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## Social Context and Determinants of HIV Transmission: Lessons from Africa

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### Why Africa?

As Africa is the continent hit first and hardest by HIV, it is the social science research conducted on the epidemic on that continent that offers the most historical insight into the epidemic in developing countries. Research conducted in Africa mirrors and, to some extent, foreshadows research subsequently conducted elsewhere in the developing world and in the so-called 'second wave' countries, including China, India, and Russia. Until recently the dominant concern of social scientists has been to explain the prevalence rates in terms of African 'specificities'. When this research began, the epidemic was viewed through the prism of its Northern epidemiology (that is, as a disease mainly of gay men and intravenous drug users) and Africa seemed exceptional. HIV epidemics are heterogeneous, comprising diverse epidemics that wax and wane at different rates (Morison 2001). These differences were initially attributed to differing modes of transmission, leading to the early distinction between epidemics that were driven by sex between men in northern Europe and North America, and those that were spread by intravenous drug use in southern Europe. These Pattern 1' areas were distinguished from 'Pattern 2' zones, such as Africa, where the epidemic was viewed as predominantly heterosexually transmitted. Previous reviewers have also mentioned the lack of data exploring alternative routes of transmission (A. Ona Pela 1989, Schoepf 2001:429) but also concluded that the evidence does support predominantly heterosexual transmission accounting for the epidemic in Africa (Baylies 1997). This literature has essentially been concerned with identifying the primary determinant of the African epidemic. The previously widespread view that African culture was somehow responsible has been largely discarded with

ongoing research which has pinpointed economic, and by extension political, factors that are particularly concentrated on the African continent. Specifically, widespread poverty and weak state capacity seem to offer a fertile ground for epidemics. This mirrors the controversy concerning the roots of gender vulnerability: are women vulnerable to HIV in Africa because of cultural constructions of femininity, or is vulnerability biological and exacerbated by interactions between sexuality and power exacerbated by economic circumstances? New directions for research concern the linkages between political ideologies, macro-economic policy and both social and biological vulnerability to HIV. From an initial focus on gender and women's vulnerability, new approaches stress masculinities and sexualities as key sites that link broad-scale social forces with individual vulnerability. Increasing attention is being paid to violence, both within and without conflict situations, and how this may be fuelling HIV epidemics, which in turn links epidemics to geopolitical struggles. The following section traces the main developments in these controversies. Given the abundance of the literature, only the most relevant references are cited, with the most recent given preference.

### **Explaining the Epidemiology of AIDS in Africa: From Culture to Political Economy**

Extensive epidemiological profiling of the epidemic in Africa was early on complemented by social science literature that described the social context of HIV transmission. This research initially sought to identify endogenous, social factors to explain the high HIV prevalence in Africa. As a result, cultural factors were the object of much scrutiny in the earlier years of the epidemic. Surveys of knowledge, attitudes, behaviours and practices (KABP) comprised the first wave of studies, and in epidemiologically important 'high risk' settings continue to be carried out (Ali 2001, particularly Fritz 2002, Mataure 2002). Although these yield useful data and insights they are subject to methodological limitations (Schopper 1993). Researchers also examined how representations of AIDS and its clinical syndromes related to local understandings of the body, sexuality and death (Ingstad 1990, Irwin 1991, Carton 2003), with an eye to developing 'culturally appropriate' interventions (Airhihenbuwa 1991, Schoepf 1992). Interestingly, initially this early research did not address the issue of stigma that was so prominent in social research and cultural theory about the epidemic in the North (Treichler 1991, Patton, 'Sex and Germs' 1985, Clatts 1989). Research also sought to identify 'cultural determinants' of risk (McGrath 1992), but relatively less attention was paid to the hypothesis that poverty might be a driving force, perhaps because of a few initial studies reporting higher rates in those better off (Dallabetta 1993). These results were likely spurious and the result of reporting bias. More recently, protective factors have also been sought in the realms of culture and religion (Lagarde 1997, Takyi 2003).

