To end monkeypox, we must return power to our patients

The US’s response to monkeypox fails to put patients and their care at its center, writes Eric Kutscher

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As a primary care and addiction medicine physician, I have been dismayed by the number of patients I’ve treated over the past few weeks who’ve been infected with the vaccine-preventable monkeypox virus. Most have been in considerable pain and required strong analgesics, with some unable to even sit because of their skin lesions. Yet for many, the most agonizing and scarring aspect of their infection is not their physical symptoms, but the complete removal of their humanity by the medical response to monkeypox.

As a medical and public health community, we are exhausted after covid-19, and our compassion fatigue is showing in our policies and procedures for monkeypox. The spread of the virus to previously non-endemic countries was only recently declared a public health emergency of international concern by the World Health Organization. Cases have been reported in parts of Africa for decades, but outbreaks of the disease across Europe and the US over the past few months, and its detection particularly among gay, bisexual, and other men who have sex with men (MSM), has caused alarm. Unlike with covid-19, this is not a novel virus—we have the appropriate diagnostic testing, treatment, and even vaccines that we need. Yet, just as we have failed to deploy these tools to assist in outbreaks in African nations, we are now also failing our patients from a sexual minority—patients who are already underserved and justifiably mistrusting of a medical system that less than 50 years ago considered the idea of men having sex with men a psychiatric illness.

Many of the patients I’ve seen have had to come to the emergency department for testing, unable to get a simple swab performed in urgent care settings, health department clinics, or with primary care doctors. They wait in isolation for hours for a special pathogen team to swab their sores, and often don’t receive the results for five to eight days. They are asked to isolate—often without a confirmed diagnosis—for an indefinite period of time until their lesions scab over and new skin forms, without being provided a place to isolate, a non-stigmatizing medical reason or note to provide to their employers, or financial protections for work missed. My patients attempting to avoid infection have been unable to obtain vaccines, rolled out in a mechanism that greatly favors those with medical literacy and privilege.

As healthcare professionals, our role should be to improve care, not impede it. We should be enhancing access and educational resources, not limiting them. We should be creating systems that allow individuals to make healthy decisions that protect themselves and other people and give them power over their bodies. We must empower our patients if we are to end this monkeypox outbreak, and there are concrete steps we can take to do this.

A patient centered approach

Firstly, our vaccine rollout must be overhauled to include the expansion of distribution sites, greater privacy protections, and provisions for vaccines that prevent other diseases that MSM are at a higher risk of. We cannot continue to offer vaccines only through government health agencies, but instead must provide them to federally qualified health centers and primary care providers who have built trust and relationships with the most vulnerable communities.

When people register for a monkeypox vaccine that requires certification of eligibility and the disclosure of sensitive information (sexuality and/or number of sexual partners), they should be informed of the protections in place to keep that information confidential. Individuals should be able to register for appointments without giving a name to allow those who are fearful of their sexuality being made public a way to gain access to vaccination. All MSM who are being vaccinated against monkeypox should be offered other vaccines they might be eligible for, including hepatitis B, HPV, and meningitis.

Secondly, monkeypox testing must be made available as a free, at home swabbing kit in multiple languages. We should ensure that these swabs can be ordered online in the same way that covid-19 tests can be, with the ability to pick them up at public health clinics and community centers that are accessible to high risk populations. Given that intimate and sexual contact has been put forward as a common transmission route in the current outbreak, home swabs can be automatically dispensed with every prescription for pre-exposure prophylaxis (PrEP). Self-collected swabs could be mailed to public health labs for free, and trained healthcare professionals can contact each patient to discuss their results and review important prevention or treatment information. Anonymous contact tracing—which we’ve depended on so heavily for other infectious diseases—can empower those who test positive to help contacts obtain priority access to limited vaccinations.

For those who are positive, we must create a mechanism of paid sick leave that does not require individuals to disclose their diagnosis to their employer. With a stigmatized virus, we can’t ask patients to tell their employers about why they need time off. Individuals could be shamed, outed against their will, and lose the income necessary to keep their homes and access to food. Universal paid sick leave could do this, but in the interim we need government guidance to employees and employers...
as to what their rights are, and how to navigate isolation periods and maintain financial stability without compromising patient confidentiality. Otherwise, individuals who are actively infectious may need to continue to work without isolating, inadvertently putting others at risk.

Patients similarly need access to places to isolate without putting those they live with at risk of contracting the virus—we turned hotels into isolation venues for patients with covid-19, why not for monkeypox? We need to expand the meal delivery services and other essential goods provided to those isolating with covid-19 to those isolating with monkeypox.

And lastly, we must recognize that the least stigmatizing and least homophobic approach to this infectious disease is to provide individuals with information on how it spreads and what steps can mitigate their risk of disease. Our patients have the autonomy to figure out what’s best for them. As a healthcare community, it’s our job to help individuals make informed decisions about what they want to do with their bodies, and provide empathetic care regardless of what that decision is. As doctors, we must show the basic compassion that is missing in all of our policies for monkeypox.

Competing interests: None declared.

Provenance and peer review: Not commissioned; not externally peer reviewed.

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