Reasserting the Social in a Biomedical Epidemic: The Case of HIV-Prevention
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Susan Kippax
Social Policy Research Centre
UNSW.

Introduction

Before the development of a successful treatment for HIV in 1996, in the form of anti-retroviral therapy (ART), prevention was all that we had to respond to HIV. Biomedical and clinical researchers were joined by researchers from other disciplines skilled in prevention. Some countries (e.g. Uganda, Australia, Brazil, Thailand,) recognised the need for a social and political response alongside the biomedical one and engaged civil society in their prevention efforts. These countries were the exceptions and, in general, epidemiology and psychology rather than sociology, anthropology, and political science, were and continue to be the disciplines that dominate HIV-prevention (Mykhalovskiy and Rosengarten, 2009; Kippax and Holt, 2009). An individualistic model of HIV-prevention was embraced by medical researchers and psychologically oriented social scientists. Public health – especially the ‘new’/‘modern’ public health that positions those at risk of HIV as neoliberal subjects, as rational agents - not only continues to dominate but has strengthened its hold: the biomedical paradigm is hegemonic and we now have what is referred to as biomedical prevention. Indeed since the advent of ART, as Race (2009) has so cogently argued, treatment has taken the ‘public’ out of public health. We need to put the ‘public’ - members of society or ‘citizens’ – back into HIV-prevention and ensure they have a voice.

My argument is that given the HIV is spread by sexual practice and by injecting drug use – both profoundly social practices – social transformation is needed to prevent HIV (Auerbach, 2009; Kippax, 2009; Stephenson and Kippax, 2006; Vincent, 2009). As social scientists (e.g. Adam, Barnett, Aggleton, Auerbach, Campbell, Crewe, Friedman, Parker, Patton, Race, Treichler, Waldby, Whiteside,...) and others including biomedical scientists (such as Epstein) have argued, the exclusive adoption of the biomedical paradigm may not be the best way forward – at least in the absence of a safe and effective prophylactic vaccine. Indeed such an exclusive adoption may well undermine successful prevention efforts. At the very least the biomedical approach, which has been used to develop efficacious intensive practitioner-delivered lifestyle-change interventions, male circumcision and biomedical prevention technologies such as PrEP, needs to be integrated within a broader public health approach, which involves consideration of the whole spectrum of cultural, socio-behavioural and environmental factors that are central to the production of health and illness (Oldenburg, 2002) and which engages civil society and its members thus enabling social transformation (Stephenson and Kippax, 2006).
Biomedical Prevention

What does this biomedical model look like?

In general, HIV prevention has been medicalised as ‘interventions’, where interventions are:

1. Top-down – and individuals (‘patients’) are informed by experts (healthcare workers) typically privately in the clinic via counselling and often in the context of HIV testing (VCT)
2. The individual is informed of the ‘facts’ of HIV-prevention (based on epidemiological and medical research)
3. On the basis of which, s/he, it is assumed, will act rationally on the basis of the information – unless psychologically unable to do so (e.g. irrational) or vulnerable in some other way (e.g. economically)
4. The focus of interventions is on behaviour as opposed to and health messages focus on risks associated with intercourse rather than those associated with its social forms, e.g. marital sex, or casual sex, ...
5. Change in behaviour is expected in a relatively short period of time following the HIV-prevention intervention/s
6. And the best way of assessing the effectiveness of the prevention interventions is the randomised controlled trial (the ‘gold standard’ of evaluation)

The above biomedical HIV-prevention model positions people as individual (and unconnected) subjects, emphasising rights to freedom of choice and privacy. Within the new public health and with reference to HIV-prevention, medical experts demonstrate the efficacy of a particular technology or tool – condoms, male circumcision, ... On the basis of this evidence those at risk/the vulnerable – who are understood as rational agents/ideal neoliberal subjects who take control of their lives – are informed/counseled about the efficacious technologies or tools and how they should act to prevent HIV-transmission. It is assumed that most will adopt the advice and health services are put in place to ensure access to the appropriate prevention technologies.

Is it successful?

Notwithstanding a general levelling in HIV-prevalence and a small decline in HIV-incidence since 1996 (UNAIDS Annual Report, 2009), many believe prevention is failing or that is has stalled (Potts et al., 2008).

HIV-Prevention Failure?

