including treatment refusal, in patients with HIV.^{12,13,14,15}

Trust and Therapeutic Alliance

In the case, Dr D knows only 3 things with certainty about M and ART: M is not taking ART; M has been reluctant to discuss HIV infection, at least in certain ways; and M is open to "immunity booster pills," whatever that might mean to him. It would be easy for Dr D to assume that M's behaviors stem from low health literacy or mistrust. They might be. Dr D should not make this assumption, however. Instead, Dr D should gently explore an array of potential interpretations of these facts in a nonjudgmental conversation with

M (see Figure). Approaching this conversation with respect and openness is more likely to build therapeutic alliance and yield a wider array of actionable hypotheses for Dr D than making unfounded assumptions about what motivates M's behavior.

Figure. Potential Interpretations of Patient Statements Regarding Treatment for HIV Infection



Trust is central to therapeutic alliance and thus to the success of therapies like ART. Black and Latino patients in particular have suffered a legacy of institutional racism, unequal access to health care, and mistreatment at the hands of clinicians that long antedates the HIV epidemic, and perceived discrimination is related to mistrust in physicians.^{6,16} HIV-related stigma and clumsy clinician assumptions can simply confirm patients' preexisting mistrust and thus lead to their further ostracism from high-quality care.

Avoiding **stereotyping** is key to establishing trust, particularly when clinicians and patients come from different demographic and socioeconomic backgrounds. On first meeting M, Dr D is seeing M as a person with AIDS and as a Black man. M is likely having similar perceptions of Dr D based on her speech, her dress, and the ways she reacts to him. In time, hopefully these first impressions will fall away and each will see the other as unique individuals, but this rarely happens during a first encounter. It takes time for clinicians to build trust with patients through listening, being open to questions, avoiding judgmental communications, and sharing both information and decision making with patients.^{17,18} A wise clinician balances a personal, individualized connection with the patient in front of her with awareness of complex dynamics, such as those discussed above.

Lying

Dr D fears for M's life. It would be tempting to attempt to initiate ART and other potentially lifesaving therapies rapidly and by any means necessary. The temptation is understandable: M's low CD4+ count and AIDS-defining illnesses do suggest his life expectancy might be measured in months.¹⁹ Temptations that arise from positive motivations, like the desire to save a life, can be the most difficult to resist. Dr D should, however, resist the temptation to lie. M is not likely to die today or this week. A lie today is not likely to save his life tomorrow and, in fact, it could have just the opposite effect. Even though a drug is prescribed through subterfuge, M is very likely to discover he is taking ART at some point. If this discovery makes M feel violated, M is unlikely to see Dr D again and may well be less likely to seek clinical care in the future. M's adherence to ART will surely falter if he feels it was initiated under false pretenses. Deceit itself could thus be lethal, converting a misguided attempt at beneficence into an act of maleficence. Dr D should ensure that good, lifesaving intentions do not overshadow commitment to honest, transparent interactions with M. Deception is generally ethically and legally prohibited for the reasons above and because it expresses disrespect for patients' dignity and autonomy. Hiding the nature of treatment from patients could prevent them from receiving care they want. Regardless of whether deception is regarded as legal in the face of HIV denial, most clinicians tend to understand deception as so unprofessional as to make its legality irrelevant.

Although outright deception thus runs afoul of more than one foundational value in bioethics, Dr D is not obligated to use a single set of words to describe ART, particularly if M might not understand or feel comfortable with her original word choice. Dr D is welcome to explore M's level of health literacy and his vocabulary preferences and to probe gently to find a shared vocabulary for the medications she hopes will save his life. Perhaps M understands that Dr D wants to prescribe ART and is signaling with his reference to "other ways" of boosting his immune system that he is open to it. On the other hand, he may truly desire to avoid ART and be beset by a false belief that there is some other treatment that can prolong his life in a similar fashion.

Honesty

To identify patient knowledge gaps or attitudes that obstruct ART acceptance, Dr D can ask exploratory questions.

- What are M's goals of care (eg, is longer life his goal)?
- Are there aspects of his health or HIV that M is willing to discuss?
- Are there words that M is comfortable using to address these topics?
- What does M understand about ART?
- Does M believe ART will prolong life?
- What does M mean by "other ways" of strengthening his immune system?

After probing M's wishes, understanding, and preferences—and, in the process, building trust and a better sense of M's needs—Dr D will be better positioned to offer ART adherence support via evidence-based interventions, including cognitive behavior therapy, education about the health benefits of ART adherence, treatment supporters, directly observed therapy, and dose reminders.²⁰ Throughout these conversations, Dr D should always be clear that the treatment she is offering is treatment for HIV.

It is appropriate for concerned clinicians to want to initiate an urgently needed intervention, such as ART for M. This impulse, however, should never overshadow one's obligation to be honest or distract from focus on therapeutic alliance and trust. With the same avidity with which she seeks ways to prescribe lifesaving ART for M, Dr D should find ways to build trust with M. Dr D should spend unstructured time getting to know M. In so doing, she can demonstrate that she is a good listener who has his best interests at heart. She should seek to understand what makes life worth living for M and what M fears most, and she should work with M on a course of care that fits with his goals and fears. This process will take time. In time, the development of trust and solidarity and continued offers of ART will give M the best chance to regain his health, to feel supported, and to live to see the day he thanks Dr D for saving his life, with respect.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

Should Patients Who Receive Postexposure Prophylaxis After Sexual Assault Be Considered for Preexposure Prophylaxis for HIV?

Michela Blain, MD and Julia C. Dombrowski, MD, MPH

Abstract

Clinicians who encounter patients after sexual assault must offer competent, compassionate, trauma-informed care that fosters a patient's sense of safety and trust. In this case, a patient presents for HIV postexposure prophylaxis after a second sexual assault by the same perpetrator. This article considers how to balance providing a potentially beneficial intervention and avoiding retraumatization and stigmatization. Clinicians who facilitate patient-centered decision making about preexposure prophylaxis can respond to a patient's immediate needs and support her autonomy.

Case

Dr A routinely sees patients who have had possible exposures to HIV through consensual sex, exchange sex, sexual assault, health care work, or injection drug use. When a patient is potentially at risk for acquiring HIV, Dr A prescribes a 28-day prescription for postexposure prophylaxis (PEP) medications. Patients with ongoing risk for acquiring HIV are encouraged to begin preexposure prophylaxis (PrEP).

T is a new patient who comes to Dr A's clinic to be evaluated, for a second time, for PEP after a second sexual assault by an acquaintance who sometimes stays at the home T shares with a roommate. Dr A plans to prescribe PEP medications for T. Dr A discusses T's case with a colleague, Dr B, who encourages Dr A to recommend PrEP for T as well. Dr B remarks, "This is the second time this has happened with the same guy, and he's still coming by the house, so this could happen to T again. Besides, the data are better for preexposure than for postexposure prophylaxis. Next time, T might not come in soon enough."

PrEP could help T protect herself, but Dr A wants to carefully consider how to present PrEP to T so that T won't feel judged or blamed for her assaults. Dr A wonders how to help T.

Commentary

Sexual assault is common, with approximately 20% of women and 1% to 2% of men in the United States reporting a lifetime history of rape.^{1,2} Survivors of sexual assault come

to medical care in a particularly vulnerable state and, unfortunately, often feel blamed, judged, and shamed for what has happened to them, even by health professionals.³ Seeing patients who have recently experienced sexual assault can be a source of anxiety for the clinician who is trying not to say the wrong thing, imply blame, or make a comment that the patient could perceive as judgmental regardless of the clinician's intent. As the clinician caring for T, Dr A should make it the first priority to facilitate a **trusting and supportive relationship** with her. It is crucial that T's visit helps ease her suffering rather than compounding it. Dr A should begin the visit with clear and unequivocal statements that convey empathy, such as "I'm sorry this happened," "It's not your fault," and "I am here to listen or help in any way I can."⁴ Without first creating a foundation of trust, any additional interaction might be futile.

The central ethical tension in this case is the potential conflict between Dr A's obligation to provide an intervention that could benefit the patient and the obligation to avoiding harming the patient through retraumatization or **stigmatization**. Will offering PrEP signal blame, imply acceptance of repeated assaults, or suggest that it is T's responsibility to protect herself from a harm inflicted upon her? We posit that it is ethically appropriate to offer PrEP in this context, and the principles of trauma-informed care provide guidance for doing so.

Not All About HIV or Pills

Although T has come to Dr A for evaluation for HIV PEP, it is important to recognize that her risk of acquiring HIV is not the biggest issue at hand. The probability of acquiring HIV via one episode of receptive penile-vaginal intercourse or receptive anal intercourse is estimated to be 8 and 138 per 10 000 exposures, respectively.⁵ To deliver care with a patient-centered approach, it is important to respond to the patient's request for PEP but also to consider issues beyond HIV risk and PEP, such as physical trauma, psychological trauma, pregnancy, and other sexually transmitted infections. Dr A should offer resources to help T obtain an evaluation from a sexual assault nurse examiner, if available in the community; attend counseling for her mental well-being; and report her assault to police if she wishes to do so. Intervening early with psychological support and providing resources for sexual assault survivors can diminish the long-term effect of trauma and increase the likelihood of ongoing engagement in services to support recovery.^{6,7}

Trauma-Informed Care

Recognition of the pervasiveness of trauma—including sexual assault—in the United States has inspired clinicians to strengthen their ability to provide **trauma-informed care** to all patients. There are 4 core principles of trauma-informed care: first, to acknowledge the widespread experience of trauma; second, to recognize the signs and symptoms of trauma; third, to minimize the potential for inadvertent retraumatization; and fourth, to respond with appropriate action and support.⁸ Because at least part of this patient's trauma history is already known, Dr A can use the third and fourth principles to guide her approach with T.