Although higher risk was subsequently found to be linked with poverty and associated phenomena such as migration (MacDonald 1996, Brockerhoff 1999), initial interest in exotic African 'sexual rites', such as the use of local preparations for vaginal douching and the application of leaves and powders prior to sexual intercourse for the purpose of enhancing the male sexual experience, has persisted (Runganga 1995, Gresenguet 1997, Kun 1998, Wijgert 2001). Non-sexual cultural practices were also investigated, with practices such as 'blood brotherhoods' and contact with non-human primates portrayed as cultural culprits in the expanding epidemic (Hrdy 1987), or female circumcision (Grisaru 1997). It was even claimed that the 'African sexual system' was characterised by promiscuity and therefore could explain the extent of the epidemic there (Caldwell 1989). Needless to say, the claim was spurious, being based on a selective reading of data (Le Blanc 1991). In an article that proved prescient, Epstein and Packard (Packard 1991) demonstrated parallels between social science research on AIDS and earlier studies of tuberculosis and other infectious diseases, warning that failing to engage with the political economic determinants that make the poor vulnerable would lead to research that essentially blamed the victims for circumstances over which they had no control. Such theories continue to be given credence because they conveniently blame those most vulnerable (Farmer 1992).

The slow demise of culturalism as an explanatory paradigm began in the second decade of the epidemic after a tide of research (Herrell 1991) that indicted poverty as the epidemic's primary social determinant. This research was the tip of an iceberg of literature and identified the mechanisms by which poverty led to vulnerability (for a review see Whiteside 2002). Poverty leads to riskier behaviour, either by favouring transactional sex, or by driving migration – an observation that helped develop the concept of vulnerability (Kalipeni 2000), in an effort to shift attention from individuals – who often have minimal control over their circumstances and must struggle just to get by – to social structures. Initially, however, little research sought to link everyday poverty to the broader political, social, and economic climate. This research was hampered by an excessively individualistic focus, invoking notions of a 'culture of poverty' that had been widely criticised decades earlier in social research on poverty (Gesheker 1995).

The habit of treating poverty as inevitable, rather than as a product of social processes, broke down with the publication of a critical article indicting structural adjustment programmes for creating conditions favourable to the epidemic by deepening poverty and cutting back health services at a time when the continent was already vulnerable to the scourge of infectious diseases (Lurie 1995). Lurie et al.'s controversial article stimulated critical thinking and its publication in a medical journal gave new respectability to the 'political economy of disease' thesis that was already well established in research on health in Africa. In this view, political ideologies are refracted through state and macro-economic policy to shape the disease environment, either directly through health care spending or indirectly in

the way they allocate resources that can mitigate underlying health status (Turshen 1992, Bond 2003). Neo-liberal economic policy, often dictated to cash-starved African governments, has not only decreased access to curative health services but compromises public health by privatising basic necessities such as electricity and water (Fiil-Flynn 2001, McDonald DA 2002).

Lack of access to clean water and electricity can be hypothesised as leading to increased vulnerability to HIV by favouring the spread of diseases associated with poor hygiene, thus weakening the immune systems of the poor. Evidence for a more direct link exists. Epstein and Packard had warned that the early focus on sexual behaviour risked foreclosing other explanations for the epidemic in Africa, such as high prevalence of STIs and iatrogenic spread through unsafe use of injection equipment. Others pointed out the potential significance of STIs, which viewed in either an historical context (Jochelson 1991) or in the context of social change and urbanisation (Good 1991), and offered important lessons for AIDS prevention. These suspicions were widely shared by bio-medical researchers, and a solid body of research has now firmly established that STIs greatly enhance HIV transmission by up to 100-fold, in effect fuelling HIV epidemics. Effective diagnosis and treatment of STIs has been shown to decrease HIV incidence by as much as forty percent, indicating that lack of STI diagnosis and treatment services would be a significant determinant of HIV epidemics (Philpott 2002). This provides a direct link leading from macro-economic policies that reduce health expenditures to HIV epidemics.

Inadequate funding of health care may have fuelled iatrogenic spread of HIV by making unsafe use of injection equipment more likely. For instance, the privatisation of health services, when conjugated with the imposition of user fees in public health facilities, creates a market for unregulated injectionists. This hypothesis has yet to receive serious attention in social science literature. Iatrogenic spread is increasingly invoked to account for anomalies in the epidemiological paradigm, but has yet to receive serious epidemiological investigation (Gisselquist 2002, Gisselquist 2003). This is warranted, as it has important implications for future prevention programmes which, if iatrogenic spread is shown to be of epidemiological significance, would need to address determinants of unsafe injections.