Although I don’t think HIV-prevention has failed, it is less successful than it might be because there has been an exclusive focus on the biomedical paradigm within the ‘new’ public health. In particular, the wrong paradigm is being used to promote HIV-prevention technologies and tools and
to **evaluate** the effectiveness of HIV-prevention interventions or programs. I illustrate the problems with the current biomedical approach with particular reference to:

1. The ways in which HIV-prevention information is taken up by those deemed to be at risk of HIV and how people act with reference to this information (points 1-3 above),
2. The importance of practice and the failure to distinguish practice from behaviour (point 4 above)
3. The way in which an insistence on experiment and RCTs distorts the HIV-prevention effort (points 5-6)

I also suggest a way forward.

**1. The Appropriation of HIV-Prevention Information**

What is wrong? First of all, HIV-prevention information – educational or otherwise – is rarely simply passively accepted by those for whom it is intended. Rather it is appropriated – that is, actively taken up. How it is taken up will depend upon a number of factors including the communicator of the message, its content, the social and cultural conditions and contexts of its receipt, and so on.

People actively interpret the HIV-prevention advice they receive; they appropriate it and make sense of it – with reference to their own lives, and with reference to the prevailing norms and social understandings about sex and relationships. While much HIV-prevention knowledge is acquired via HIV-prevention interventions and broader education campaigns, knowledge is also acquired by listening and talking to one’s friends and peers. HIV-prevention information is not as Campbell (2003, pp25-6) noted with reference to the miners she studied in the Summertown project in South Africa “passively accepted” : “...while miners are often in possession of the basic facts about HIV, which they had internalised through health education programmes, these facts were embedded within a range of doubts, qualifications, contradictions and uncertainties.... Health education messages are not simply passively accepted by their audiences, but must compete with alternative beliefs, experiences and logics that may be more compelling than the information that the health educator seeks to impart”.

And as Australian researchers have shown, gay men have appropriated HIV-prevention information and on the basis of medical knowledge gleaned from a variety of sources and their own everyday knowledge of what it means to be gay, they have fashioned risk reduction strategies for themselves. So, for example, studies have shown that gay men, especially but not exclusively in the context of committed love relationships, dispense with condoms under certain conditions – negotiated safety, and positive-positive sex, (serosorting) (Kippax and Kinder, 2002; Rosengarten, Race, & Kippax, 2000; Zablotska et al., 2009). HIV-prevention programs or interventions did not advocate such strategies – at least initially – and indeed some researchers referred to the practice as ‘negotiated danger’ (Eckstrand et al...). Since then in Australia and very recently in South Africa (Soul City, 2009)
– public health campaigns / HIV prevention programs have included reference to strategies such as ‘negotiated safety’ and strategies similar to it. Like condom use, these risk reduction strategies came from the communities – not from biomedical or, indeed, social scientists.

Other studies have demonstrated the emergence of new strategies such as reliance on undetectable viral load. These studies have shown that condoms are dispensed with in some serodiscordant relationships – again before the publication of the Swiss Declaration (Vernazza et al., 2008). Gay men in serodiscordant relationships began to do so because they had worked out – on the basis of medical knowledge – that the likelihood of HIV transmission was greatly reduced if the HIV-positive partner (on treatments) had an undetectable viral load (Van de Ven, Mao, Fogarty et al., 2005; Bernard, Holt & Race, 2008). Meanings other than risk and safety also intervene: as Persson and Richards (2008) have shown for some HIV-positive men living in discordant heterosexual relationships, undetectable viral load signifies a ‘proxy negativity’ and a redeemed masculinity.

What the above findings indicate is that knowledge of HIV, including knowledge of clinical markers such as HIV status and viral load and knowledge of HIV-prevention information, does not lead people to do as requested: abstain, be faithful, refrain from unprotected intercourse or always use a condom. Knowledge is acted on and what one does with it depends on a range of factors – cultural, social and interpersonal. For example, while evidence does show that counselling associated with being informed that one is HIV-positive leads to safe sexual practices, the same does not apply when being informed that one is HIV-negative (Kippax, 2006) or at least not consistently (Turner, 2009). HIV information is not simply passively accepted from the medical experts and acted on as advised.

The psychological models of behaviour change such as the theory of reasoned action (Fishbein & Azjen, 1975) do not satisfactorily explain the changes (or lack thereof) witnessed (Kippax and Crawford, 1993). People select from medical knowledge what makes sense and via talk and action in the public domain collectively fashion a range of risk-reduction tools/strategies to regulate their sexual and drug using practices and reduce risk.

