Social Aspects of HIV

Volume 4

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Editors

Structural Dynamics of HIV

Risk, Resilience and Response

Springer

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Foreword

Over nearly four decades of the history of the HIV epidemic, understanding of the ways in which structural factors shape the epidemic and condition possible responses to it has changed dramatically. While the earliest perceptions of AIDS focused primarily on behavioral factors associated with HIV transmission, and on the need for behavior change as the primary form of HIV prevention, as the global response to the epidemic began to take shape, growing awareness of the importance of a range of structural forces influencing the epidemic gradually began to emerge.

By the late 1980s, following the creation of the Global Programme on AIDS at the World Health Organization, attention began to focus on what was described as "the third epidemic" (following on the heels of HIV infection and diagnosed cases of AIDS) – an epidemic of social responses to HIV and AIDS, characterized almost always by levels of stigma, discrimination, and denial that created serious structural barriers to effective policies and programs necessary to address a growing global pandemic. As research and analysis on these dimensions of the epidemic grew in the early to mid-1990s, greater understanding developed of factors that might be understood as social determinants of HIV infection itself and of the ways in which infection evolved into disease progression in different populations. Concepts such as "social vulnerability" and "structural violence" were adapted in order to analyze how factors such as social class and economic exclusion, racial and ethnic discrimination, gender power differences, and sexual oppression, among other similar social structural forces, shaped the path of the epidemic – just as they conditioned the kinds of responses that different communities and polities developed in response to HIV.

Awareness and concern with such issues came to a head in the late 1990s and the early 2000s, as clinically effective treatments for HIV infection finally emerged, becoming the harbinger of interventions that finally might make control of the epidemic a realistic possibility, only to collide with the reality of a global political economy that imposed barriers to the inclusion of those living with HIV who were unlucky enough to live in the poorer countries of the Global South (or, for that matter, in the poorest sectors of society in the Global North). The international treatment access movement came ultimately to be driven by this understanding of the ways in which political and economic structures created barriers to treatment access,

threatening to determine who would live and who would die under the conditions of globalized capitalism that had emerged as almost universal by the end of the twentieth century.

As the response to the global epidemic entered the new millennium, the struggle for treatment access – understood fundamentally as a struggle for social justice played out on a global stage – began to carry the day in moral debates about policies that should drive the global response to the epidemic, and an important "scale-up" of programs aimed at guaranteeing prevention and treatment access gradually began to become a reality, promising the hope of real breakthroughs in relation to the goal of ultimately controlling an epidemic that had once seemed almost unstoppable.

If this history of roughly the first 25 years of the AIDS epidemic thus seemed to be one of growing awareness of structural factors shaping HIV and AIDS, at almost exactly the same time that global scale-up of HIV programs reached a kind of zenith in the late 2000s, two very different trends began to take place. On the one hand, an extended global financial crisis constrained previously expanding budgets for the global HIV response and for global health more generally. On the other hand, in what can only be seen in retrospect as somewhat misplaced optimism, enthusiasm about the growth of treatment access around the world, and excitement about the potential of "treatment as prevention," "test-and-treat" programs, the "HIV treatment cascade and care continuum," and new biomedical approaches to HIV prevention began to draw attention away from concern with structural issues, reigniting hope for the discovery of biomedical magic bullets that had seemed impossible since the earliest days of the AIDS response. By the early 2010s, this optimism had turned to misplaced triumphalism on the part of many United Nations and bilateral development aid agencies, with promises of "the end of AIDS" (or the arrival of "an AIDS-free generation") in the near future (seemingly oblivious to the contradictory reality that more than 20 years after the availability of effective treatment for HIV, still only roughly half of the people in the world who needed access to such treatment actually had it).