According to the third principle, to prevent retraumatization, Dr A should avoid asking unnecessary details about the assault and should keep in mind that every sexual assault survivor is unique and may respond differently during recovery. If a physical exam is indicated, Dr A should ask for consent beforehand and ask what would make the **exam more comfortable** for the patient. Relative to the fourth principle, Dr A must provide an empathetic response to T and verbally acknowledge her situation (eg, "I'm so

sorry this happened to you. My job is to support patients who have experienced sexual assault, and I hope to be a helpful resource for you”). A qualitative study of survivors of sexual assault demonstrated that survivors highly prioritized having a clinician who emphasized empathy, confidentiality, validation, and individual agency during their visits.⁹ After expressing empathy, Dr A can focus on T’s current concerns and use those concerns to guide her recommendations (eg, “I am here to listen and help in any way I can. What would be most helpful for you today?”). Dr A can inquire about T’s perception of her vulnerability to future assaults by this or any other perpetrator. The answer to this question could both guide Dr A’s connecting her to resources for ensuring she has a safe place to stay and help gauge her interest in taking PrEP for ongoing exposure risk. Best practices for trauma-informed care enable the patient’s preferences and needs to guide the visit and permit the clinician to share resources and provide support.

PEP and PrEP

After establishing a safe, trusting environment, Dr A can discuss with T the differences between PEP and PrEP for HIV. PEP is a medication strategy to help prevent HIV acquisition after possible exposure and is recommended for individuals after either sexual assault or consensual sex. The recommended regimen for PEP is a 28-day course of 3 antiretroviral medications typically used to treat HIV.⁵ PEP must be initiated within 72 hours of the exposure; appropriate care includes initial and follow-up HIV testing. PEP has been shown to significantly decrease the risk of HIV seroconversion in observational studies and in animal models, although its precise effectiveness is difficult to quantify.⁵ PrEP is an HIV prevention strategy initiated before exposure and is available for individuals with ongoing risk, including those who have received one or more courses of PEP within the past year.¹⁰ Numerous studies have supported the efficacy of oral PrEP, reporting a 78% to 90% reduction in HIV infections in heterosexual cisgender women with sufficient adherence.^{11,12} Patients prescribed PEP who have concern for potential ongoing exposure can be safely transitioned to PrEP after completion of their PEP course.⁵ Taking PrEP does not need to be a lifelong commitment; recommended PrEP duration is based on how long the patient remains at risk for HIV acquisition and can be safely stopped when the patient is no longer at risk. While on PrEP, patients should be seen periodically in clinic for monitoring.^{5,10} Both PEP and PrEP regimens are generally well tolerated, and development of drug resistance and serious side effects is rare.⁵ These treatments are not mutually exclusive and can be combined for HIV prevention.^{5,10}

Some clinicians might view offering PrEP to T as inappropriate because this option does not address the root cause of her predicament or diminish her risk for future sexual assault. The central flaw in this viewpoint is the assumption that T’s risk environment can be changed. Victims of sexual assault are often unable to simply remove themselves from risk; keeping herself safe is likely not entirely within T’s control. Clinicians are unable to control many elements of patients’ risk environments but can offer strategies to help patients protect themselves from dangerous or threatening circumstances. Common strategies for patients include connecting with groups that support rape survivors, reaching out to trusted family members and friends, seeing a mental health professional for counseling, and engaging in self-care activities. Offering resources as part of trauma-informed care can help Dr A provide holistic care and demonstrate awareness that PrEP does not address the root causes of T’s plight. Discussing both PEP and PrEP with T would empower her with options to decrease her risk of HIV acquisition, even if other aspects of her current situation might not be completely within her control. In our view, the best approach to determining whether T

will take PrEP in the future is for Dr A to offer the option and engage in a process of shared decision making with T. Some patients might view PrEP as a means to protect themselves that helps them regain some control in a risk environment, while others might consider it to be an unwelcome continual reminder of sexual assault. If T indicates that she is not prepared to discuss or make a decision about PrEP at the initial visit, Dr A should arrange a follow-up visit to discuss PrEP before the end of the PEP course.

Barriers to PrEP Access

Dr A needs to be attuned to the practical considerations involved in starting PrEP in order to be honest and forthright with T about potential barriers to local resources for assistance. This approach is consistent with the principle of avoiding retraumatization that could occur if T is offered something that she cannot access due to external factors beyond her control. Unfortunately, even if T wants to take PrEP, she might be unable to obtain it due to cost (nearly \$2000 per month without insurance).¹³ Particularly in states that opted out of Medicaid expansion, payment assistance can be difficult to access,¹³ and out-of-pocket costs put PrEP out of reach for most individuals at risk. PrEP access in the United States is vastly inequitable in terms of not only geography but also race/ethnicity. It is underprescribed to Black and Latino men who have sex with men, who bear the highest burden of new HIV infections.¹⁰ In many areas, PrEP navigators are available to help patients access payment assistance for PrEP.¹⁴

Shared Decision Making

In summary, the overall goal is to provide competent, compassionate, trauma-informed care for T in the immediate aftermath of her sexual assault and to support her autonomy through shared decision making about HIV prevention in the future. By applying principles of trauma-informed care, Dr A can resolve the tension between offering a beneficial treatment and avoiding harm to the patient. Options like PEP and PrEP are important for T to consider as ways to regain agency. Our role as clinicians is to support patients holistically—their physical, mental, and emotional needs—while also empowering them with choice and providing the resources they need to make informed decisions for their own health.

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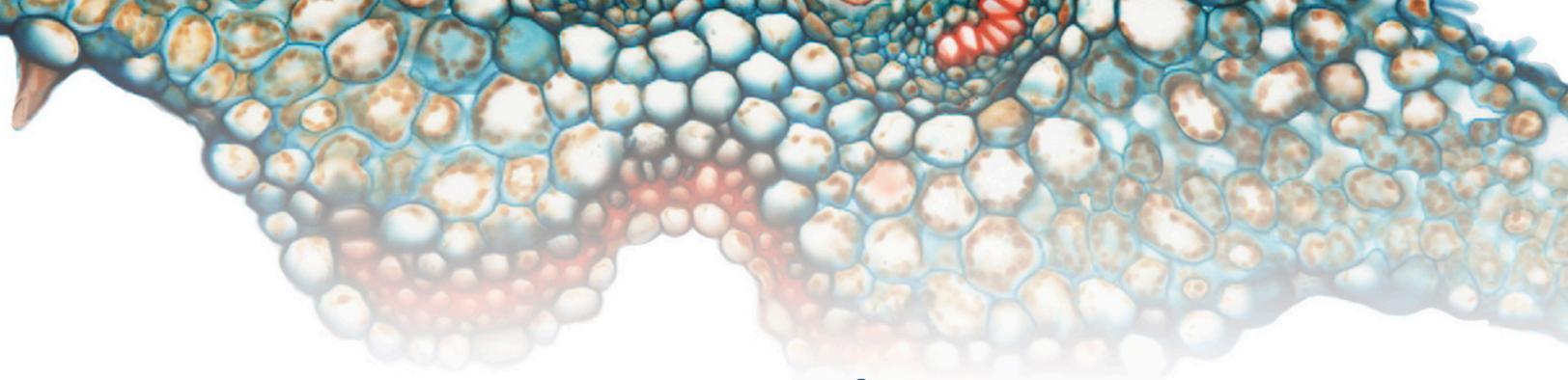
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ORIGINAL RESEARCH: PEER-REVIEWED ARTICLE

Are Financial Incentives Appropriate Means of Encouraging Medication Adherence Among People Living With HIV?

Toorjo Ghose, PhD, Virginia Shubert, JD, Sambuddha Chaudhuri, MBBS, PhD, Vaty Poitevien, MD, and Alison Updyke, PhD

Abstract

BACKGROUND: Financial incentives have been shown to improve antiretroviral (ARV) adherence for people living with HIV, but scholars have argued that this commodifies treatment and have debated the ethics of doing so. This article summarizes research on ethical processes and factors involved in an intervention that successfully improved ARV adherence among socially vulnerable people living with HIV.

METHODS: Thirty qualitative interviews were conducted with intervention participants and field notes documenting organizational processes were analyzed. The protocol utilized a preexisting framework to assess the ethics of using financial incentives to motivate adherence.

RESULTS: Financial incentives supported an ethical service provision framework by (1) establishing and strengthening client agency, (2) revising organizational protocols to prioritize adherence, and (3) promoting resource redistribution.

CONCLUSIONS: Financial incentives, when embedded in wrap-around services, innovative client-centered organizational processes, and a justice orientation, constitute an ethical intervention requiring ethical investigation.

Introduction

Financial incentives have been shown to be an effective intervention to boost antiretroviral (ARV) adherence among people living with HIV (PWH).^{1,2,3,4,5} Examining the effects of combining intensive case management services to maintain adherence with financial incentives (\$100 gift voucher for viral load < 50c/ml at quarterly assays), Ghose et al found that the Undetectables Intervention (UI) significantly improved ARV adherence and maintained it over a 4-year period in a sample of socially vulnerable PWH with a high prevalence of homelessness, substance use, and mental illness.⁶

Despite the proven effectiveness of paying participants to maintain medication adherence and achieve wellness goals, the **ethics of financial incentives** have been debated. Scholars have expressed concern that financial incentives coerce participation, exacerbate inequities, subject life and health to valuation processes, undermine therapeutic relationships, and prioritize financial over health outcomes.^{7,8,9,10,11} Drawing on a framework put forth by Christensen¹² that describes an ethical orientation to community mental health service provision, Claassen argues that the provision of incentives needs to take into account: (1) complications in the process of informed consent, (2) the possibility of incentives being paternalistic and coercive, (3) issues of resource allocation that address organizational resource capacity and what constitutes optimal incentives, (4) organizational relationships shaped by this incentive, (5) beneficence, and (6) nonmaleficence.¹³

Extending the previous study by Ghose et al,⁶ this qualitative study examines the ethical dimensions of the financial incentives used in the UI. We apply Claassen's adaptation of Christiansen's framework to examine and interpret our results.