2. **The focus on behaviour rather than practice.**

Until we have an efficacious vaccine, the enactment of the medical advice does not simply involve taking a pill – but changing sexual practices such as making love, ‘having a one-night-stand’, ‘proving their manhood’ or ‘losing their virginity’ (Kippax, 2010) or, in the case of male circumcision, intervening in a cultural practice (Aggleton, 2007). These practices are social and cultural practices that are infused with shared and contested meanings as opposed to behaviours that are supposedly abstracted form their social context. The psychological models that posit some simple causal pathway between knowledge, attitudes, intention and behaviour are flawed. Reasons for actions are not the same as causes of behaviour.
Within the biomedical paradigm, the focus is primarily on behaviours – and this is problematic. There is only a small number of different sexual behaviours in which two or more people can engage: sexual intercourse (both vaginal and anal), oral–genital sex (fellatio and cunnilingus) and oral–anal sex; a number of more esoteric behaviours, such as sadomasochism; as well as a range of behaviours that involve touching, mutual masturbatory behaviours. Sexual practice, on the other hand, is more fluid: it is fundamentally social and cultural, being produced within particular historical times and particular geographical regions and embedded in specific locations and social formations, such as gender (Jewkes, 2009). Sexual practice is different in Australia than in France or Botswana; it was different in medieval times than now. It changes depending upon whether it is enacted within a stable relationship or a casual encounter; whether it is imposed, as in rape, or mutually agreed upon. It is different for men and women; and for heterosexuals and homosexuals. Sexual practice differs in terms of its location with respect to the prevailing discourses or common understandings that relate to sexuality, love, intimacy, pleasure, reproduction, and so on and people take up positions with respect to these discourses. In real life, people do not engage in sexual behaviours – penis-in-vagina – rather they enact sexual practices to communicate their love for one another, in response to sexual desire, to build intimacy and trust, and so on (Kippax, 2010).

As many researchers have pointed out, the most powerful influences on human sexuality are social norms – morals, taboos, laws, beliefs – that regulate and govern its expression. The scale of the regional diversity in sexual behaviour is matched only by the range of cultural constraints on practice (Wellings et al. 2006). It is these that need to be changed – the focus must be on the practices – and the norms that regulate their expression. It is these social and cultural forms of sexual practice – serial monogamy, concurrency, ... and the structures that produce them that need to be addressed by HIV-prevention programmes.

3. Evaluation of HIV-Prevention

I now turn to the third set of issues that focus on effectiveness (with reference to points 6 and 7 above) and my claim that the insistence on experiment, which is appropriately used to assess efficacy, as the basis for knowledge about effectiveness is distorting prevention efforts.

Efficacy and Effectiveness

As Aral and Peterman (1999) define them:
‘Efficacy’ is the improvement in health outcome “achieved in a research setting, in expert hands, under ideal circumstances”
and
‘Effectiveness’ is the improvement in health outcome “achieved in the real world, under resource constraints, in entire populations, or in specified subgroups of a population.”
While we know the efficacy of some prevention technologies (condoms -95%, male circumcision – 58% for the insertive partner) and PrEP and microbicide trials are underway to assess efficacy, we also need to know how **effective** these technologies are and for how long their use can be sustained. Phase 4 trials (effectiveness trials) as Kelly et al. (2008) rightly note are needed to assess the true public health benefit of any of these new (and old) technologies. But where are they? In the one paper I could find on the subject (Kelly et al., 2008, p.S29) note that while Phase 4 trials are “an essential culmination” few have ever been carried out.

How do we appropriately assess the effectiveness of our HIV-prevention interventions/programs? The dominant biomedical answer to the question is I believe conceptually confused (Kippax, 2003); it mistakes or conflates efficacy and effectiveness and then attempts to assess the wrong object. For any particular intervention it is often unclear whether a ‘successful’ as opposed to an ‘unsuccessful’ outcome indicates that the HIV-prevention technology or life style change advocated – abstinence, condoms, PrEP,... – is what is being evaluated or whether the manner in which their use is promoted (counselling and testing, mass media, peer education) is the object of evaluation. This distinction is rarely made in discussions of or research on HIV-prevention, for example, Potts, Halperin et al. (2008), and as a result it is extremely difficult to know what it being assessed in any outcome evaluation: it is difficult to know whether non-efficacious HIV-prevention strategies are being promoted (such as promoting sexual abstinence to gay men in Sydney or San Francisco, or promoting male circumcision to Hindus); or whether we are ineffectively promoting efficacious prevention strategies (such as counselling people to use condoms without any reference to the context of the sex). Whichever it is, the confusion stems from the failure to address the socio-cultural and political contexts which will to a large extent determine whether this or that particular HIV-technology is deemed to be socially and culturally acceptable by those who are the recipients of the HIV-prevention messages.

