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Expanding the Space: Inclusion of Most-at-Risk Populations in HIV Prevention, Treatment, and Care Services

Chris Beyrer, MD, MPH¹, Stefan Baral, MD, MPH¹, Deanna Kerrigan, PhD¹, Nabila El-Bassel, PhD², Linda-Gail Bekker, MD, PhD³, and David D Celentano, ScD¹

¹Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA

²Columbia University School of Social Work, New York, NY, USA

³Desmond Tutu HIV Research Center, University of Cape Town, Cape Town, South Africa

Abstract

The provision of appropriate HIV prevention, treatment, and care services for most-at-risk populations (MARP) will challenge many health care systems. For people who sell sex (SW) or inject drugs (IDU) and for men who have sex with men (MSM), stigma, discrimination, and criminalization can limit access to care, inhibit service uptake, and reduce the disclosure of risks. Several models for provision of HIV services to MARP may address these issues. We discuss integrated models, stand-alone services, and hybrid models, which may be appropriate for some MARP in some settings. Both public health and human rights frameworks concur that those at greatest risk should have expanded access to services.

Keywords

most-at-risk populations (MARP); HIV; health systems; stigma; discrimination; models of care

INTRODUCTION

The global HIV pandemic continues to challenge our best efforts to provide prevention, treatment, and care. A central challenge is the marked diversity of individual and community-level risks for HIV acquisition and transmission—and the dynamic nature of those risks. Although the greatest burden of HIV disease is in sub-Saharan Africa, where heterosexual sex has been the primary transmission mode, HIV epidemics in Eastern Europe and Central Asia continue to be driven by injecting drug use (IDU) and by flawed policy responses to people who use drugs.¹ In much of Latin America, men who have sex with men (MSM) account for the majority of infections.² And in South and Southeast Asia, complex epidemics involving sex workers (SW), men who have sex with men (MSM), transgender persons, and people who use drugs challenge service provision.³ Further, the pandemic remains dynamic: Injecting drug use is emerging as a risk factor in Africa; MSM HIV subepidemics are being reported across Africa and Asia; and simple dichotomies of concentrated versus generalized epidemics no longer characterize these complexities.⁴

Correspondence to: Chris Beyrer, MD, MPH, Department of Epidemiology, Johns Hopkins Bloomberg School of Public Health, 615 North Wolfe Street, E 7152, Baltimore, MD 21205. Tel: 410-614-5247, fax: 410-614-8371, cbeyrer@jhsph.edu.

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Most-at-risk populations, or MARP, have likely always been an important part of the global HIV burden. They and their communities are in need of services in virtually every context where HIV infections are found,⁵ including settings where MARP are hidden, stigmatized, AND discriminated against in health care settings; where they may be criminalized; and where the provision of appropriate services for those most at risk has just begun.⁵⁻⁷ These needs raise fundamental questions for implementation science and for health systems: How best to provide services to those most at risk? Will integration into mainstream services decrease stigmatization (or accelerate it)? Do some populations in certain settings require stand-alone services, at least until social tolerance will allow for integration? How can those at risk, their providers, and donors address the reluctance or outright hostility of decision makers to the needs of these populations?

Variably defined, “MARP” has referred not only to such key groups as SW, MSM, and IDU, but also to truckers, prisoners, soldiers, internally displaced people, refugees, and orphans and vulnerable children. For clarity and simplicity here, we focus on SW, MSM, and IDU. However defined, what is shared by MARP nearly universally is high vulnerability to HIV infection and low access to HIV services. This is what must change to improve HIV responses in health systems.

MARP AND PUBLIC POLICIES

The HIV pandemic is slowing: UNAIDS estimated 1.8 million new infections in 2009, compared to 2.2 million in 2001.⁵ Yet infections among MARP continue to increase, among MSM,^{2,8,9} among IDU,^{5,10} and among SW.⁵ Donor resources have largely not matched these realities. The Global HIV Prevention Working Group has estimated that in epidemics where HIV is concentrated among MARP, less than 10% of HIV-related expenditures target them. In generalized epidemics, less than 1% of expenditures support MARP populations, with 0.5% for SW, 0.1% for MSM, and ~0% for IDU.¹¹

Government policies outside the health sector, including legal and policing practices, can enforce stigma and limit access to care.^{12,13} An assessment by Kamarulzaman of services for IDU in Malaysia, where IDU are the predominant risk group for HIV infection, found that the most significant barrier to scaling up harm reduction services was punitive drug policies, including police raids and arrests at methadone and needle and syringe (NSP) programs.¹⁴ In Russia, Central Asia, Eastern Europe, and China, drug users must officially register in order to obtain drug treatment and health care; however, many make efforts to avoid registration, limiting access to the health care system.⁶ SW also face discrimination and legal sanction. A recent study of male, female, and transgender SW in Eastern Europe and Central Asia found that 42% of SW reported physical violence and 36% sexual violence at the hands of the police during the last year.¹⁵ A study of SW from Botswana, Namibia, and South Africa¹⁶ found that SW encountered repeated violence, extortion, and detention by law enforcement officers, with migrants and transgender sex workers at particularly heightened risk.

These issues are also relevant for MSM. Same-sex practices are illegal in more than 80 countries in 2011, and these laws can limit coverage of services, especially in the public sector.¹⁷ A key issue for MSM, IDU, and SW in settings where their behaviors are criminalized is that they may have to conceal their high-risk practices from health authorities in order to seek care, making appropriate care less likely and blunting the impact on HIV prevention of access to clinical care.

