

Unintended consequences: evaluating the impact of HIV and AIDS on sexuality research and policy debates

Conseqüências não-intencionais: a avaliação do impacto do HIV/AIDS sobre a pesquisa em sexualidade e o debate de políticas

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Abstract

The HIV epidemic has had a profound impact on how we think about, talk about, and carry out research on sexuality. The epidemic opened up a wide range of approaches and methodologies within sexuality research, helping to encourage more open public discussion and debate concerning sexuality, sexual values, and sexual norms. Sexuality became one of the key contested spaces of public discourse in a previously unimaginable way, and both conservative and progressive forces have entered the debate in ways that have had a lasting impact on sexual policies in the last two decades. The current article seeks to briefly evaluate some of these important changes. It suggests that recent advances have decelerated or become more timid, while emphasizing the continued importance of seeking to address sexuality as a central issue within the context of HIV and AIDS. Although such developments may have been unintended, the ways we respond to the epidemic can have a significant impact (for better or worse) on how issues related to sexuality and sexual health are addressed.

HIV; Acquired Immunodeficiency Syndrome; Sexuality; Public Policy

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Introduction

For more than 25 years now, the HIV epidemic has had a profound impact on the ways in which we think about, talk about, and carry out research about sexuality. In the wake of the epidemic, a profound transformation took place in the field of sexuality research, with new space opening up for a wide range of approaches and methodologies, and it is impossible to imagine the current state of knowledge in the field of sexuality studies without taking account of the impact that the epidemic had in relation to this field of research. This, in turn, has helped to stimulate a new openness for public discussion and debate concerning sexuality, sexual values and sexual norms. Sexuality became one of the key contested spaces of public discourse in a way that would have been previously unimaginable, and both conservative and progressive forces entered into the debate in ways that have had a lasting impact on sexual politics over the past two decades. This article seeks to briefly evaluate some of these important changes. Yet it also suggests that in recent years these advances seem to have slowed or become more timid, and it emphasizes the continued importance of seeking to address sexuality as a central issue within the context of HIV and AIDS. It suggests that even though these developments have perhaps been unintended consequences of the evolving epidemic, the ways in which we respond to it can have an important impact, for

better or worse, on how issues related to sexuality and sexual health are addressed more broadly.

The impact of HIV on sexuality research

Among the most immediate consequences of the growing HIV epidemic in the 1980s was the massive increase in sexuality research activity that it brought about. It quickly became apparent that the long-term neglect of investment in research focusing on sexuality over the course of the 20th century had left us with an exceptionally limited knowledge base about many of the key issues that needed to be understood in order to respond to an inevitably fatal disease that was transmitted primarily through sexual contact. The urgent need to respond to the HIV epidemic through social and behavioral research provided the justification for a massive increase of investment in available research funding on sexuality and sexual behavior among diverse population groups. New resources became available relatively quickly, especially for the collection of behavioral data perceived to be necessary both for an understanding of the epidemiology of HIV infection as well as for the development of prevention programs and interventions^{1,2,3,4}.

Driven, at least at first, by epidemiological concerns, research on sexuality in relation to AIDS emerged within medical and public health institutions and frameworks. Much of the research activity in response to AIDS in the mid-1980s therefore focused on the knowledge, attitudes and practices that might be associated with the risk of HIV infection. Most studies sought to collect quantifiable data on numbers of sexual partners, specific sexual practices, sexually transmitted diseases, and a range of similar issues understood to contribute to the spread of HIV. On the basis of this documentation, research sought to point the way for prevention policies and intervention programs aimed at reducing the behavioral risk of infection^{1,5,6,7}.

The demand for quantitative data on sexual behaviors that might exacerbate the risk of HIV infection provided the justification for a wave of survey research on sexual practices – first among specific populations, such as gay and bisexual men or commercial sex workers, who were identified as potential “high risk groups”, and then increasingly among the broader population in countries like the USA, the UK and France, in the North, as well as in a range of countries in the global South. Agencies such as the US National Research Council and the Institute of Medicine played a key role in underscoring the urgent need for such research in order to more

fully understand, monitor, and respond to the evolving epidemic. Many of the more targeted studies were carried out with funding from governmental agencies such as the National Institutes of Health (NIH) in the USA and the Medical Research Council (MRC) in the UK, or private foundations such as the Robert Wood Johnson Foundation in the USA or the Wellcome Trust in the UK, while the World Health Organization (WHO) and a number of bilateral donor agencies played a key role in supporting survey research in a range of developing countries^{4,8}. Researchers took advantage of these opportunities in order to develop a wide range of studies addressing different surveys, both on specific population groups as well as representative samples from the general population.