### **Gender: From Women's Vulnerability to Masculinities and Sexualities**

Unlike the epidemic in the North, epidemiological data from Africa from the beginning indicated that more women were infected than men. This was central to epidemiologists' assertion that the epidemic there was heterosexually spread, and also suggested that women were more vulnerable to HIV. It became quickly clear that while the reasons for that vulnerability were both biological and social, the latter was of prime importance. Since then, social scientists have viewed HIV transmission largely through the lens of gender, emphasising the vulnerability of

women (Seidel 1993), a view that would explain findings that women with higher socio-economic status actually may be at increased risk of HIV (Chao 1994). This vulnerability is conditioned by a web of factors: cultural constructions of gender disempower women (Latre 1999) and make it more difficult for them to negotiate sexuality (Campbell 1995) and legitimise the economic disempowerment of women that makes them more dependent on transactional sex (Gysels 2002). Disempowerment is a continuum, extending from situations of sexual violence and slavery to more subtle forms of coercion (Ajuwon 2002). And it is a vicious cycle, as the epidemic has a disproportionate impact on women as they largely bear the burden of care (Upton 2003).

Disempowerment is often viewed in terms of individuals, downplaying the role of structural factors (poverty, violence, etc.) in conditioning vulnerability, which may occur even when women might be considered relatively empowered, for example, in the case of sex workers or wealthier women (Silberschmidt 2001). The importance of this distinction is underlined if we examine the female condom, which was thought to be a 'magic bullet' because it would give women control over protecting themselves. However, they may not work in situations where the social, economic and cultural context is otherwise not favourable (Susser 2000, Kaler 2001). Similarly, street youth may be empowered relative to other children, but this should not conceal the fact that selling sex is the easiest survival strategy (Swart-Kruger 1997). Understanding is thus moving away from more simple dichotomies of empowerment/disempowerment and agency/structure, and it is in the way gender is considered that this is most clear. Women, initially thought to be vulnerable and disempowered, are more pragmatic and participatory than previously thought, and this has drawn attention to the complexities inherent in sexuality and in masculinity (Davis 2000, Prazak 2000, Renne 2000, Stewart 2000). This mirrors a shift from health-education approaches to prevention to more participatory, community-based strategies (Campbell 2001). Social science research which has stressed the structural constraints of behaviour can be credited for developing prevention interventions that aim to change the gendered framework within which sexuality is negotiated (Campbell 1999, MacPhail 2001).

Increasingly nuanced views of gendered behaviour have led away from studies of 'risky' men, such as truck drivers (Gysels 2001), to focus on how masculinity is socially constructed and enacted (Campbell 1997). Ground-breaking studies in South Africa, for instance, have explored why men become abusive, while studies from Côte-d'Ivoire (Nguyen forthcoming), Senegal (Teunis 2001), Tanzania (Lockhart 2002), and Zimbabwe (Epprecht 1998) have shed light on the different contexts in which men have sex with women, showing that this may be driven by identity, circumstance, economic conditions, and emotional need, or a complex combination of all of these. Paradoxically, men can seem disempowered as well. Sex and violence appear to be refuges from expectations that can no longer be met in a deteriorating economy, and avowedly homosexual men feel obliged to

marry and have children. The significance of political mobilisation to changing gender roles (Susser 2001) may reflect the ability of political processes to address these more distal, structural constraints to women's vulnerability. The relative empowerment of men compared to women has stimulated interest in developing interventions aimed at men, which may be more effective at changing sexual behaviour than developing women's skills at, say, negotiating condom use (Agha 1998).