Although the efficacy of a technology, such as microbicides, can be established independently of the social and cultural contexts of its take-up and use, it is extremely difficult – and I would argue inappropriate – to attempt to establish effectiveness independently of the socio-cultural climate in which the technologies are likely to be taken up and incorporated in everyday sexual lives. While the issue of efficacy of the HIV-prevention technologies or tools falls within the realm of biomedicine and randomised controlled trials are appropriately used to evaluate efficacy, the evaluation of effectiveness, i.e. the uptake and sustained use of the efficacious technologies, falls within the realm of the social and political sciences and appropriate methods are needed to evaluate effectiveness.

Whether HIV-prevention technologies are **effective**, that is, whether a large enough number of individuals, the sub-population, or population, takes up the advice and adopts and sustains the risk-reduction or safer practices and there is an improvement in health outcome in the population, is rarely tested. As demonstrated by the 100s of published journal papers, these typically ‘pared-down’ interventions manipulating one variable and focusing on one or two outcome or impact measures are evaluated in the short-term for effectiveness in the same manner as efficacy is evaluated, that is,
by experimental methods (the RCT is the preferred ‘gold standard’ method). It is difficult to know whether the outcome is a measure of efficacy or effectiveness. Furthermore, with some few exceptions, such evaluations demonstrate a null result – or at best – a result that indicates very short-term impact (UNAIDS, 2009). In response to these ‘disappointing’ results, it is said that prevention has failed or stalled and there has been a renewal of the search for new tools and technologies and a concomitant lack of any attention to or analysis of what has possibly gone wrong. There is also the associated problem that funders (PEPFAR, Global Fund...) fail to question the dominant paradigm and are wary of funding HIV-prevention initiatives that do not incorporate accepted measures of effectiveness, and the flow-on attendant problem that researchers – social researchers included – embrace the biomedical paradigm in their attempts to gain funding. The result has been short-term asocial one-off interventions that yield little.

Assessing Effectiveness

While there may be exceptional circumstances that allow for a ‘natural’ experiment, for example, comparing one community with another, the likelihood that effectiveness can be evaluated experimentally is remote (Hallett et al., 2009). Inferential certainty is highly unlikely if not impossible as causes cannot be isolated and linked to particular outcomes or effects, and generalisability is implausible – from one historical time to another, from one culture to another, and from one social situation to another. That change is abetted by community activism, political will and structural change also provides evidence for the inherent unsuitability of experimental manipulation. Once it is acknowledged that change is the result of a set of complex social circumstances as well as individual decisions, and, with the exception of male circumcision, influenced by the context of the ‘here and now’ of each occasion of sex, then one has to entertain and engage with the messy social world – and draw on social science to engage with perceptions, understandings, social regulation and social practices, ... in short, the object of research and evaluation is now social transformation and all that entails. The difficulties of experimentally evaluating the effects of HIV-prevention efforts on social practices are obvious – indeed, experimental manipulations remove the very stuff that produces change – the social glue that makes us social beings. As Parker, Easton & Klein (2000) in their review the literature on structural and environmental factors that affect HIV-prevention programs point out: “…by their very nature these interventions involve large-scale elements that cannot be easily controlled by experimental or quasi-experimental research designs” (S30).

So what is to be done – social and political scientists and biomedical scientists need to work together – but on a more level playing field.

Social prevention/ Social public Health

What does this social model/paradigm look like?

In general within this model, prevention programs (not interventions) and their evaluation are:
1. Bottom-up – and citizens/community members are informed by civil society/community – typically via mass media campaigns, community out-reach and social marketing
2. Where information (based on epidemiological and medical research) – the ‘facts’ of HIV-prevention – is made public, i.e. shared, discussed and debated through collective activity
3. People/citizens, it is assumed, will appropriate the information in ways that make sense to them and in ways that will enable change
4. The focus of prevention programmes is social practice (not behaviour), and health messages focus on risks associated with particular practices (e.g. marital sex, casual sex,...) rather than risks associated with behaviour such as intercourse abstracted from its context
5. Change in sexual and other risk practices is expected over the relatively long-term and such change is not expected to proceed in a linear fashion
6. And where the best way of assessing the effectiveness of the prevention programmes involves monitoring (via behavioural surveillance) complemented by modelling and in-depth qualitative research

Within this social model, people are understood as members of societies/communities/networks – related and connected to one another in a variety of ways. As such they constitute a polity and have rights and obligations accordingly. The emphasis is on people, as members of groups, who collectively act to achieve their desired outcome (in this case HIV-prevention). The focus here is on social transformation: practice rather than individual behaviours, on collective rather than individual action. Although not guaranteed, social transformation is made more likely by ensuring that people are actively engaged in finding the solution.