In 1990, for example, the National Survey of Sexual Attitudes and Lifestyles (NATSAL) was carried out in the UK, and was made possible through support from the Wellcome Trust (though the second wave, carried out in 2000, after the Blair government had come to power, was funded by the MRC)⁹. The National Health and Social Life Survey (NHSL) was a comparable study in the USA, though its size was significantly smaller after it was subjected to acrimonious criticism on the floor of the US Congress, and the Division of Health and Human Services cancelled previously awarded funding based from NIH. Ultimately the downsized NHSL was only made possible through the intervention of a coalition of private foundations headed by the Robert Wood Johnson Foundation^{10,11}. The French National Survey on Sexual Behavior (ACSF – Analyse des Comportements Sexuels en France), on the contrary, appears to have caused relatively little controversy, and was made possible through the financial support of the French National AIDS Research Agency (ANRS – Agence Nationale de Recherches sur le Sida)¹².

What is perhaps most significant about these surveys carried out in response to HIV is that they seem to represent a “*new model for the study of sexual behavior understood as an epidemiological problem*”¹³ (p. 410). When compared with earlier sex research – such as the famous Kinsey et al.^{14,15} studies – they are marked by decreased interest in issues such as orgasm, masturbation, procreation, and contraception (other than condom use), and by a significant increase in attention to disease transmission, casual as well as regular sexual partnerships, homosexual activity, and both oral and anal sex in addition to vaginal intercourse. Yet because of the importance of HIV and AIDS, they did place significant emphasis on seeking to document and understand sexual diversity, placing significant emphasis on homo-

sexual and bisexual behavior as well as normative heterosexual practices^{4,13}.

While most of the initial surveys of sexual behavior that took place in response to HIV and AIDS were carried out in the resource rich countries of North America and Western Europe, under the auspices of bilateral development agencies such as United States Agency for International Development (USAID) and intergovernmental institutions such as the WHO, similar studies also began to be carried out in a growing number of developing countries in Africa, Asia and Latin America. In some cases this was done simply by adding a set of questions on sexual behavior to existing surveys, such as the demographic and health surveys, and in some cases by developing new survey instruments and studies focused exclusively on HIV and AIDS-related risk. But over the course of the 1990s, sexological and social demographic approaches increasingly merged in a new wave of surveys specifically focused on HIV and AIDS in resource poor settings⁷. Important large scale studies began to be carried out in countries like Brazil that moved beyond the focus on fertility that had dominated traditional demographic survey in order to explore the full range of diverse sexual practices^{16,17}. The growing number of available studies (both North and South), in turn, ultimately made possible a range of cross-national comparisons, both on a regional level¹⁸, as well as globally. In one recent comparison, for example, findings from as many as 59 countries have been compared, with representation from every major region of the world¹⁹.

While the descriptive data emerging from such large scale surveys has highlighted both cross-national similarities and differences in terms of sexual behavior, knowledge and information, and risk-related behavior change, it has also called attention to the extent to which social context shapes sexual practice and is a crucial consideration in relation to the possibilities for intervention aimed at health promotion¹⁹. Never before has such extensive social and behavioral research data been available, making one of the unquestionable impacts of the HIV epidemic a new level of empirical information about sexual practices around the world. This, in turn, has also led to a level of public discussion of sexuality and sexual behavior – in the mass media as well as in academic settings and public health debates – that surpasses anything even remotely comparable in the years before HIV and AIDS emerged as major concerns⁴.

From sexual practices to the social context of sexuality

Just as quantitative survey research received significant new attention in the wake of the HIV epidemic, more qualitative studies, focused less on sexual practices per se than on their social meaning, and on understanding the complex social contexts in which they are shaped, also took on new urgency and scientific legitimacy as the response to the epidemic evolved. If an emphasis on the social context of sexual behaviors appears to have been a relatively recent discovery in much of the survey research carried out in response to HIV, however, this understanding has long been one of the key insights to emerge from more qualitative and ethnographic research developed in response to the epidemic. By the early 1990s, as behavioral research and behavioral interventions began to be developed in a growing range of diverse social and cultural settings, the relative effectiveness of both the research instruments and intervention strategies came to be questioned. The difficulties of translating or adapting research protocols for cross-cultural application quickly became apparent in the face of often radically different understandings of sexual expression and practices in different societies and cultures – and even in different subcultures within the same society². The efficacy of behavioral interventions based on information and reasoned persuasion as a stimulus for risk reduction became evident almost immediately²⁰.