### **Conflict and Violence: Linking the Macro and the Micro**

Increasing attention is being paid to violence as an important co-factor in HIV transmission (Maman 2000, CADRE 2003). While initial studies indicated that gender roles that disempowered women relative to men made it more difficult for them to negotiate safer sex, further research suggests that sexual violence may be more widespread than previously thought (Jewkes 2003, Karanja 2003). While forced intercourse is believed to increase the risk of HIV transmission because of direct physical trauma, even in its absence the threat of violence - and the relative culture of male impunity that may favour easy resort to intimidation - could increase risk by constraining women into unprotected sexual relations when they would otherwise refuse (Wojcicki 2002). Two situations have emerged as being of particular concern. First, in South Africa, several studies of masculinity have indexed the legacy of apartheid, noting that the social emasculation of men under apartheid, which continued as liberation failed to bear economic fruit for most black South Africans, could be correlated with constructions of masculinity that stressed virility (Campbell 1997, Niehaus 2000). Recently, an 'epidemic' of rape - including child rape - has been the focus of much sensational media attention in South Africa, crystallising a 'national scandal of masculinity' (Posel 2003). Sexual abuse of children has been identified elsewhere in Africa as a cause of STIs (Pitche 2001). Secondly, war-affected populations are more vulnerable to HIV - not only because they are more vulnerable to gender-based violence, but also because of displacement and lack of access to prevention services as well as STI diagnosis and treatment (McGinn 2000) (Ward 2002). HIV is more prevalent in military personnel than in the general population (Martin Foreman 2002), power differentials between military and civilians are greater, military are often away from their wives and high HIV prevalence rates make soldiers a particularly high risk group (Heineken 2001) and conflict situations potentially explosive for HIV (Sarin 2003). More worryingly, evidence from war-torn countries such as Sierra Leone and the Congo (Melby 2002, Wakhweya 2002) indicates the use of rape as a weapon of war, and has raised concerns that HIV may have been deliberately spread in Rwanda (Elbe 2002) as well as in South Africa by the apartheid regime. If such 'weaponisation' of HIV is indeed occurring, this would mark a worrisome development.



### Several Pathways Explaining How War Fuels HIV Epidemics

Warfare displaces civilian populations, increasing vulnerability the same way it does for migrants - by broadening sexual networks and increasing the chance of exposure to the virus (Holt 2003). Displaced populations generally have less access to medical services and constitute, in effect, a 'complex medical emergency' (Khaw et al. 2000) with its own particular ecology of disease (Kalipeni 1998). And warfare, of course, results in significant troop movements, bringing high risk groups into contact with new populations. Of even more concern are 'low intensity' conflicts where the main strategy is the terrorising of civilian populations - particularly efficient at triggering and spreading epidemics. These situations are notorious for the prevalence of rape and other forms of gender violence. These concerns have been borne out epidemiologically. An HIV-2 epidemic was associated with the war of independence from Portugal in Guinea-Bissau (Lemey 2003) and, more recently, with the Congolese civil war.

Wars can be considered symptomatic of a more generalised phenomenon, which is the conjugation of weak states, generalised availability of firearms, and mounting social inequality, with the result that state breakdown is occurring in many parts of the world and in Africa in particular (Joseph 2003). HIV epidemics are thus fuelled by state breakdown but, in turn, can feed it as the social fabric is impacted by the epidemic (see below) (Ostergard 2002).

### Beyond Social Determinants

Clear determinants of HIV epidemics are difficult to discern from the complex tangle of social factors cited in the literature. While culture, poverty, gender relations, social inequality, and violence are all identified as facilitators of transmission, none has demonstrated a robust, linear relationship to HIV prevalence. There does not appear to be a relationship between risk and social capital (Campbell 2002, Djamba 2003), although further studies are clearly warranted. Recently, state capacity has been cited as another potential determinant (Joseph 2003), and is a hypothesis that also bears further investigation as it holds broad geographical interest in the light of emerging epidemics in Central Asia. In contrast, biological factors have been identified which clearly amplify HIV epidemics. While the role of STIs is most cited, there is some evidence that other infections may make immune systems more vulnerable to HIV.