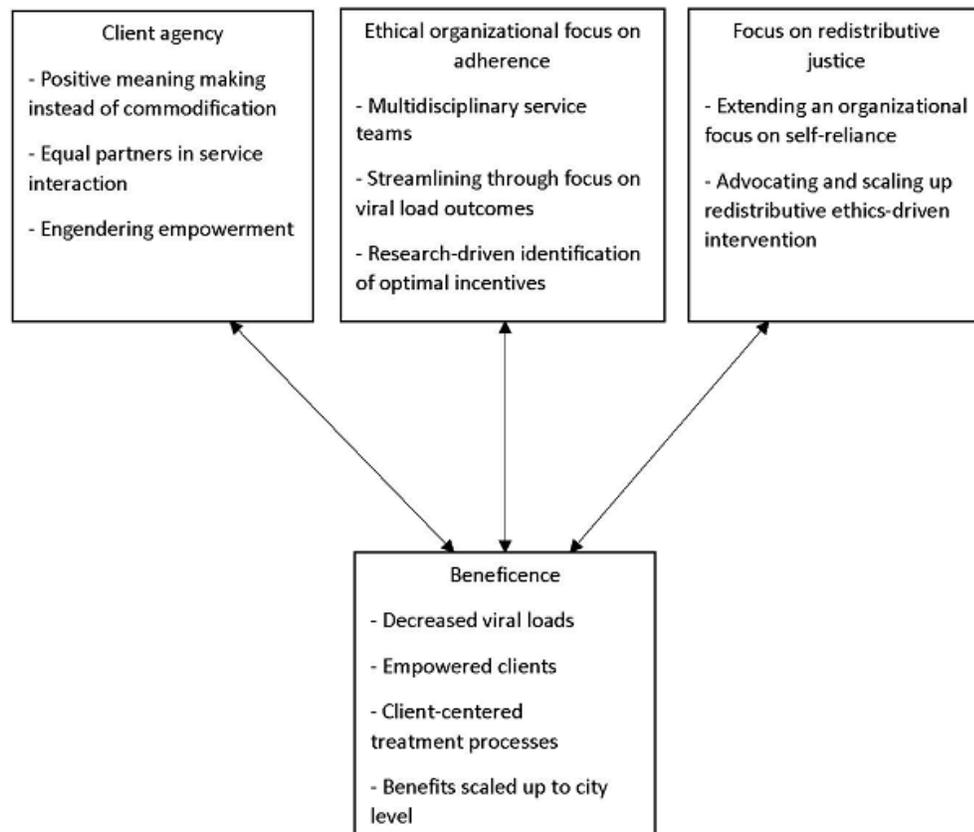
Methods

We conducted 30 semistructured qualitative interviews with UI participants recruited through snowball sampling to examine the ways financial incentives influence adherence-related behaviors. Of the final sample of 30 interviewees, 77% were African American, 13% were Latinx, and 10% were Asian American or White and 43% were men and 57% were women. We used NVivo (N6) to analyze the data. Interviews were discontinued when conceptual saturation was reached, whereby new concepts ceased to emerge from coded data. We also used field notes from service provision team meetings and trainings to support concepts. Drawing on a grounded theory approach using sensitizing concepts,¹⁴ thematic analyses were employed to identify concepts and themes.

Results

Our results indicate that financial incentives support an ethical service provision framework by (1) establishing and strengthening client agency, (2) revising organizational protocols to prioritize adherence, and (3) promoting principles of redistributive justice. We found that the principle of beneficence infuses each of the 3 ethical dimensions (see Figure).

Figure. An Ethical Framework for Considering the Delivery of Financial Incentives



Developing client agency. When examining the interview data for evidence of Christensen’s first 2 categories, informed consent and paternalism, we found that these concepts merged into a consolidated theme of developing and strengthening client agency. Participants reported that, with financial incentives, they felt less stigmatized or pressured to take medicine. One participant compared medication decisions to making decisions about work, stating: “Now I take it, that’s great; if I don’t, there’s no shame in it, I just don’t get it (the voucher). It’s like taking a day off from work.” Another reiterated this point by opining, “It makes me feel like I’m an adult. Not someone who is forgetting and has to be told about it constantly, but someone who is being paid to take the meds. That’s cool and makes me OK if I miss it here or there.”

This nonstigmatizing, nonpaternalistic orientation to missed doses allows participants to overcome shame and stay adherent. Being able to maintain adherence over the long term despite some missed doses is significant, given the evidence that “drug holidays” (whereby some doses are missed while otherwise being adherent) do not contribute to increased viral loads.^{15,16}

Ghose et al found that, far from commodifying the act of taking medicine, incentives infused it with meaning. In particular, participants felt that the incentives acknowledged their participation on the front lines of the campaign to bring the HIV epidemic to an end.⁶ We found that this meaning-making process significantly empowered participants in the clinician-client relationship by underlining the role of the participant as an equal partner in the health service interaction. As one participant put it: “I’m not paying you,

I'm being paid. That means I have something to give. I'm not just being helped, I am also helping." The development and strengthening of participant agency mitigates the possibility that **informed consent was undermined** or that clients were treated paternalistically. In fact, the incentives facilitated a decision-making process that incorporated participants' essential role in the fight against the epidemic. Rather than becoming objects of an intervention, participants championed their subjectivity in the act of being paid. In addition, the strengthening of client autonomy was infused by beneficence, demonstrated tangibly through viral load suppression and subjectively through the way participants found their voice as partners in the interaction with clinicians.

Ethical organizational protocols to prioritize adherence. Christiansen's and Claassen's concepts of allocation of organizational resources and of organizational relationships or boundaries^{12,13} merged into a theme we classified as emergence of ethical organizational practices that focused on adherence.

The relatively poor ARV adherence rates in the socially precarious community served by the organization where participants were receiving their ARV treatment led to a revamping of organizational priorities. The organization sought to improve adherence rates to bring them on par with those for PWH in the larger community, despite the demonstrated barriers of substance use, homelessness, and mental illness that confronted its clients. Previously, the organization had focused on housing homeless people living with HIV. While housing addressed one of the most significant barriers to adherence, the implicit assumption that high adherence would be the eventual outcome was not borne out across all populations of clients. Accordingly, the organization refocused on ARV adherence, ushering in tangible viral load-related goals and innovative methods to incentivize adherence. We argue that this focus on adherence for the population that was at highest risk of nonadherence brought with it an ethical clarity that enabled streamlining of organizational practices. The organization felt that higher adherence would improve individual and public health outcomes and reduce avoidable health care costs to such an extent that paying for adherence would ultimately be cost-effective, significantly beneficial for participants who could thereby achieve and sustain viral suppression, and a meaningful strategy to address **persistent HIV health inequities**.

This was the logic used in securing funding from a private foundation to conduct a demonstration program to establish the feasibility of an ethical and effective intervention. An incentive of \$100 per quarter for suppressed viral load count emerged as the optimal amount based on literature indicating that this incentive would be meaningful, noncoercive, and cost-effective.^{17,18,19} Participants routinely indicated that the incentives were meaningful in maintaining adherence. One participant noted: "It helps that me taking my meds also helps to pay for groceries." Another noted that the incentives were also a way for the organization itself to resist inadvertently contributing to the illegal market in pills: "There's always been these pharmacies [that would buy the pills]. This [payment as an incentive] just means that I can make money above the table, and not illegally. This helps."

In addition to allocating organizational resources, the organization implemented several innovative strategies to support the incentives-based intervention. A social marketing campaign framed ARV adherence as a heroic accomplishment supporting individual health. Ghose et al noted that the campaign successfully motivated participants to enroll in the intervention.⁶ Service provision teams were formed comprising doctors,

nurses, social workers, and case managers. Regular case conferences of the service provision team and the client were initiated to identify barriers to adherence and craft client-centered adherence supports. Monthly viral load suppression meetings were held in which service provision teams discussed progress and challenges, shared strategies of success, and engaged in multidisciplinary training. Often, the multidisciplinary audience would provide written and verbal feedback during these training sessions on how the intervention was forcing them to learn innovative techniques and pushing them to engage with other disciplinary perspectives to provide more integrated care. The organization also collaborated with academic partners to monitor outcomes and train service provision teams in evidence-based practices such as motivational interviewing (MI) and cognitive behavioral therapy (CBT).

On several occasions, case managers in the meetings would tackle the specter of unintended harm, especially for those who could not remain adherent. Christiansen flags this ethical concept of maleficence as one to be addressed explicitly in community health care provision.¹² Training sessions addressed these concerns by encouraging health care professionals to work with clients following a stages-of-change (SOC) model, whereby success was defined by moving to the next stage rather than by moving immediately to the ultimate goal. Financial incentives were therefore a final reward within the SOC model. In other words, failure was removed from the equation as clients could take their own time to get to the final stage, given where they started. This approach undermined distinguishing those whose viral loads were undetectable from those whose viral loads were not. In one of the training sessions, the medical director for the organization, who was supervising the overall intervention, commented that it was refreshing to learn about evidence-based social work techniques of engaging with clients through MI, CBT, and SOC techniques. These innovative processes had always been aspirational goals. The incentive initiative, with its measurable objective of viral load suppression and its financial investment in client success, appeared to galvanize the organization to concretize what had previously been merely aspirational goals for organizational process.

The innovative practices wrapped around financial incentives also inscribed beneficence into organizational practices, resulting in a systematized interdisciplinary culture that lives on in the organization. For instance, these practices have now been replicated at the organization in an intervention for promoting treatment engagement and adherence to medication for people living with hepatitis C. Initial results indicate that the initiative has resulted in significantly increased rates of enrollment in care, testing, adherence, and cure.

Focus on redistributive justice. Organizational staff advocated for financial redistributive justice more broadly following the launch of the incentive program. City officials recognized that **redistributive justice**—in transferring money directly to participants with the goal of addressing social barriers to adherence and resulting health inequities—was informed by egalitarianism and a nonpaternalistic orientation. Based on the initial success of the intervention, this message of a client-centered incentives approach hit its mark when the city's department of health funded a scale-up of the program to include other agencies seeking to improve HIV treatment effectiveness among vulnerable PWH.²⁰

It is important to note here that though redistributive justice through the mechanism of financial incentives was a new mode of patient advocacy, the organization's activities

were already rooted in principles of client self-reliance and economic justice. Formed as a membership organization of clients, staff, and volunteers, the organization has a strong commitment to advocacy with and on behalf of low-income PWH. It also has a well-established practice of hiring clients who have graduated from its job-training programs for staff positions, supporting their ongoing education, and promoting them through the ranks. From its inception, the organization has employed social enterprise, including upscale thrift shops, to generate funding for its operations and provide employment opportunities for clients. The use of financial incentives, therefore, was both an outgrowth of applying the organization's principles of client self-reliance and economic justice and an accelerant for seeking broader redistributive justice.