As the range of broader social forces shaping the HIV epidemic began to be perceived as centrally important, the limitations of traditional behavioral research approaches also became more apparent. Influenced by concurrent developments in relation to the social construction and production of sexual relations, research in response to HIV and AIDS began to draw on approaches from interactionist sociology and cultural anthropology, as well as on moves to radicalize social psychology, in seeking to focus on the broader social and cultural structures and meanings that were increasingly understood as shaping or constructing sexual experience in different settings²⁰. Stimulated by such concerns, an important shift of emphasis began to take place from a focus on individual psychology to a new concern with “inter-subjective” cultural meanings related to sexuality, and their shared and collective qualities as the property not of atomized or isolated individuals, but of social persons integrated within the context of distinct, and diverse, cultures. Social science research on the HIV/AIDS epidemic and related issues of sexual and reproductive health increasingly sought to

go beyond the calculation of behavioral frequencies and the identification of statistical correlates of sexual risk behavior, in order to examine what sex means to the parties involved, the contexts in which it takes place, the structure and scripting of sexual encounters, and the sexual cultures (and sub-cultures) present and emergent within particular societies^{2,21,22,23}.

Over the course of the 1990s, this emphasis on the social organization of sexual interactions, on the contexts within which sexual practices occur, and on the complex relations between meaning and power in the constitution of sexual experience, has led to a new focus on the investigation of diverse "sexual cultures". Research attention has thus moved increasingly from sexual behavior, in and of itself, to the cultural settings within which it takes place – and to the cultural rules which organize it. Special emphasis was given to analyzing the cultural categories and the systems of classification that structure sexual experience in different social and cultural contexts^{20,24,25,26}. Ethnographically-grounded research on the social and cultural construction of sexual meanings has thus provided important insights on the representations shaping HIV-related risk, and thus offers the basis for the development of more culturally sensitive and culturally appropriate, community-based HIV/AIDS prevention programs.

While this emphasis on culture marks an important advance in broadening the focus of research on sexuality, by the mid-1990s it had also become increasingly evident that the range of factors influencing the construction of sexual realities in relation to HIV and AIDS is in fact far more complex than had previously been perceived. In particular, it became clear that not just cultural, but also structural, political and economic factors shape sexual experience and hence constrain the possibilities for sexual behavior change. Such factors have thus been responsible for many of the most complex barriers to effective AIDS prevention programs. Just as cultural analysis had emerged as an important corrective to the perceived limitations of earlier behavioral approaches, a new focus on historical and political-economic analysis of the structural factors associated with the increased risk of HIV infection and barriers to risk reduction likewise emerged as central to the evolving response to the epidemic^{27,28,29,30,31}.

Indeed, poverty, more than any other single socio-economic factor, was identified as perhaps the key driving force of the epidemic, and the synergistic effects of poverty, when linked to other forms of social inequality, instability and discrimination, have been highlighted in virtually all the research conducted on structural

and environmental factors associated with the epidemic^{29,31}. Linked to poverty, in much important research, was the issue of gender and gender power inequalities. Indeed, the investigation of gender power inequalities and forms of sexual oppression has been central to building a fuller understanding of the importance of a wide range of structural factors in organizing sexual relations and HIV/AIDS-related vulnerability. This has been particularly true in relation to work focusing on women's vulnerability, especially in situations in which gender power inequalities cross with economic exclusion and/or racial or ethnic discrimination²⁹. This growing interest in understanding the role of gender and sexuality structures in promoting HIV vulnerability particularly among heterosexually-active women and men has increasingly generated a number of impressive analyses that are attentive to both cultural and political economic factors⁴.

Although less research focusing on structural factors has been carried out on individuals involved in same-sex relations, at least as compared with the quantity of work focusing on heterosexual women, recent findings nonetheless suggest structures of gender inequality are typically replicated in relation to transgender and other gender non-conforming persons, who often have few options for earning a living other than sex work, and who are in many instances subject to socially sanctioned forms of physical violence. The extension of gender power inequalities together with pervasive heterosexism have thus also increasingly been understood as interacting with other forms of structural violence, including both poverty and racism, in creating situations of extreme vulnerability in relation to gender non-conformity, transgender and male sex work, gay men from ethnic minority groups, and among young men who have sex with men generally^{32,33}.