The recent controversy over the historical origins of the AIDS epidemic suggests another direction of study. The hypothesis that polio vaccine trials, conducted in the former Belgian Congo, may have inadvertently triggered the epidemic by inoculating hundreds of thousands of Africans with biological matter potentially contaminated by HIV's chimpanzee ancestor virus, SIVCPZ, was widely publicised. Molecular epidemiologic methods were used to shed light on the issue. The HIV epidemic stems from a zoonotic event, when human populations were infected with an ancestral retrovirus derived from the Simian Immunodeficiency Virus

present in wild chimpanzee populations in the Congo River basin (Yusim 2001). Molecular methods were used to calculate when HIV and SIV strains diverged. This divergence occurred in the inter-war period (Chitnis 2000), at a time of significant social upheaval in the Belgian Congo (Headrick 1994). This social context lends credence to the hypothesis that zoonotic spread led to the divergence of HIV and SIV. These social transformations, driven by colonial labour policies, were ultimately to lead to the death of an estimated ten million Congolese from starvation and epidemics of trypanosomiasis (Lyons 1992). These social and ecological changes suggest that humans would have been more exposed, or vulnerable to chimpanzee viruses (Lemey 2003). The origins of the epidemic were thus neither purely biological nor social, but were entangled from the beginning. While numerous others have pointed to the need for bio-social approaches, there are few examples in the literature.

Bio-social interactions include societal (that is, social, cultural, political and economic) responses to epidemics. These change both social relations and disease ecologies, with important implications for public health. For instance, colonial public health efforts aimed at containing infectious diseases throughout Africa, being the aspect of colonial government most widely experienced by Africans, were to profoundly shape African social life and politics with implications for future epidemics, including HIV (Dozon 1991). The efficacy of bio-medical treatments for infectious diseases became obvious with the introduction of parenteral anti-infectives after the Second World War. As a result, injectable treatments were widely sought-after. Re-use of needles in treatment and vaccination campaigns have been implicated in the emergence of blood-borne epidemics on the continent including HIV (Marx 2001). Reluctance to confront the epidemic in its early years on the continent can be attributed to suspicions lingering from the colonial era when notions of 'diseased natives' were used to enforce segregation. This story underlines that bio-medical responses to disease ecologies are, by their very nature, very powerful at shifting those disease ecologies and need to be part of the picture in understanding how epidemics evolve. Causes and determinants of epidemics are bio-social, and understanding them must include examination of the responses to epidemics.

### **The Response to the Epidemic**

Africa has become a veritable laboratory for HIV prevention – and now treatment programmes – and has been fertile ground for an increasingly sophisticated civil society, active in combating the epidemic. The first generation of prevention programmes concentrated on mass information, education and communication ('IEC') campaigns to raise awareness, and social marketing to increase condom availability. A second generation stressed translating knowledge into behaviour change through interpersonal strategies, such as peer education and testimonials by PLWHIV. These have had limited results, probably because the ability of

individuals, particularly the poor, to effect change in their circumstances is actually quite low. This indicates that behavioural change to reduce HIV transmission risk is unlikely to be achieved without addressing structural determinants. Increasing the visibility of people living with HIV created a strategic imperative to achieve greater involvement of PLWHIV in the fight against the epidemic. This imperative fuelled initiatives to foster self-help and empowerment amongst PLWHIV, particularly by supporting self-help groups and disseminating techniques to encourage individuals to testify publicly. These were an important tool for building awareness and contributed to growing activism on the part of African people with HIV/AIDS. However, until now, these have largely been 'cookie-cutter' campaigns fashioned out of standardised strategies and interventions applied throughout the world, often by the same consortia of NGOs and international aid donors.

### Emerging Challenges to the Consensus

Compared to a wealth of technical documents, critical social science literature on the response to the epidemic is sparse (with the exception of South Africa, which will be discussed below). Since an early rejection of the epidemic as a purely bio-medical or public health problem, the consensus has been that the epidemic is a problem of development (Hemrich 2000), and not just a health issue, and that as a result broad multi-sectoral responses are required, essentially calling for technical solutions (Haddad 2001). The legacy of the late Jonathan Mann (former Director of the WHO's Global Programme on AIDS in the early years of the epidemic) has been to enshrine human rights as an anchoring principle of the response: specifically, HIV testing must be voluntary and confidential, and risk groups and people living with HIV must not be stigmatised (Leslie 2002). More pragmatically, this has translated into widely, if not necessarily explicitly adopted, affirmative action policies that call for greater involvement of people living with HIV, and communities affected by HIV, in the response to the epidemic (UNAIDS 2000). This is the cornerstone of a range of widely agreed-upon strategies that seek to empower those most vulnerable. Much of the 'rights and empowerment' response, however, has remained confined to the discursive realm (Seidel 1993), although there is evidence that, as funding is ramped up, meaningful changes are occurring on the ground (Nguyen 2002, Simon-Meyer 2002).