It is within this context that this volume in the Social Aspects of HIV series of books takes on special importance. *Structural Dynamics of HIV: Risk, Resilience, and Response*, edited by Deanna Kerrigan and Clare Barrington, brings together a cutting-edge collection of analyses by leading figures working on the structural dimensions of the HIV epidemic. It highlights the need for renewed attention to the structural dynamics of risk and resilience among key affected populations and communities, including sex workers, people who inject drugs, women and girls, transgender women, gay and other men who have sex with men, migrants, and people living with HIV. It also documents the ways in which structural factors have been confronted in different national settings as diverse as Brazil, South Africa, Ukraine, and the USA.

Together, the chapters in this volume provide a vivid account of the structural forces that shape vulnerability to HIV across such highly diverse populations and the ways in which communities have mobilized and become empowered to respond to HIV and AIDS – as well as the positive and negative ways in which governments support (or fail to support) these efforts. Chapters highlight the difficult challenge of

sustaining effective responses – and, indeed, what might be described as the vulnerability of the AIDS response itself in the face of political backsliding and conservative political movements. At a time when it is increasingly clear that promises of an imminent end of the epidemic have been exaggerated, and that what is needed to sustain the global HIV response is greater realism, critical analysis, and long-term commitment to confronting the structural factors that have shaped the epidemic in the first place, this volume on the *Structural Dynamics of HIV* provides a major contribution to the research literature on the social aspects of HIV. It offers an important corrective to the recent tendency to imagine that biomedical innovations or technocratic interventions can somehow serve as magic bullets capable of escaping or circumventing the social, political, and economic structures that create global inequalities in health – and highlights the long-term commitment that will be required if we are ever to achieve real progress toward the goal of a world without AIDS.

Columbia University Mailman School of Public Health, New York, USA — Richard G. Parker

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Acknowledgments

We would like to start by thanking Richard G. Parker and Peter Aggleton for inviting us to serve as editors of this book, which is part of the Social Aspects of HIV series marking the contributions of the social sciences to the global response to HIV. Working with and learning from them in this process has been a distinct honor and privilege.

Next, we would like to extend our gratitude to all of the chapter authors that took time and care to share their work, drawing on years of field experience in many cases. These contributions provide unique insights into how to conceptualize and respond to HIV using innovations in social theory and methods. Their work, which often crosses disciplinary boundaries throughout the chapters, stimulates new opportunities for more equitable public health policies and programs and collective action for social change.

None of this work would be possible without those on the front lines, which includes members of the diverse populations discussed in this book, as well as research teams, nongovernmental organizations, intervention staff, government officials, and activist colleagues across the globe advocating for a rights-based response to HIV.

We would also like to thank colleagues who helped us organize, coordinate, format, and copyedit this volume particularly Paige Hammond, Wendy Davis, and Andrea Mantsios from the Johns Hopkins University and Bernadette Deelen-Mans and Evelien Bakker from Springer. We are grateful for the contributions of these Springer staff and the support of Springer for this special work that commemorates the role of the social sciences in public health.

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Introduction

Since the beginning of the HIV epidemic, approximately 78 million people have been infected with HIV globally, and 35 million have died from AIDS-related illnesses (Joint United Nations Programme on HIV/AIDS [UNAIDS] 2016). At the time of writing, it is estimated that 36.7 million people are living with HIV, with the majority (~70%) of those people living in sub-Saharan Africa (World Health Organization [WHO] 2016a). Approximately two million people have been infected with HIV each year since 2010, with no significant declines in the rate of new infections, globally, from that time to the present date (UNAIDS 2016).

As a result of growing access to antiretroviral therapy (ART), with 18.2 million people receiving treatment for HIV in 2016, AIDS-related mortality has declined to 45 % since 2005 (UNAIDS 2016). Yet, in 2015 alone, approximately 1.1 million individuals died of AIDS-related illnesses (UNAIDS 2016), highlighting major ongoing gaps in HIV prevention, treatment, and care for people living with HIV. Additionally, less than half (46%) of people who are in need of HIV treatment are currently receiving it (WHO 2016b), limiting both critical individual health benefits and the significant population-level impact of viral suppression resulting from optimal ART use or treatment as prevention.