A greater awareness and a fuller understanding of the synergy that exists between sexuality and multiple forms of social inequality and exclusion – especially poverty and class oppression, gender power inequity, racial and ethnic discrimination, but also less obvious power differentials related to age, to the destabilization of dislocation, and similar social factors – is surely one of the most important long-term results of the research that has been carried out in recent decades on the social dimensions of HIV and AIDS. By shifting paradigms, and moving from the kinds of epistemological frameworks that have dominated more mainstream behavioral and epidemiological research on sexuality and sexual conduct in relation to the epidemic, critical social science research has highlighted both the cultural *and*

the structural forces shaping the epidemic, helping to open the way for a fuller understanding not only of the social and cultural context, but also of the political and economic factors that impact on the sexual interactions and relationships that have been so intimately linked to AIDS since it emerged in the early 1980s^{4,20}.

Like the massive expansion of survey research that has taken place in response to HIV and AIDS, then, over the course of the past two and a half decades, significant new attention has also focused on a range of social science approaches to the social, cultural, political and economic contexts that shape sexual experience. Like the results of survey research, the findings from these studies have stimulated important new debates in the public arena about sexual diversity, relations of power, the importance of social inequalities, and the most effective means of addressing sexual stigma and discrimination. The impact of HIV and AIDS has simply been astounding in opening up new forms of knowledge and new fields of debate in relation to sexuality and sexual conduct.

The de-sexualization of the epidemic?

As important as these trends have been in the development of sexuality research since the beginning of the HIV/AIDS epidemic, in recent years, and in particular over the course of the past decade, it has begun to appear that a gradual change of perspective and emphasis may be taking place – a change that for lack of a better term might be described as the de-sexualization of the epidemic, and of the ways in which research related to the epidemic, has been framed and focused. For some years now, a number of social investigators have raised concerns about a tendency to disregard the bodily experience – the corporeality of sex – in much contemporary HIV-related research³⁴. In 2004, at a satellite meeting that was held in conjunction with the International Conference on AIDS in Bangkok, a group of leading social researchers began to call attention to the need to put “sexuality (back) into HIV/AIDS”³⁵. I have also written elsewhere of what I fear may be a growing “sanitization” of the field of sexuality research more generally, independent of whether or not it is linked to the investigation of HIV and AIDS, in which our growing concern with issues of social context may inadvertently be drawing attention away from the lived experience of sexual practice in much recent social science research²⁰.

These developments are certainly not absolute, and my concern about them should not

be read as in any way a rejection (or condemnation) of the important effort to broaden our understanding of the social and cultural contexts in which sexuality takes place – and through which it is shaped. At the same time, it is a note of caution that I think is worth pausing on and examining in greater detail. In particular, I think that there are at least three important tendencies emerging from both research and practice over the course of the past decade that may be responsible for a reduced emphasis on sex and sexuality as part of the broader response to the HIV epidemic. In particular, I think that it is an important coincidence that growing concern with the social context of sex, with the political and economic factors that shape and condition it, has taken place at the same time that there have been significant advances in available treatments for HIV infection. At least since 1996, when combination antiretroviral therapies began to become available, and many of us involved in advocacy related to HIV and AIDS began to focus heavily on the struggle for access to treatment in resource poor settings, attention previously given to sexuality may have shifted and even waned. An unintended consequence of advances in treatment access may well have been that it has shifted emphasis away from sexuality and toward a number of other issues (with the possible exception of new research attention given to the supposed sexual “disinhibition” that some researchers have suggested may be a possible result of antiretroviral treatment access)³⁶.

Equally important, I think, within this era of antiretroviral treatment access, the critical analysis of the limits of biomedical science and its apparent inability to respond effectively to the epidemic in earlier decades has lost at least some of its cutting edge, as we have witnessed a kind of “re-medicalization” of the field of HIV and AIDS in the wake of new treatment options. Because of this, even when some voices began to call for a return to prevention in an era of treatment access, these calls have typically lacked the critical approach to the social dimensions of sexuality that characterized debates around prevention issues in the first two decades of the epidemic. On the contrary, HIV prevention itself has been profoundly re-medicalized, with primary emphasis being given to relatively simple techniques and simplistic interventions – such as the call for widespread circumcision or the renewed emphasis on reducing numbers of sexual partners, especially concurrent partnerships – that are noteworthy precisely because of the perceived *insignificance* of social context and circumstances as meaningful considerations³⁷. One of the major ironies here is precisely the fact that this

re-medicalization of HIV prevention efforts is increasingly justified as a response to the failure of approaches that have emphasized cultural and structural factors such as gender power relations or poverty and economic exclusion. A return to a narrow, medicalized approach to sexuality – which for two decades had been systematically questioned and critiqued in HIV and AIDS research – has now been reasserted precisely because of the supposed failure of social, cultural, political and economic framings of HIV/AIDS and sexuality research.