A citywide scale-up of financial incentives for ARV adherence, based on the same innovative and collaborative practices that made the intervention effective within the organization, helped to promote justice by spreading benefits to similar populations beyond the organization.

Conclusion

Our results indicate that financial incentives, when embedded in wrap-around services, innovative client-centered organizational processes, and a justice orientation, constitute an ethical intervention. Beneficence was infused in every element of the framework, as discussed above. While we found evidence for some of Christiansen's and Claassen's categories of ethical service provision, new themes emerged in our data. Specifically, we found that by emphasizing factors of ethical concern in financial incentives, Claassen's framework, with its emphasis on paternalism and coercion, undertheorizes the possibility of positive ethical outcomes in providing financial incentives. In particular, we found that incentives trigger innovative processes on the personal, organizational, and citywide levels, all of which strengthen ethical treatment. Our results support a conceptual ethical framework for assessing incentives-based interventions and other interventions in the field of HIV care.

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AMA CODE SAYS

AMA Code of Medical Ethics' Opinions Related to "Ending the HIV Epidemic: A Plan for America"

Robert Dinallo

Abstract

The *AMA Code of Medical Ethics* offers guidance on HIV screening that respects patient autonomy and protects public health in Opinion 8.1, "Routine Universal Screening for HIV." This article examines the relationship between this opinion and the Ending the HIV Epidemic: A Plan for America initiative and discusses the *Code's* guidance on the role that physicians can play in diagnosing and treating patients with HIV and mitigating the stigma surrounding the disease.

Ending the HIV Epidemic

As of 2018, more than 700 000 people in the United States had died from HIV/AIDS, and an estimated 1.2 million Americans were living with HIV.^{1,2} In 2019, the president proposed \$291 million in new funding for fiscal year 2020 for the US Department of Health and Human Services (HHS) to implement Ending the HIV Epidemic: A Plan for America (EHE), a new initiative that would leverage landmark biomedical and scientific research advances across HHS agencies and offices to tackle the HIV epidemic.^{2,3} American Medical Association (AMA) *Code of Medical Ethics'* opinions describe how physicians can help combat the HIV epidemic through testing, treatment, and dismantling the stigma of the disease, all of which work in conjunction with the EHE initiative.

Roles of Physicians

The *AMA Code* addresses HIV most directly in Opinion 8.1, "Routine Universal Screening for HIV," which provides important information on testing and treating patients with HIV.⁴ Opinion 8.1 states that physicians should support "routine, **universal screening** of adult patients for HIV with opt-out provisions."⁴ The opinion also counsels that physicians should "work to ensure that patients who are identified as HIV positive receive appropriate follow-up care and counseling."⁴ Routine screening and quick treatment of HIV to reach sustained viral suppression are essential parts of accomplishing the first steps of the EHE central strategy.³ The *AMA Code* clarifies the role that physicians can play in accomplishing these steps,³ and physicians and other clinicians can use the resources provided by HHS, such as the EHE resource on HIV hotspot regions in the United States,⁵ to ensure that these steps are accomplished as quickly and effectively as possible.

The AMA Code and the EHE also recognize the role that physicians can play in mitigating the stigma surrounding the disease and in preventing transmission. The EHE acknowledges that **overcoming the stigma** associated with the disease—which can prevent patients at risk or living with HIV from receiving the health care and services they need—is one of the central challenges faced by the initiative.³ Indeed, in 2016, nearly 40% of people with HIV either did not know they had HIV or were diagnosed but not receiving care.³ In order to combat this social challenge, Opinion 8.1 states that physicians should “make efforts to persuade reluctant patients to be screened, including explaining potential benefits to the patient and to the patient’s close contacts.”⁴ Moreover, it also states that physicians should “attempt to persuade patients who are identified as HIV positive to cease endangering others.”⁴ In short, physicians have a responsibility to engage with the social context of HIV through the patient-physician relationship by persuading reluctant patients to be tested and to protect their partners and by actively addressing the disease’s stigma.

For physicians who wish to engage with the social aspects of the epidemic outside of the patient-physician relationship, Opinion 1.2.10, “Political Action by Physicians,” offers guidance on how physicians can ethically perform such social advocacy.⁶ For example, the opinion states that “physicians have an ethical responsibility to seek change when they believe the requirements of law or policy are contrary to the best interests of patients,” as long as “the health of patients is not jeopardized and that patient care is not compromised.”⁶ This flexibility allows physicians to engage with a wide variety of HIV activist and support groups and is another way that physicians can address the disease’s stigma.

In light of the COVID-19 pandemic, it can be difficult to remember that the HIV epidemic is still an ongoing problem in the United States. The AMA Code has various guidelines that can help physicians best address the virus and facilitate the EHE’s goal of virtually ending the number of new HIV infections by 2030.^{2,3}

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STATE OF THE ART AND SCIENCE: PEER-REVIEWED ARTICLE

What We Know About Long-acting Injectable Antipsychotics Can Help Innovate HIV Care

Olivia S. Kates, MD

Abstract

Long-acting injectable antiretroviral therapy (LA-ART) is a powerful new addition to the treatments available for patients living with HIV, but broad acceptance and uptake could be compromised by what we know about patients' and clinicians' experiences with long-acting injectable antipsychotics (LAI-APs). Treatment of stigmatized conditions, such as psychiatric illness or HIV, using long-acting injection is ethically fraught with patients' fear of coercion and forced administration. Strategies that emphasize patient-centered, patient-directed care and that place limits on when LAI can be administered forcibly can help promote LA-ART's acceptance and use.

To claim one AMA PRA Category 1 Credit™ for the CME activity associated with this article, you must do the following: (1) read this article in its entirety, (2) answer at least 80 percent of the quiz questions correctly, and (3) complete an evaluation. The quiz, evaluation, and form for claiming AMA PRA Category 1 Credit™ are available through the [AMA Ed Hub™](#).

Comparing LA-ART and LAI-APs

Long-acting injectable antiretroviral therapy (LA-ART) is effective for treatment and prevention of HIV. A once-monthly injectable formulation of the medications cabotegravir and rilpivirine was approved by the US Food and Drug Administration for treatment of HIV in certain patients in January 2021.¹ The first radical reimagining of HIV treatment in nearly 25 years, LA-ART offers enormous promise for people living with HIV and for the Ending the HIV Epidemic program, which seeks to reduce new infections at least 90% by 2030.² Participants in studies of LA-ART have reported favorable views of its convenience and simplicity.³ Yet ethical questions related to these and other anticipated benefits of LA-ART should be explored.

Similarities between LA-ART and long-acting injectable antipsychotics (LAI-APs) and structural and sociocultural overlaps between HIV and psychiatric illnesses suggest that their comparison is useful. Although HIV and psychiatric illness are very different in terms of both biology and lived experience, both diagnoses have historically been stigmatized. Additionally, both HIV and psychiatric illness disproportionately affect marginalized populations, with higher burdens and

worse outcomes among people of color, people of marginalized gender and sexual identities, people living in poverty, and people who are incarcerated.⁴ HIV and psychiatric illness are also recognized as important to public health and safety: HIV is a communicable disease and psychiatric illness is one of several syndemic burdens connected to joblessness, homelessness, and crime.⁵ In consequence, patients with HIV and psychiatric illness are subject to special legal privacy protections as well as protective and criminalizing statutes.^{6,7} Finally, care of patients with HIV and patients with psychiatric illness each has fraught ethical, clinical, and public health histories, and some clinicians have (perhaps unwittingly) **participated in patients' stigmatization**, marginalization, and mistreatment.

Patient Experiences of LAIs

When treated orally, both HIV and pharmacologically managed psychiatric illnesses (eg, schizophrenia) typically require at least once-daily pills and long-term adherence for treatment success. LAIs can be used to (and were indeed designed to) promote adherence, since they are administered in-clinic as shots, 3 to 12 weeks apart. While most oral medications are self-administered, injectable medications are administered by clinicians; this is ethically relevant for 3 reasons: (1) clinicians' authority can cause anxiety for patients, (2) the long-acting nature of the drug effectively requires therapy continuation with no way to opt-out for weeks or months, and (3) in-clinic administration of LAIs enables **close adherence monitoring**, which some patients experience as intrusive.⁸

Likely designed with good intention to make it easier to adhere, LAIs have an ethically relevant side-effect: they restrict patients' liberty while administered medications endure in their bodies. Clinicians have centered this effect in decisions to treat patients with LAI-APs; the drugs may be regarded as a "treatment of last resort" and are often recommended for patients thought to have severe or refractory illnesses, nonadherence, lack of insight, or treatment "failure."⁹ Although LAI-APs demonstrate benefits to patients at all phases of psychotic illness and more than half of psychiatrists in one survey consider them for patients who experience multiple relapses, only 10% of surveyed psychiatrists recommend them to newly diagnosed patients.¹⁰ Patients who have never used LAI-APs report negative attitudes about the drugs and pessimism about their purported benefits, even though patients with long-term experience with the same medications report favorable views.¹¹ These dimensions of patients' and clinicians' experience with LAI-APs suggest the importance of considering the impact of similar features of LA-ART. LA-ART should not be presented as a solution to nonadherence but instead should be seen as a way to promote equity in treating all patients with HIV. LA-ART should be broadly available such that patient-centered treatment goals like U = U (undetectable viral load equals untransmissible virus) are obtainable.