In the face of ever-rising HIV rates, with few successes to cite, cracks in the consensus have emerged, with dissenting views coming from field workers, public health quarters, and political activists. Those writing from the front lines point out that while the notion of vulnerability provides a useful framework within which to develop and assess these responses (Delaunay 1999), it may be disconnected from the realities in the field where scarce resources must first be directed to the most valuable rather than the most vulnerable. Rationing has largely escaped attention, (for an exception, see Kenyon 2003), although the use of

'selection criteria', particularly in deciding who gets scarce treatment, indicates that this is the case (Nguyen 2003). From the standpoint of public health and social justice, the 'rights and empowerment' approach has recently been challenged (Cock 2002). By undermining classical approaches to epidemic control, it is argued that 'AIDS exceptionalism' - especially as concerns voluntary testing as opposed to universal screening, is in effect 'promoting an African holocaust' (Alcorn 2001). While activists have long been vocal in the demand for more resources, in the past years they have clearly linked this to the problem of third-world debt (Dely 1999). Without debt relief (Cheru 2000), and indeed structural reform as well as changes to the global order (Poku 2002), the AIDS crisis will only get worse. Neo-liberal prescriptions, which advocate decreasing the role of the state and privatising services, increase vulnerability even as they decrease the ability to respond to the epidemic (Odhiambo 2003). These challenges to the consensus raise fundamental concerns about the efficacy of the current response as it now stands. Presumably, if the development, rights and empowerment approach does not address the root causes or is at cross-purposes with the reality on the ground, the responses it advocates should be ineffective. What does the literature tell us?

### **Improving the Response: From Learning Lessons to Best Practices to Critique**

The most substantial body of research concerned with the impact of the response has been understandably concerned with directly improving that response as quickly and as broadly as possible, and the bulk of it forms a voluminous literature of technical reports and evaluations. Epidemiological evaluations are rarer, as this entails time-consuming randomised-control trials that are not only difficult and expensive to perform, but often do not translate into results that are valid in the 'real world'. While the interventions that have been scientifically evaluated are briefly reviewed below, this should not be taken to imply that these are the only, or even the best, available. Most often, it is only interventions where there is some controversy or lack of clarity that are submitted to full scientific evaluation.

The bulk of the evaluation of the response has been a blend of qualitative and quantitative insights summarised and disseminated as lessons learnt through a broad range of grey literature. Considerable attention has been devoted to systematising these lessons in order to identify 'best practices', initially defined by UNAIDS as 'anything that works whether fully or in part and that provides useful lessons learnt' (Funnell 1999). Best practices have been identified for practically every conceivable issue raised by HIV/AIDS, and these are easily consultable via the web-sites of UNAIDS, FHI, the International HIV/AIDS Alliance, and other organisations. However, even if a programme 'works' in delivering intended outputs, the chain of causality from these to broader socio-behavioural outcomes - including decreased HIV rates - is difficult to evaluate. The sheer complexity of intervening variables and circumstances means that successes, or failures, must be

explained after the fact. For example, the explosive HIV epidemic in South Africa has been attributed to highly specific local circumstances. These include the legacy of apartheid, particularly in how the economic system of apartheid and the struggle against the regime shaped masculinities (Campbell 1997, Niehaus 2000), concurrent epidemics of STIs (particularly herpes, Chen C. Y., 2000), the political 'distraction' of the post-apartheid transition to democracy (Marais), as well as poverty and social inequality (Delius 2002). Conversely, the apparent success that has met some AIDS control programmes has been attributed to political will, an ill-defined and under-researched concept that is argued to have been behind existing efforts (Boone 2001). Complex social phenomena cannot be reduced to a handful of variables, indicating that further understanding of the impact of the response will require scrutiny from more qualitatively oriented approaches. In addition to surveys and focus groups, ethnography has been crucial to developing an understanding the relationship between social change and epidemics. Newer methods include developing 'scenarios' to predict what the epidemic will look like in twenty years (UNAIDS 2003).