Stigma and Discrimination in Health Care Systems

Health care systems can perpetuate, not reduce, discrimination against MARP. Stigma and discrimination by medical professionals and staff towards individuals who use drugs has been shown to reduce HIV care seeking, quality of care, and retention in the health care systems.^{13,18} In Russia and Central Asia, China, and Southeast Asia, people who use drugs face multiple barriers to accessing health care and are often systematically denied primary and specialized HIV care.⁶ Health care systems may face new challenges in Africa, where IDU-associated infections are increasing, as in Kenya and Tanzania, but providers have little experience in managing dependent patients.⁴

Women who use drugs are may be doubly stigmatized and discriminated in health care systems. Pregnant drug users may face significant barriers to accessing HIV prevention services and to staying in treatment and may face criminal sanctions if they continue to use while pregnant.^{13,19} Several states in the United States have criminalized drug use during pregnancy, with incarceration the penalty.^{13,20} In Russia, health care providers may pressure drug-involved women to terminate pregnancies or abandon their infants to the care of the state. Often, women who use drugs avoid contact with the health care system altogether, forgoing antenatal care and thus missing opportunities to address critical health needs such as for enrollment in antiretroviral therapy (ART) to prevent mother-to-child transmission of HIV.^{6,13} Pregnancy can drive women to conceal their addictions from health care providers, which keeps them from learning about available HIV prevention, treatment, and care.^{13,21}

Discrimination against SW and the conflation of sex work with human trafficking is also a significant problem in relation to access to services. Allman et al (2010) reported significant confusion among HIV prevention implementation partners supported by the United States as a result of the 2005 Anti-Prostitution Pledge policy of the US PEPFAR program.²² Many organizations were reportedly unclear whether and how they might provide services to SW, and some reported avoiding the provision of such services to SW so as to comply with the pledge, despite the fact that PEPFAR permit SW services.²³ In India, negative attitudes and practices of government health care workers toward SW have been shown to be a significant barrier to accessing antiretroviral drugs (ARV).²⁴

MODELS OF SERVICE PROVISION

Given the widespread stigma and discrimination and the demonstrated need, what are potential models of service provision for MARP populations?

Full Integration

Full integration, where MARP services are integrated into mainstream HIV programs, may be optimal in some settings. Methadone maintenance therapy (MMT) and NSP may be particularly well suited to integrating medical, drug treatment, and HIV services.²⁵ The prescribing of buprenorphine by community-based physicians in the United States and Europe, implemented as a means to reduce overdose, has been found to be an effective model for integrating addiction treatment and HIV prevention into primary care settings.²⁶ Full integration will likely require active efforts to reduce stigma and discrimination in service delivery. Health care worker training and sensitization to MARP will be essential in settings where integrated models are considered.²⁷ All levels of staff need this training—it is often at the level of security guards, intake clerks, and other nonmedical staff that MSM, SW, and IDU are actively discouraged from seeking care.²⁵ Levels of stigma may also vary between at-risk groups in integrated ART settings. A woman with HIV seeking ART may have no reason to disclose past or current SW, and the same is doubtless true for many MSM—there is little benefit to disclosure and considerable potential harm. IDU, however, may be unable to hide their substance use history from providers and may need management

of both ARV and the substance they are using, and the quality of clinical care may be dependent on disclosure.⁷

Stand-Alone Services

Stand-alone HIV service delivery for MARP is currently a topic of debate. Stand-alone services, while potentially protecting MARP from some forms of discrimination, may also increase stigma.²⁸ Stand-alone clinics for SW were developed in the Sonagachi program as one component of a successful approach to community mobilization and HIV prevention.^{5,29} To ensure respectful, rights-based services, peer educator SW were an integral part of the provision of care. But these peer services could not include ARV management. Senegal has a mandatory program for registered SW to be periodically screened for STI,³⁰ ensuring access to services and treatment for many SW. However, the model has been criticized for being nonvoluntary and coercive.³¹ In the most homophobic environments, stand-alone services can be targets of attack, as occurred in Senegal in 2009.²⁸ Striking a balance between stand-alone services as protective and the potential for ongoing discrimination will be a challenge wherever this model is implemented.

Hybrid Models

Models will likely vary markedly by the type of services provided, most notably for prevention and ART. Community-based groups have records of success in providing outreach and prevention services to MARP.³²⁻³⁴ Harm reduction networks are good examples, where users and their communities provide essential outreach and key services, including NSP.¹⁰ But these same groups may be unable to provide ART or other needed clinical services. MSM organizations, too, are often the only groups in many settings capable of doing outreach, education, and condom and lubricant distribution. But such groups may have limited capacity for HIV treatment.³⁵ Hybrid models, where prevention is done through community groups linked to integrated but MARP-friendly treatment programs, may be an optimal approach, where both sets of services exist or could be established and where public programs are open to collaborating with community-based service providers.

DISCUSSION AND LESSONS LEARNED

MARP integration into health systems will provide multiple and varied challenges. Engaging affected communities will be key to the success of these programs. Flexibility will also be critical—one size will not fit all. Vertical and stand-alone programs may be harmful in some contexts, helpful in others. Whatever approach is taken, some fundamental principles will apply. Universal access means just that: No one should be excluded from HIV services based on sexual orientation, status as a SW, or active or past substance use. The benefits of increasing capacity to address these vulnerable populations will not be limited to simply increasing access to evidence-based services for HIV. There will be secondary benefits when sensitizing health systems, as health care workers become better equipped to address specific needs of other vulnerable populations, such as those who need reproductive and family planning services or mental health services, or those presenting with other sexually transmitted infections. The health care system will also benefit by increasing institutional and human capacity and efficiencies in addressing primary and second prevention needs of those most vulnerable to both communicable and noncommunicable diseases. Public health mandates and human rights principles concur that those most at risk should be among those with greatest access to services.³⁶

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