Equity, Coercion, and Force

LAIs can be perceived as coercive and as prioritizing clinical or social goals over patients' self-determination. Some patients feel that LAI-APs, as opposed to oral antipsychotics, restrict their autonomy, and 68% of surveyed psychiatrists agree that patients taking medication by choice are more likely to be taking oral antipsychotics than LAI-APs.¹² Compared to patients treated orally, patients for

whom LAI-APs are prescribed are more likely to be people of color, have a police history, or have a **substance use disorder**. It is unclear whether prescribing practices differ due to clinician preferences or need, patient preferences or need, or clinician biases that prompt clinicians to direct therapy to promoting adherence.¹³ LAI-APs can be also used forcibly for court-ordered inpatient or outpatient treatment for patients who lack decision-making capacity because of severe psychiatric illness. Such treatment plans can be developed between a patient and physicians to promote that patient's best interest.¹⁴ In criminal courts, LAI-APs can be used to restore a defendant's competency to stand trial, to treat patients experiencing incarceration, or to help meet a person's conditions for supervised release from incarceration, all of which treatment plans may consider interests external to the patient.^{15,16}

While involuntary administration of short-acting or long-acting antipsychotics is common, involuntary HIV care is very unusual, because HIV does not directly impair decision-making capacity. In addition, long-term willingness and ability to adhere to treatment are key indicators of a patient's readiness to start ART, because sporadic treatment can lead to antiretroviral resistance.¹⁷ These differences between LAI-APs and LA-ART suggest that LA-ART would be unlikely to be used to treat patients involuntarily for HIV. In the most plausible scenario, patients with HIV who lack capacity to make health decisions could be treated forcibly with LA-ART but with an appropriate surrogate's consent, based on substituted judgment or the patient's best interest.¹⁸

LA-ART could possibly be used to forcibly treat patients with HIV who lack decision-making capacity (ie, as court-ordered treatment), but extant laws would likely have to be construed to justify force in an extreme case. Many states' laws criminalize nondisclosure of one's HIV-positive status (often targeting people with HIV experiencing incarceration), and there is legal precedent for **public health-mandated treatment** of sexually transmissible infections, including HIV.¹⁹ But these laws should not be understood as broad legal or ethical endorsement of forced HIV care, a violation of patients' autonomy that is unlikely to result in long-term treatment adherence. In fact, to continue to advance HIV decriminalization efforts, health professionals should neither support nor participate in court-ordered HIV treatment.²⁰

Navigating Novelty

LA-ART, like LAI-APs for psychiatric illness, expands treatment options available to people living with HIV, offering convenience, continuity of care, privacy (eg, for patients uncomfortable storing medications used to treat stigmatized illnesses), and adherence support. As discussed here, adherence promoted via LAIs decreases risk of relapse and slows disease progression, but whether LAIs are prescribed also reflects clinicians' preferences or bias and patients' preferences or needs. Clinicians can work with patients to address any anxiety, reservations about lack of opt-out opportunity, or discomfort with increased monitoring and to ensure that LAIs support patients' health goals, align with their preferences and needs, and promote health equity. Lessons from experience with LAI-APs illuminate clinically and ethically relevant similarities and differences between LAI-APs and LA-ART and can help early adopters and leaders to deploy LA-ART in ways that promote broad acceptance of an important novel therapy for responding to needs and vulnerabilities of patients with HIV.

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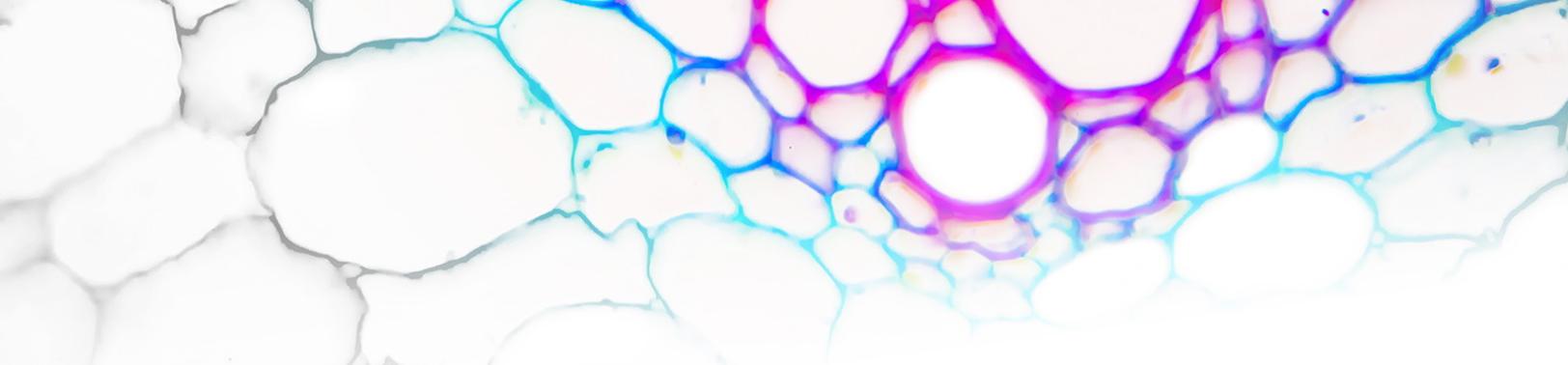
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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

Exceptionalism at the End of AIDS

Adia Benton, PhD, MPH and Thurka Sangaramoorthy, PhD, MPH

Abstract

HIV/AIDS exceptionalism promoted compassion, garnered funding, built institutions, and shaped regulatory and research agendas under emergency conditions. Globally, however, HIV/AIDS exceptionalism has further fragmented fragile health service delivery systems in vulnerable, marginalized communities and created perverse incentives to influence seropositive individuals' behaviors. Even where HIV epidemics are viewed as "controlled" or "resolved" (as in the United States), ending AIDS requires eliminating exceptionalism, normalizing justice-based approaches to HIV care, and explicitly acknowledging how power dynamics shape popular narratives and practices.

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HIV/AIDS Research

When we began planning this essay, we talked about the experiences that led us to HIV/AIDS research.

A.B.: In 1997, I enrolled in my first (and only) undergraduate anthropology course, "AIDS in International Perspective." It was a small seminar—no more than a dozen students—for which we read hundreds of pages per week and, on a weekly basis, met someone from the AIDS community in southern New England. The course's instructors also required us to volunteer in one of the many AIDS programs in our small state. I joined an AIDS peer-education group geared toward out-of-school youth and became the group's co-leader the following year. Over the next 5 years, I worked for prison doctors who specialized in HIV treatment, interned in the Department for HIV/AIDS Prevention at the Centers for Disease Control and Prevention (CDC), and consulted for a range of HIV/AIDS programs for international nongovernmental organizations in sub-Saharan Africa. Ten years after that first anthropology course, I completed dissertation fieldwork among HIV-positive Sierra Leoneans, funded by an AIDS training grant from the National Institutes of Health (NIH).

T.S.: From 1998 to 2001, I worked for 2 nonprofits alongside renowned international scholars in the social sciences and medicine from sub-Saharan Africa and the United States, conducting research and managing fellowship programs focused on higher education, social medicine, and medical ethics. On extended work assignments to South Africa and Ghana, I first became attuned to the devastating effects of HIV/AIDS. The prevalence rate in Ghana at this time was 3% to 4%, and women, especially commercial sex workers, were severely affected by the epidemic.¹ In South Africa, AIDS more than doubled the country's mortality rate; AIDS-related deaths accounted for half of the nation's total death rate from 1999 to 2000.² I accompanied colleagues to villages and cities where makeshift cemeteries had cropped up, children were caring for ailing parents, and activists were protesting for the widespread provision of antiretroviral drugs. Forever changed by this experience, I enrolled in a public health program and worked on one of the longest-running longitudinal studies of people living with HIV. A few years later, I completed my NIH-funded dissertation fieldwork in anthropology with HIV-positive Haitians living in South Florida and finished postdoctoral training in HIV and sexually transmitted diseases at the CDC.

We provide these autobiographical details not to establish our legitimacy as AIDS experts, but to demonstrate the extensive reach of what Cindy Patton long ago referred to as “the AIDS industry”³ and the **exceptional status** afforded to HIV/AIDS. In this essay, we address what it has meant for the disease to have achieved exceptional status—in our work, for our interlocutors, for the institutions we routinely encountered as a condition of that exceptionalism. We describe this trajectory of AIDS' exceptionalism within a broader history and political economy, briefly examining the challenges that lie ahead as we seek the end of AIDS.

HIV/AIDS Exceptionalism

The idea that HIV/AIDS is an exceptional disease requiring an equally exceptional response has a fraught history.^{4,5,6} The new viral syndrome emerged at a time when public health and clinical medicine had become confident in their ability to identify, trace, diagnose, and treat infectious diseases with relative efficiency and efficacy. AIDS shattered that confidence when it was first recognized among White, gay men in US cities like San Francisco, Los Angeles, and New York City in the early 1980s. It initially appeared to affect mostly young, otherwise healthy, individuals in ways that confounded the clinicians and epidemiologists who first encountered it.^{7,8}

By 1983, the designation of AIDS risk focused on a handful of groups, collectively called the “4H club”: homosexuals, hemophiliacs, Haitians, and heroin users. (Others—notably David Black, author of *The Plague Years: A Chronicle of AIDS, the Epidemic of Our Times*⁹—added “hookers” to the club's membership roster.) The specious and discriminatory lumping of nationality, sexual orientation, cultural practice, occupation, and biological traits guided health policy, clinical practice, and public messaging, producing a number of deleterious effects globally.^{10,11,12} Among those effects was the exclusion of the general population from those perceived to be at risk for or living with HIV/AIDS^{3,13} and the further **stigmatization** of and discrimination against already marginalized groups.^{14,15} It soon became clear to caregivers, clinicians, social science researchers, and activists that the ripple effects of AIDS in families, communities, and wider systems necessitated a broad-based response that addressed not only the biological and clinical facets of the disease, but also its political, social, and economic dimensions.^{12,16,17,18} HIV/AIDS thus constituted a public health emergency of an unprecedented nature.^{19,20}

As is the case during emergencies of this magnitude, the institutions, practices, and norms forged in crisis may persist long after the crisis has receded from view. HIV's exceptional status, in other words, has (re)produced durable, resilient institutions, norms, and practices worldwide. Within US government agencies like the NIH and the Food and Drug Administration, expedited trials for experimental therapies and potential vaccines ensued in response to aggressive lobbying by AIDS activists.^{8,21} At the international level, entirely new institutions were established to coordinate AIDS activities. The Joint United Nations Program on HIV/AIDS (UNAIDS) was established in 1994,²⁰ while the World Health Organization's 3-by-5 Initiative was created to improve access to highly active antiretroviral therapies to 3 million individuals in poor countries by the end of 2005.²²