Other important advances, such as pre-exposure prophylaxis (PrEP), have also begun to reshape the HIV landscape for those at higher risk in some settings, but for most of the world, PrEP remains largely inaccessible for those most in need. Moreover, fears and concerns regarding the prioritization of biomedical interventions such as PrEP or "test and treat" over more comprehensive, rights-based responses to HIV have emerged, creating debate regarding how to best bring together biomedical, behavioral, and structural approaches.

In the midst of these trends, statistics, and debates, HIV prevalence among populations such as female sex workers (Shannon et al. 2015), men who have sex with men (Beyrer et al. 2012), transgender women (Poteat et al. 2016), and people who use drugs (Mathers et al. 2008) is still staggeringly high, reaching or surpassing 50 % prevalence in many settings. HIV prevalence in these groups, which are often criminalized and marginalized, is often more than 10–15 times greater than the overall population in a given country (UNAIDS 2012). Other groups, such as young

women and girls, migrants, and transport and fishing industry workers, while not generally criminalized, also face significantly increased HIV risk due to the socio-economic inequalities that they face. These issues underscore how the toll of the HIV epidemic is not only still profound, but that specific populations continue to experience highly disproportionate risk of infection, as well as poorer treatment outcomes, as a result of the socio-structural context in which they live and/or work.

These "higher-risk" populations have been characterized in different ways over the course of the global response to HIV, including initial epidemiologic language that was found to be stigmatizing, such as "core transmitters" and "vectors of disease." Language such as "vulnerable populations," "most-at-risk populations," and "key populations," has now generally taken the place of this initial epidemiologic terminology to describe groups at heightened risk for HIV infection and has begun to acknowledge the social and contextual nature of risk. More recently, this emphasis on context has come to produce its own set of related terminology such as the "risk environment," implying the potential primacy of place over a given "population" or the interplay between the two.

In parallel to these notable changes in terminology, other important conceptual shifts have taken place. The initial, nearly exclusive focus on changing individual risk behaviors associated with HIV transmission has been broadened to include attention to understanding and addressing the sociocultural contexts that shape risk and more recently the structural production of HIV risk (Parker et al. 2000; Sumartojo 2000). It is now more generally accepted that the risks faced by members of "key populations" do not occur in a socio-structural vacuum and that heightened vulnerability for HIV acquisition is largely the product of the larger environments and structures in which individual behaviors take place (Auerbach 2009; Blankenship et al. 2006; Gupta et al. 2008).

However, the ways in which "structural factors" are defined are still quite varied, with differing implications regarding the nature of appropriate interventions or responses. For example, for some, structural factors may refer to social norms and the need to shift or reshape public opinion or attitudes regarding appropriate sexual behavior, whereas for others, structural factors refer to power dynamics and socio-structural inequalities that constrain the possibilities to adopt or sustain HIV protective behaviors and to access HIV prevention, treatment, and care interventions, resources, and services (Evans et al. 2010). The distinction between these two understandings is critical, in that the former implies a reshaping of attitudes, whereas the latter implies challenging power dynamics. Of additional importance is the need to examine the intersection between individual and structural factors or attention to the interconnections between "structure *and* agency" (Kippax et al. 2013), given the interplay between shifts in individual perspectives and practices and engagement in and the impact of broader social change that influences HIV behaviors and outcomes.

For populations such as sex workers, men who have sex with men, transgender persons, and people who inject drugs, as well as young women and girls and migrant workers, the environments and socio-structural contexts that shape their HIV risk across settings, while diverse and dynamic in important ways, are often character-

ized by similar and long-standing constraints including legal constraints, poverty, gender inequality, and stigma, discrimination, and violence related to HIV status and the negative moral charge of "deviant behaviors" associated with group membership. This deeply ingrained paradigm of what constitutes "good behavior" and "good people" feeds and facilitates the production and reproduction of the aforementioned structural constraints.