It is also important to note that many of these developments linked to a re-medicalization of HIV and AIDS – and, by extension, through HIV and AIDS, a re-medicalization of sexuality – have also taken place during a time when there has been a veritable explosion of mobilization related to sexual rights. At least in part shaped by (and often also funded by) work in response to HIV and AIDS-related stigma and discrimination, social movements struggling for sexual freedoms have emerged and prospered in countries and communities around the world over the past decade, and have increasingly coalesced in alliances and coalitions focusing on sexual rights as one of the major battlegrounds of the early twenty-first century³⁸. Again, many of us, including myself, who consider ourselves to be engaged researcher-activists, and whose work has tended to build a bridge between the fields of HIV and sexuality, have played key roles in seeking to move forward such movements and the agendas that they have articulated. Yet in this case, much like the re-medicalization that seems to have been an important and unexpected by-product of our struggles for treatment access, there is also the risk that struggles for sexual rights have been moving in the direction of a kind of judicialization of the field of sexuality that is potentially as problematic as its long history of medicalization. Indeed, as the history of sexuality in Western societies (and, through colonialism and its heritage, in many non-Western societies as well) should surely make clear, medicalization and judicialization as two interacting and often complementary forms of disciplining sexuality and sexual pleasures have long gone hand in hand, and may very well be reasserting themselves even within

the context of many supposedly progressive approaches to sexuality and HIV even today.

While the impact of HIV and AIDS on sexuality research over the course of the past three decades has for the most part been to provide strong incentives for a significant increase in research activity, and to broaden the focus of research to address a wide range of contextual issues, it is nonetheless of serious concern that at least during the most recent period, the past five to ten years, a variety of factors seem to have combined to reduce attention to issues of sexuality within the context of HIV-related research. This is all the more worrisome given the fact that there has been a major scale-up of financial resources for HIV prevention and control, in some cases closely associated with conservative moral agendas – as in the case of the US President's Emergency Plan for AIDS Relief (PEPFAR) program implemented by the USA under the Bush administration, with its strong emphasis on abstinence and monogamy as the key building block for HIV prevention programs³⁹ – to the extent that sexuality seems to have received significantly decreased attention, at a time when both the re-medicalization of approaches to HIV, and a certain judicialization of many discussions of sexual freedoms appear to be reshaping many of the most important public debates related to sexuality in the early twenty first century. Within this evolving context, there is potentially a serious risk that some of the very real advances that confronting HIV and AIDS forced us to make in the field of sexuality might be lost rather than consolidated in the future. While many of these outcomes appear to be unintended consequences of issues that the epidemic has raised, they are nonetheless also clearly shaped by the ways in which we, as researchers, advocates, and policymakers, have responded to these issues – and they can be moved in various directions depending on the nature of our response. Now, more than ever, we may need to fight to find ways of “putting sexuality (back) into HIV/AIDS”³⁵, not only to help advance the field of sexuality, but to be sure that we do not witness a major reversal of important accomplishments made during the early decades of our response to the HIV epidemic.

Resumo

A epidemia de HIV teve um impacto profundo sobre nossos conceitos, discursos e pesquisas relacionadas à sexualidade. A epidemia abriu uma ampla gama de abordagens e metodologias na pesquisa sobre sexualidade, levando a uma abertura maior na discussão e debate sobre sexualidade, valores sexuais e normas sexuais. A sexualidade tornou-se um dos principais espaços contestados no discurso público, de maneira antes inconcebível, e forças conservadoras e progressistas entraram no debate de tal maneira que tiveram um impacto profundo sobre políticas sexuais nas duas últimas décadas. O artigo procura avaliar algumas das mudanças

mais importantes nesse campo. O estudo sugere que os avanços recentes já desaceleraram ou tornaram-se mais tímidos, ao mesmo tempo em que enfatiza a importância da tentativa de tratar a sexualidade como questão central dentro do contexto HIV/AIDS. Embora esses desdobramentos tenham sido não-intencionais, nossas respostas à epidemia podem ter um impacto significativo (para bem ou para mal) sobre o enfrentamento das questões de sexualidade e saúde sexual

HIV; Síndrome de Imunodeficiência Adquirida; Sexualidade; Política Social

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