Funding mechanisms for HIV/AIDS programming expanded globally as well. Among the best-known **financing efforts** are the Global Fund to Fight AIDS, Tuberculosis and Malaria, established in 2002 by a transnational private-public partnership; George W. Bush's President's Emergency Plan for AIDS Relief; and AIDS-specific funding through US government agencies like the NIH, CDC, and the Substance Abuse and Mental Health Services Administration. AIDS has also reconfigured public health governance in the form of national AIDS secretariats in low- and middle-income countries and the enshrinement of "AIDS czars" within governmental agencies.^{23,24}

Of course, institutional and structural changes wrought by HIV's exceptional status were not solely generated through or by powerful institutions and individuals. Activists involved in social movements and political struggles organized to address inequalities rooted in misogyny, patriarchy, heterosexism, racism, and capitalism were at the forefront and influenced early HIV activism.^{3,25,26,27,28} Residential segregation and affordable housing, labor, wages and livelihoods, incarceration, and access to comprehensive and **affordable health care** were among the issues that activists tried to address not only for those living with HIV/AIDS, but also for vulnerable populations more broadly.^{6,29} Such movements paved the way for social, legal, and political change concerning life-and-death matters, including access to treatment, the ethics of experimentation, and knowledge production.³⁰

The AIDS-centered marketing, media, and advocacy campaigns of the 1990s and 2000s ushered in a new era of social marketing,²⁰ with a wide range of organizations committed to raising public consciousness and capital to support AIDS prevention, treatment, and support programs (eg, ACT UP, Red Ribbon Campaign, Product RED).²⁰ And, finally, new legal and legislative frameworks emerged in the wake of discrimination, stigma, and fear of HIV-positive individuals, including the Ryan White Care Act and the development of policies addressing workplace discrimination, privacy, and the criminalization of AIDS.^{23,24}

Yet our work also shows that durable institutions never fully cede their power; instead, they tend to absorb and coopt the movements that initially pushed for social change.^{31,32} Nongovernmental organizations, once devoted to structural interventions to address HIV/AIDS but now funded by a growing nonprofit industrial complex, began to fill a void in areas where state-sponsored social service resources and offerings were scarce.³³ Field-based, empirical studies highlight how far-ranging HIV-specific programming had distorting effects, particularly among communities where deep disparities and inequities persist. A.B.'s ethnographic research in Freetown, Sierra Leone, for example, suggests that the quality of and access to health care may be slightly better for HIV-positive urban

residents than seronegative individuals of the same social status; notably, other people and other health issues were marginalized in a siloed system in which HIV constitutes its own subset of health priorities and social issues.³⁴

The expectation that the benefits of HIV programming—better labs, better access to pharmaceuticals, better training for clinical staff, better health education, and outreach that attends to social and economic needs—would trickle “sideways” to other health issues and “down” to the most vulnerable was not fully realized in the first decade of widespread access to antiretroviral therapies.^{35,36,37,38} The HIV industry in Freetown offered a means for poorer HIV-positive individuals to improve their status through participation in workshops and international forums dedicated to people living with HIV/AIDS, to join support networks tailored to their condition, and to access resources allocated for HIV-positive people.^{35,38,39}

Continued Inequity

In the US South, HIV is a continuing crisis linked to historical legacies of segregation, underfunding of safety nets, retreating welfare states, and federal funding directives. T.S. and colleagues’ ethnographic research has documented the severe disconnect between official discourses of unified global HIV response and local realities.^{40,41} Although HIV programs and policies aimed at allocating resources to populations with the highest disease burden, African Americans and Haitian Americans were not afforded equal access to necessary resources—despite their disproportionately higher rates of infection, morbidity, and mortality due to health financing structures and discriminatory policies.³¹ HIV exceptionalism also makes it possible to displace the responsibility of care from social welfare and public health institutions to individuals themselves, so that the continued rise in HIV disparities becomes attributable to individual and collective risk, rather than to the broader structural constraints generated by institutional directives.

As HIV policy discourse and practice focuses on the end of AIDS, we are faced with 2 significant challenges, which are also artifacts of decades of exceptionalist planning and programming: living with a chronic HIV infection and rising and new infections among racial and ethnic minorities, transgender people, and users of injection drugs. In this third decade of life-prolonging antiretroviral therapies, what does it mean to grow old with HIV? What might a lifetime on these therapies do to aging bodies? Much of HIV funding continues to focus on biotechnical advances rather than on developing better knowledge of antiretroviral drugs’ effects on aging and older people. T.S. and colleagues’ ethnographic research among aging women and men, for example, suggests that medications and their weathering effects might be responsible for other chronic conditions, frailty, and disability.^{38,41,42,43}

Controlling rising and new infections in certain groups in the US South and the Global South, where many HIV-positive people reside and most new infections occur, is challenged by health systems that are fragmented and under-resourced in ways that make the interventions outlined in the Ending the HIV Epidemic strategy difficult.⁴⁴ The US South, for example, simply does not have the human, infrastructural, and organizational resources to develop comprehensive prevention programs, nor has it been adequately equipped to provide quality and timely care for the management of HIV.⁴⁵ This lack of resources is especially challenging for a population suffering from chronic conditions associated with HIV and aging.

The End of AIDS

Going forward, as we look to ending AIDS, we must acknowledge the strides made over the course of 40 years—particularly as the laser focus on the disease and its biological, social, political, and economic dimensions has channeled activism into changing regulatory mechanisms, institutional practices, and sociocultural norms. But a thriving AIDS industry has made these achievements under conditions in which interlocking oppressions and concomitant privileges have continued to shape the risk of contracting and dying from the disease in the first place. Thus, we must also consider how HIV's exceptional status, which in a sense served to disrupt and unsettle conservative institutions, also helped to reproduce and entrench the inequalities that set the machine in motion. In this brief commentary, we have shown how this dynamic most seriously affects low- and middle-income countries in sub-Saharan Africa, where exceptionalist donor agendas have skewed health systems away from comprehensive primary care. In high-income countries like the United States, increasing incidence among some racial and ethnic minority populations highlights how long-standing issues related to uneven resource distribution, racism and discrimination, and lack of access to care continue to drive acute racial disparities in HIV.^{46,47} As we discuss the end of AIDS, then, we would be wise to revisit its beginnings, before AIDS exceptionalism became institutionalized in ways that elided broader justice struggles that AIDS merely amplified. Doing so will enable us to enlarge and extend an agenda for care and justice rather than merely reproduce inequalities engendered through exceptionalism.

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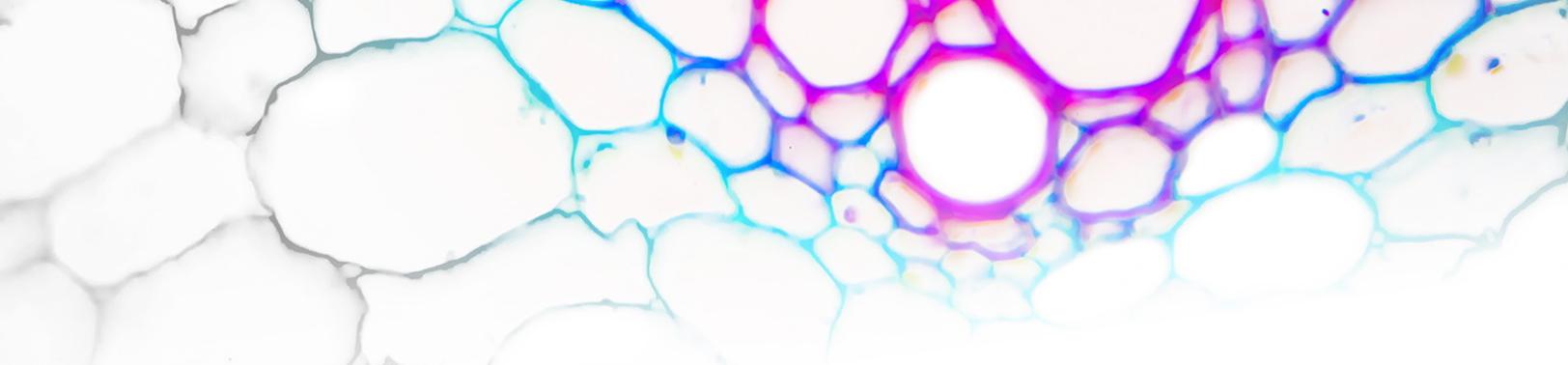
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Is “Undetectable = Untransmissible” Good Public Health Messaging?

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Abstract

This article considers merits and drawbacks of “undetectable = untransmissible” (U = U) messaging in the global HIV response. First, viral suppression might be achieved with effective treatment, but not everyone living with HIV has access to such intervention and care. Second, although U = U can help individuals living with HIV, this messaging might stigmatize those for whom interventions have not achieved viral suppression. Third, although biomedical advances have attempted to address infectiousness, syndemic drivers that predispose individuals to HIV acquisition are not well accounted for by U = U messaging.

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Treatment Innovation and U = U Messaging

Since the first case of HIV was reported in 1981, more than 75 million people have been infected with HIV, and more than 32 million have died from AIDS-related illnesses.¹ Since then, life expectancies of people living with HIV have improved.² Biomedical advances produced highly active antiretroviral therapy (HAART) in 1996,³ and, as of August 2020, more than 30 ART medications across 6 classes were available to people living with HIV.⁴ Prospective cohort studies after 1996 demonstrated that individuals with low viral loads only infrequently transmit HIV to HIV-negative partners.^{5,6,7} This finding led, in 2008, to the “Swiss Statement”: individuals on fully suppressive HAART for at least 6 months who have no sexually transmitted infections cannot transmit HIV through sexual contact.⁸ While many remained unconvinced, more recent evidence from several large-scale, observational cohorts and trials in HIV prevention—including HPTN 052, PARTNER, and Opposites Attract—suggests that HIV transmission risk from an individual with an undetectable viral load to an HIV-negative sexual partner is effectively zero.^{9,10,11} These studies have motivated global support for “undetectable = untransmissible” (U = U)¹² messaging to reduce stigma and encourage individuals with HIV to start treatment as early as possible. But the merits of U = U messaging must be considered in light of what we should be cautious about; this is the purpose of this article.