A growing body of literature has contributed to our understanding of how the HIV risk of these populations cannot be separated from structural dynamics, including the material and social processes of "othering," that marginalize and exclude their members from the benefits of full citizenship such as access to resources to promote, protect, and fulfill their human rights, including the right to health and the right to HIV prevention, treatment, and care (Goffman 1963; Link and Phelan 2001; Terrence Higgins Trust 2001). Recent literature has also begun to demonstrate how these various forms of "othering" and social stigma intersect in complex manners, to intensify the risk of groups that cross or transgress multiple societal boundaries associated with gender, sexuality, race/ethnicity, class, occupation, and/or substance use (Deacon et al. 2005; Herek 1999; Parker and Aggleton 2003).

Given the significant and ongoing challenges facing the global response to HIV today, further critical exploration regarding how these structural factors play out, as well as documentation of the innovative strategies being employed to challenge and modify these factors to reduce HIV risk and improve outcomes in diverse populations and settings, continues to be urgent. *Structural Dynamics of HIV: Risk, Resilience, and Response* aims to depict, interrogate, and problematize social and structural factors related to the heightened HIV-related vulnerability of key populations due to their marginalization from society and exclusion from access to interventions and services, with an eye toward reframing and/or strengthening public health and social policies, programs, and responses.

This book not only seeks to describe and examine how distinct socio-structural contexts shape and drive higher risk for HIV infection but also works to document how affected populations have responded to these contextual forces through community-driven approaches building upon rights-based frameworks. The book also explores how national governmental responses to HIV have or have not attended to the needs and realities of key populations historically and the implications of these varied responses on the current state of the HIV epidemic across geographic settings.

The first section of the book, entitled *Risk*, includes a set of chapters that focus on the structural dynamics of HIV risk among key populations such as transgender women in Guatemala; migrant workers in Vietnam, Mexico, and Nigeria; and injection drug users in Tanzania. In these chapters, we are reminded that the patterns of HIV risk observed within key populations are consistently and strongly culturally, economically, and sociopolitically constructed. In essence, the nature of their risk is structured by dynamics of power related to group-level access to resources or the lack thereof. These chapters also serve to advance our understanding of how these social and structural determinants shape and affect the behaviors that are the shared

proximal determinants of HIV risk across populations regardless of their social and structural positioning.

A second set of chapters provides examples of community-driven, structural, and multilevel HIV responses including examples among female sex workers in India and the Dominican Republic and young women and girls in three sub-Saharan African countries (Botswana, Malawi, and Mozambique). Despite the challenges posed by social and structural inequity, the chapters in the *Resilience* section demonstrate that communities of resistance can and must form and use their voice and collective agency to challenge the current power structures that limit their access to health and human rights. These chapters again highlight how processes of collective action can occur across distinct settings, as well as the challenges and difficulties inherent to promoting and achieving sustainable social change.

In a third set of chapters, *Response,* the authors explore how national governments have responded to the heightened HIV burden of key populations in Brazil, the USA, Ukraine, and South Africa with particular attention to men who have sex with men, sex workers, and people who inject drugs. In this last set of chapters, the contributors force us to question the "appropriate" role of government in the HIV response as it relates to marginalized populations. We are confronted with questions surrounding the state's role and responsibility to recognize, conceptualize, fund, implement, and/or partner to make possible social and public health actions that reduce the dramatically heightened risk for HIV infection among key populations.

Ultimately, the book seeks to share insights from multilevel efforts and actions to characterize and respond to the structural nature of HIV in a diverse set of populations and sociopolitical and economic contexts; to identify gaps in understanding for future research related to the structural production of HIV risk, outcomes, and the uptake of interventions and services; and to inspire continued solidarity and social change. The complexity of the structural forces described here reinforces the need for holistic thinking and multi-sectoral action and make clear that there is no magic bullet or one intervention, biomedical or otherwise, likely to curb the global HIV epidemic.

Ongoing efforts therefore must continue to focus on the elimination of the root causes of risk, which in many cases are linked to intersecting social inequalities and forms of stigma. These efforts to advance equitable and just social change must continue in close communication with biomedical research to end AIDS. Ultimately, only when cutting-edge social science and biomedical science work together can the quest to eliminate the negative health impacts of HIV become a reality.

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