Whether one invokes social capital (Putnam,) and the sociological theories underpinning it (Bourdieu), or theories of social transformation (Stephenson & Kippax, 2006) or the more social psychological social diffusion theory of Katz (used by Jeffrey Kelly (Kelly et al. 1992; 1997; 1999) and others) is open to debate – but what we need to move away from the individualistic paradigms that lean to narrowly focused interventions that with very few exceptions do not work – at least at the population level - especially in contexts where the neoliberal active subject who commends control of his/her life is at best a limited fiction.

Is it successful?
There is some evidence that HIV prevention has been and is effective ... especially in those countries where there has been recognition of the importance of the engagement of civil society to bring about social transformation. Early evidence from Uganda, Senegal, Thailand, Australia, ... and more recently from Brazil (Roy Anderson, 2004 – Durban International AIDS Conference; Global HIV-prevention Working Group 2006, 7, 8) point to involvement of government and civil society : a public voice.

More recently on the basis of improved methods for assessing incidence and in some cases, modelling expected HIV incidence, researchers such as Garnett et al. (2009) have demonstrated that
HIV-prevention has been reasonably effective in Thailand, Uganda, Zimbabwe, Kenya, Rwanda, Ethiopia and Malawi. These studies have demonstrated that the methods are useful in understanding the impact of programs at scale, i.e. of whole programs of combination prevention, rather than determining the efficacy of particular tools or attributing effectiveness to any particular HIV-prevention intervention. They argue for the need more timely measures (assessing effectiveness over 5-10 years), greater confidence in representativeness of samples, and better behavioural surveillance and links to HIV-program or intervention process measures.

Sullivan et al. (2009) and Stall et al. (2009), also focusing on HIV incidence as an outcome measure, report a decline in HIV incidence among gay men in some high income countries between 1996 and 2000 followed by increases in HIV notification rates between 2000 and 2005. In examining the figures and noting the far higher declines and recent smaller increases in Australia, Stall et al. (2009) ask whether it might be possible to learn from the Australian HIV prevention response. While there has never been an RCT done in Australia to evaluate the effectiveness of the Australian overall response – or indeed any aspect of it, the role of gay community in finding and promoting effective HIV-prevention strategies via government funding is central as is the research of both social and biomedical scientists in informing the response (Mindel and Kippax, under review).

Conclusions

We need Phase IV trials in which social and biomedical scientists work together to evaluate effectiveness – in the long term; behavioural surveillance or rather the surveillance of sexual practices complemented by in-depth qualitative research. We also need to convince the funders to fund such research. Together we need to describe how people understand, and take-up HIV-prevention messages, how they incorporate the prevention technologies into their everyday lives, and how the new technologies such as PrEP affect the use of on old technologies, such as condom use (disinhibition). We also need research on how to engage with communities and ensure that their voices are heard – and heard very clearly – in the development of HIV-prevention programs. We need to move away from a sole reliance – or indeed major reliance on ‘prevention in the clinic’ and to engage in the social and political world.

As Barry Adam notes in (Mykhalovskiy & Rosengarten, 2009, p.16) social scientists can and have played an important role: they need to be resourced so that they can describe the discourses that circulate through cultures of people at-risk and understand how social and cultural contexts in which people live and work produce the particular practices that place them at risk. Unless we understand the above we will not be able to respond to two major questions:

1. How are people and resources best organised to stem the proliferation of HIV
2. How are communities and individual community members best mobilised to avoid HIV without sacrificing the pursuit of pleasure and intimacy that HIV threatens
In the same paper, Steven Epstein (p.9-10) takes these issues further and calls on researchers to help reconsider the preconditions for activism “that unites and cuts across disease constituencies to mount more broad-based challenges to the present day organisation of biomedical research, pharmaceutical drug development and distribution and access to health care”.

I think that we need to think very carefully how social scientists, biomedical scientists and community members can work together effectively. Robert May has been pondering a similar question in relation to climate change. How, he asks, can we encourage people to come together and act together on the information provided by science to reduce carbon emissions? How, I ask, can we engage civil society to transform itself to eliminate HIV?

References


Ekstrand (REF?)