Merits

Awareness and implementation of U = U messaging campaigns are gaining global traction,¹³ including among physicians and their patients,¹⁴ and has benefited individuals living with HIV and HIV prevention efforts. U = U messaging, for example, has led to new evidence-based guidelines from the Centers for Disease Control and Prevention that endorse condomless intercourse among serodiscordant couples planning to conceive, so these couples no longer require infertility clinic referral for *in vitro* fertilization, which is costly and, for many, inaccessible.¹⁵ Furthermore, gay, bisexual, and other men who have sex with men (GBMSM) living with HIV who are aware of U = U messaging view having an undetectable viral load as an achievement, as a symbol of having attained optimum health, as a sign of personal and social responsibility to their communities, and as a means of having sexual and romantic partnerships.¹⁶ “Becoming undetectable” allows GBMSM to feel more comfortable having sex and disclosing their HIV status to their sexual partners.¹⁷ For GBMSM, living with an undetectable HIV viral load also means having control over their HIV status and having autonomy in their health and relationship decisions, experiencing a sense of normalcy in their lives, and knowing that their risk of transmitting HIV is, at a population level, dramatically reduced.

Cautions

Yet uncritical advocacy of U = U messaging is unwise without close scrutiny from ethics and public health standpoints of how the messaging is promulgated and received.

Achievement? First, we must be cautious about accepting that U = U messaging is domestically and globally inclusive and closely attentive to structural and psychosocial barriers faced by many to quality care and treatment. Undetectable viral load might be achievable for most, but people living with HIV who have unreliable or irregular access to testing or medication could feel left behind or demoralized by U = U messaging. People in resource-poor settings might lack facilities in which viral load testing can be properly conducted, which problematizes the view that U = U should be, clinically or ethically, regarded as an achievement.¹⁸ Because marginalized people living with HIV, including racial and ethnic minorities and sex workers, experience poverty, discrimination, and other barriers to care, seeing their or anyone’s failures to adhere to HAART regimens and “achieve” undetectability is as stigmatizing^{19,20} as it is expressive of one’s incomplete understanding of HIV care’s complexity. Social determinants and cultural or material conditions that undermine adherence must be carefully considered in U = U messaging, since poor adherence can contribute to evolution of drug-resistant mutations of HIV and since virologic failure and HIV drug resistance have emerged in many low-to-middle-income countries (LMICs).^{21,22} Frequent medication stockouts, economic and political displacement, and other barriers in LMICs^{23,24} suggest how considering viral load suppression as an achievement is unjust and unhelpful.

Othering. Second, U = U messaging can empower some individuals who are living with HIV but inadvertently stigmatize and otherize those for whom HAART intervention has not yet achieved viral suppression. If U = U messaging misfires to deepen divides between HIV-negative and HIV-positive individuals or is interpreted as a means of parsing infectious people with HIV from those who have achieved undetectability and uninfectedness,²⁵ then U = U messaging will likely have undermined hard-won advances in HIV care, undermined solidarity by designating normal and deviant ways of being a person with HIV, and undermined unity to confer privilege to some and disadvantage to others.^{26,27} Communities inequitably affected by HIV, such as GBMSM,

might develop identities along serological lines, identifying as “undetectable” rather than as “HIV positive” or as being on ART.²⁸ Otherization is a product of stigmatization, and it could result in HAART hesitancy, which would help no one.

Biomedicalization. Third, U = U messaging uses viral load as a biomarker in a social, cultural, and public health change campaign. We must take care that a physiological indicator does not overly biomedicalize HIV, which could muddle how we respond to needs and vulnerabilities of people experiencing the syndemic of HIV, gender inequality, and comorbidity, such as **substance use disorder**.^{29,30} Treatment-as-prevention is a key part of U = U messaging, but it risks oversimplification of how deeply individual biographies and life histories are affected by psychosocial and environmental factors that undermine health equity.^{31,32} Messaging strategies must be sufficiently designed to resist oversimplification, or at least not to invite it, and to express respect for the plurality of factors that need attention in a good HIV response.

Message Translation

U = U messaging looks to translate game-changing breakthroughs in science to attract the attention of people living with HIV who could benefit from HAART interventions, and it should continue.³³ The cautions we’ve suggested here should help us deploy this messaging responsibly and equitably and with great attention not only to what the message is but also how it’s **interpreted and received**. Messaging should express commitment to equitable access to HIV testing and medication—especially in LMICs—and should help identify and respond robustly to factors that obstruct HIV prevention.

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MEDICINE AND SOCIETY

Lessons on Surviving a Pandemic From 35 Years of AIDS Cinema

E. Berryhill McCarty, MA, MSHCPM and Lance Wahlert, PhD

Abstract

Global transformation demanded by the COVID-19 pandemic prompts consideration of how prior epidemics have contributed to and continue to shape our cultural and sociological understandings of health care and patients. Documentaries and cinematic narratives have charted the 1980s AIDS epidemic in the United States, and this article traces a historical arc of that crisis, contrasts historical (HIV) and current (SARS-CoV-2) contagion experiences, and reviews thematic representations of AIDS and COVID-19 experiences among vulnerable patients and populations.

*When near your death a friend
Asked you what he could do,
'Remember me,' you said.
We will remember you.*

Thom Gunn (1992)¹

Some of the agonies that burn in the heart forever begin as brief as snapshots.

Paul Monette (1998)²

From Headlines to Activism to Cinema

On July 3, 1981, the *New York Times* published an article on a mysterious and rare cancer affecting 41 homosexuals in New York City and California³—*mysterious* because this “cancer” behaved like a contagion and *rare* because, prior to this outbreak, such cancers were typically seen in the elderly or immunocompromised. This condition was being diagnosed in younger, healthier men, most of whom identified as homosexual. This was one of the earliest reports of a phenomenon that would define a generation—the AIDS epidemic. Within a year of the article’s publication, the infection rate had increased 4-fold, with case numbers and fatalities rising exponentially over the next decade.^{4,5} The early reports bear an eerie similarity to the daily tallies of cases and deaths during the COVID-19 pandemic. In the midst of the current pandemic, examining iconographic and thematic representations of the AIDS epidemic over the last 35 years can illuminate the effects such a contagion can have on trust, both personal and political.

The December 1981 edition of *Mandate*, an erotic magazine for gay men, featured an article on the new disease with the words “Gay Cancer” plastered in hot pink over 70% of a 2-page spread in an attempted reclamation of a term that would come to shape responses to AIDS for decades.⁶ The article itself opens with a report of a “sudden outbreak within the homosexual community,” noting escalating infection rates and calling the outbreak “a menace that must be dealt with logically and quickly if we are to overcome it, and knowledge of the disease, its causes and effects, is our best weapon.”⁶ Yet by 1985, little had been done to combat the HIV/AIDS crisis. Not complacent in the face of this potentially literal erasure, lesbian, gay, bisexual, and transgender (LGBT) and AIDS activists intensified their efforts. Groups like Gay Men’s Health Crisis and the AIDS Coalition to Unleash Power (ACT UP) emerged, and, to the chorus of “FIGHT BACK, FIGHT AIDS!,” they strategically combined anger-fueled, highly visible, dramatic protesting with well-researched understandings of the disease and what it might take to treat it.⁷ As David France, director of the AIDS documentary *How to Survive a Plague*, stated in a 2019 interview with *NPR*, “They were no longer invisible sufferers of a disease. They were terrifying sufferers of a disease.”⁸ Policy changed: increased funding was devoted to research, and experimental medications became more widely available.^{9,10}

Our aim in this article is to gesture to some of the key moments in film that have actively shaped our cultural understanding of the AIDS epidemic and those impacted by it. We suggest that these cinematic representations serve 3 primary roles: to eulogize those who might have vanished from our collective memory, to mobilize a group by providing plague survival guides, and to humanize those stigmatized by disease.

Eulogize

Through eulogy, certain films have the power to rescue individuals from social erasure. The 1993 drama *Blue*¹¹ does this literally. Directed by Derek Jarman and released a few months before his death, the film consists entirely of a blue screen (representing his failing eyesight from AIDS complications) over which Jarman muses about his life as a gay man living with AIDS in London in the early 1990s. The blue screen infuses whimsy and melancholy into a narration that explores what it means to succumb to a disease that strips control. *Blue*, for all its dreamy quality, is infused with muted anger as it struggles to honor a complete life while acknowledging its forced erasure—both through the literal illness and through the social death resulting from the stigmatization of diagnosis and visible decline.

Stephen Daldry’s film, *The Hours* (2002),¹² offers a different sort of eulogy in a plot that follows a single day in the life of 3 women living in 3 different times and places, seemingly linked only by Virginia Woolf’s *Mrs Dalloway*. By drawing on this novel’s focus on mundane details in the life of a high-society, single woman in post-World War I England, the film illuminates the seemingly quotidian moments in the lives of 2 other women. These women struggle with the pain of waiting, of living when death seems inevitable and true happiness unattainable. The tension of suicide—the most extreme form of self-erasure—permeates the film, reaching a climax when one character’s ex-husband, a poet living with AIDS, throws himself from a window. His suicide serves as a reclamation of control against unceasing deterioration by illness; it prompts the film’s surviving characters to reevaluate the value of their hours and offers a *Dalloway*-inspired eulogy of a whole life lived and reflected upon during the hours of a single day.

If *Blue* and *The Hours* are solemnly reverential when eulogizing those lost to AIDS, the Canadian musical *Zero Patience*¹³ is positively bawdy. This 1993 film is unapologetically

eccentric, direct, and hilarious in its quest to refute the legend of the inaccurately labeled “Patient Zero,” the Canadian flight attendant Gaetan Dugas, who was falsely believed to have spread AIDS across North America. The plot follows the eternally young Victorian sexologist Sir Richard Francis Burton as he attempts to create a museum exhibit on the origin of HIV/AIDS. Burton becomes literally haunted by Dugas, inadvertently falling in love with the ghost he is trying to vilify. The musical’s final duet is of the 2 lovers bidding each other farewell as the vindicated ghost of Dugas reclaims his legacy, disappearing in a truthful eulogy.

Mobilize

Zero Patience was written in response to the well-regarded but rather controversial 1993 docudrama, *And the Band Played On*,¹⁴ based on a nonfiction book of the same name by Randy Shilts. Like France’s *How to Survive a Plague*,⁹ *And the Band Played On* provides a generally accurate (if dramatized) depiction of the beginnings of the AIDS epidemic and how activists effected change. A series of documentaries released from 2011 to 2018, including *United in Anger: A History of Act Up* (2012),¹⁵ *We Were Here* (2011),¹⁶ and *5B* (2018),¹⁷ sought to educate the public in self-advocacy. The release of these films reflected a growing yearning for historic instruction from the AIDS community.

Some of the most powerful movies of mobilization are fictional accounts like *Longtime Companion* (1990)¹⁸ or biographical dramas like *Dallas Buyers Club* (2013).¹⁹ Whereas *Longtime Companion* presents a literal timeline of the epidemic from 1981 to 1990, *Dallas Buyers Club* tells the story of the electrician and rodeo cowboy Ron Woodroof who was diagnosed with AIDS in the early 1980s. When faced with a medical system unwilling to advocate for him and a society all too willing to ostracize him for his disease, he smuggles experimental drugs from Mexico to Texas and distributes them to his fellow AIDS patients (for a fee, of course) while battling interference from the US Food and Drug Administration. Woodroof’s story, while spectacular in its circumstances, demonstrates the self-advocacy and self-education typical (and ultimately required) of members of the HIV/AIDS community in the early years of the epidemic.

Humanize

Transforming a patient from a statistic into a person is at the root of nearly every film made about the AIDS epidemic. From pioneering feature film *Parting Glances* (1986)²⁰ to the documentary *Common Threads: Stories from the Quilt* (1989),²¹ cinematic focus turned from primarily documenting the crisis to the telling of more intimate human stories. Few films do this as effectively and deliberately as *Philadelphia*.²² Released in 1993, this Hollywood production tells the story of Andrew Beckett, a gay lawyer with AIDS, who sues his former law firm for wrongful termination. Like *Dallas Buyers Club*, *Philadelphia* highlights how individual patients were forced to bear the mantle of self-advocacy during the crisis.

The 2009 drama *Precious*²³ uniquely pauses to examine the stories of those who are overlooked, both in AIDS narratives and in life. Directed by Lee Daniels, the film tells the bleak yet surprisingly affirmative story of Precious, an overweight, illiterate, and imaginative 16-year-old living in 1987 Harlem. She is pregnant with her second child, a product of rape by her father, and the film follows her as she escapes into fantastical daydreams in which she retreats from repeated trauma. Towards the end, Precious demonstrates astounding inner strength as she come to terms with her own HIV diagnosis. Throughout, it is clear that sometimes humanizing is accomplished not only in

telling the narrative (as in *Philadelphia* or *Dallas Buyers Club*) but also in simply allowing the camera to settle on the day-to-day moments, honoring dreams and small triumphs, and not reducing a person to their social circumstances.

Humanizing is not accomplished only through stories of suffering, however. Through laugh-out-loud humor and moments of sweet and sincere connection, the 1995 comedy *Jeffrey*,²⁴ directed by Christopher Ashley, follows a sex-loving gay man, Jeffrey, as he navigates the fear, frustration, and irony of living in Manhattan at the height of the AIDS epidemic. He faces a dilemma defined by his fear of the contagion and his desperate need for intimacy—a plight that many of us can relate to during the COVID-19 pandemic. With the help and support of his friends, he learns to thrive despite his fear.

This is a theme threaded through many of the films canvassed here—human resilience and the importance of striving even in the face of illness and disease. Perhaps Darius, a character in *Jeffrey*, says it best: “Just think of AIDS as the guest that won’t leave, the one we all hate. But you have to remember: Hey, it’s still our party!”²⁴ This quotation not only represents a powerful LGBT response to AIDS, but also offers a lesson in learning how to live fully—with love, fellowship, and laughter—despite the threat of contagion.

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ART OF MEDICINE

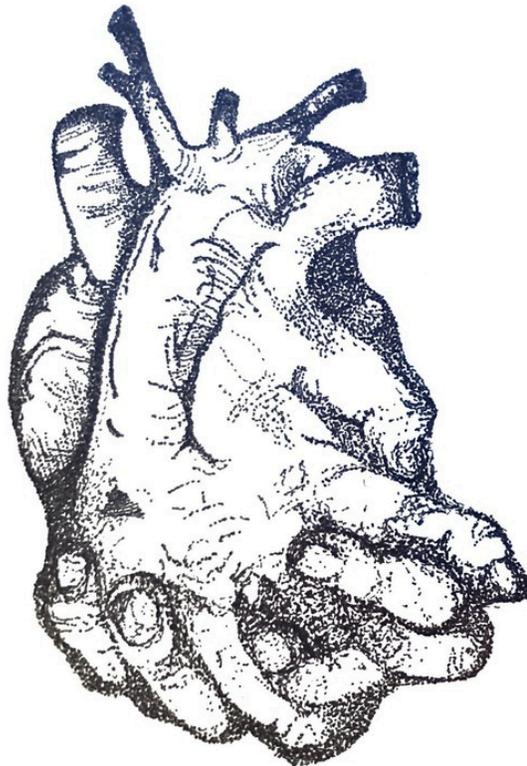
Patient Care, Self-Care

Cyril Patra, MPH

Abstract

This drawing considers how healers' abilities to help patients grow come from their partnerships with patients and from their capacity for self-care.

Figure. *The Heart and the Hands*



Media

Stabilo point 88 pen on Leuchtturm 1917 Whitelines Link smart notebook.

Caption

An anatomical heart represents clinicians' years of learning to respond to patients' illness and injury and to practice healing. Union of heart and hands remind us that, when **caring for an individual**, a healer must see the patient as a whole human person, not as a set of signs and symptoms. A healer's humanity must also be attended to with diligence and care. This drawing suggests holistic unity of both patients' and clinicians' wellness: hand in heart, heart in hand.

Cyril Patra, MPH is an eager learner with a passion for medicine, public health, scuba diving, traveling, and art. Her inspiration for medical illustration is from Frank H. Netter. She hopes to inspire seeing art in everyday moments.

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ART OF MEDICINE

Death Has Us in Check

Beltran N. Torres Izquierdo

Abstract

This digital self-portrait considers what pending loss of patients to a novel coronavirus (SARS-CoV-2) feels like. *Your Move* represents clinicians' struggles to help patients as a game of chess against death, who seems always one step ahead. The clinician is tired, and death is cheating, but giving up is not an option, no matter how bad his position on the board.

Figure. *Your Move*



Media

Photoshop composite.

Caption

This self-portrait was created in Photoshop using brush tools to blend over 25 images and to modify light, shadow, and color gradations. Death's pawns include SARS-CoV-2 novel coronavirus proteins and are backed by bacteriophages. The physician deploys hand sanitizers, syringes, steroid vials, and prescription medications to **try to win**, but he lacks a queen; unavailability of a powerful tool, in most cases, will not position him well on the board to win against death. This game is probably lost. He keeps playing.

Beltran N. Torres Izquierdo is a third-year medical student at Universidad Central del Caribe in Bayamón, Puerto Rico. Previously, he served for 3 years as a translator at Casa de Salud, a clinic for underserved patients, and for 2 years as part of a Red Cross disaster action team. He graduated with a bachelor of science degree in biological sciences from Webster University.

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ART OF MEDICINE

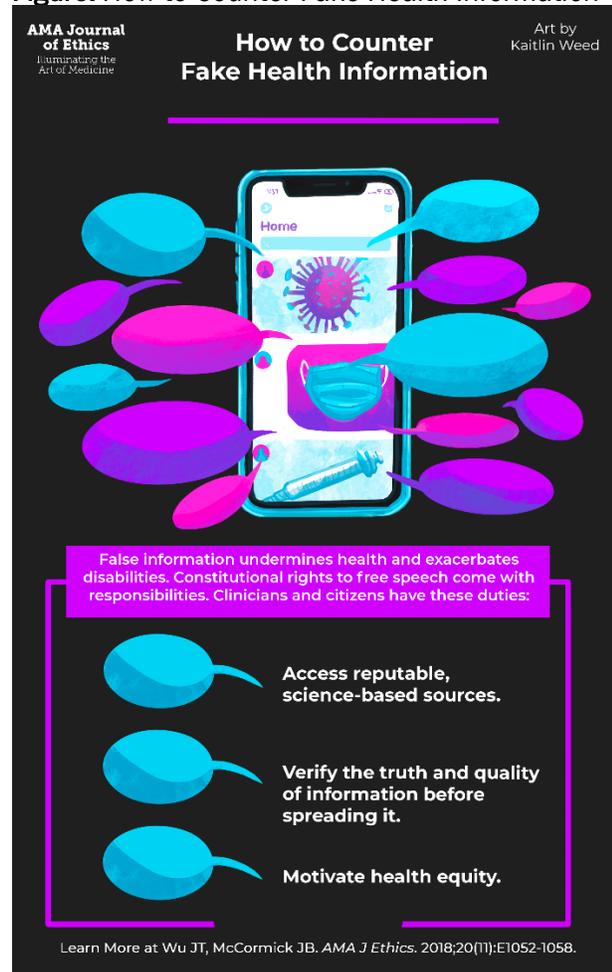
How to Counter Fake Health Information

Kaitlin Weed

Abstract

False information undermines health and exacerbates disabilities. Constitutional rights to free speech come with responsibilities. Clinicians and citizens have duties to counter **false health information**.

Figure. How to Counter Fake Health Information



Kaitlin Weed completed a bachelor of fine arts and writing degree at the School of the Art Institute of Chicago (SAIC) in 2020. They also pursued an interest in graphic medicine and disability as a 2020 SAIC Art of Medicine Intern with the *AMA Journal of Ethics*.

Editor's Note

This visual is freely available to all online and as a PDF for digital and print circulation in any clinical or teaching setting.

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