#### **Quantitative Evaluations of Specific Interventions Exist, Particularly in the Arena of Prevention**

Change in sexual behaviour has been the major goal of these programmes. While behaviour change has been shown to result in decreased HIV incidence at the population level (Kamali 2000), the ability of prevention programmes to change behaviour has been limited. Epidemiological high-risk groups are priority targets for intervention, as it is here that interventions are likely to have the most impact and are therefore most easily measured. The best evidence for efficacy comes from studies of interventions promoting condom use done with commercial sex workers. In a landmark study, Laga and colleagues demonstrated that condom promotion and STI treatment decreased incidence of HIV in sex workers in Kinshasa (Laga 1994). Surprisingly little research has evaluated prevention interventions aimed at other traditional high risk groups: youth, men and migrants, although these are the focus of increasing attention (see, for example, Campbell 2001). Of a range of potential 'structural interventions' – that is, interventions aimed at changing the environment rather than behaviour – only condom distribution programmes have been formally evaluated (Rosenfield 2001). This represents a significant gap, which may reflect the persistence of the tendency to assume epidemiological risk is solely attributable to individual behaviour, the difficulty of developing, implementing and evaluating 'structural' interventions and, finally, that many interventions either never get documented or there is a time lag inherent in documenting interventions.

The point was made early on by anthropologists and cultural critics that behaviour is embedded in and enacts meanings that are context-dependent, explaining why appeals to abstract rationality do not universally translate into

behaviour change (Parker 1995). 'Culturally appropriate' awareness-raising campaigns have since become the mainstay of prevention campaigns. The difficulties in evaluating these campaigns likely explain why so few of these have been examined. On the basis of published studies, the results are mixed. While some studies have shown campaigns are effective at raising knowledge (Rogers 1999, Stadler 2002, Tambashe 2003) this does not appear to reliably translate into behavioural change (Yoder 1996, Snell 2002). Similarly, research neither supports nor contradicts the notion that behaviour change will result from 'putting a face' to HIV by encouraging positive people to 'come out' (MacIntyre 2001, Camlin 2003).

In the arena of treatment, the literature on best practices for treatment is still relatively sparse for developing countries relative to the wealth of research conducted in the North. The clinical efficacy of anti-retroviral drugs and drugs to prevent opportunistic infections has been established in African settings (Laurent 2002). However, these initial studies, as well as others currently underway, are being conducted in (relatively) resource rich clinical settings under highly structured circumstances, making it difficult to evaluate what obstacles to successful treatment outcomes will be encountered in the 'real world' of urban clinics or rural primary health care centres, and what the most effective measures for addressing them will be.

The availability of data on the efficacy of interventions makes them subject to cost-efficacy analyses. This allows interventions to be ranked, usually by the cost per infection averted and eventually comparing these to the cost of treatment (Marseille 2001, Hutton 2003). Cost efficacy studies have come under fire by activists for putting a price on human life that inevitably discriminates against the poor (Boelaert 2002) and constituting a barrier to action (Nelson 2002). In response, it has been argued that priorities must be set and that economic tools are important in making rational decisions (Brunet-Jailly 1999).

In summary, the literature indicates that while there is solid evidence for achieving meaningful outcomes for a handful of interventions, for the rest the tangle of variables makes it difficult to demonstrate quantifiable efficacy. While the programme evaluation literature has been vital to improving the response and has improved our understanding of the epidemic and its context – it is often in the context of the evaluation of an intervention that previously unsuspected but important information may be gleaned – it is necessarily concerned with programme outputs rather than broader social impacts of programmes. Arguably, it is to these complex phenomena that social science is poised to add value. The surprising lack of studies so far indicates that this will be important to improving future responses.

### **Lessons – and Questions – from South Africa**

South Africa, as examples already cited indicate, has been an exceptional case. In addition to the recent historical context of apartheid and the transition to democracy, it has also had the fastest growing epidemic - mushrooming from

less than one percent of the population in 1990 to over twenty percent ten years later (Abdool Karim 2002, Williams 2001). It also has the most resources to respond to the epidemic - and to document it - as the most developed country on the continent. Its strong research capacity is reflected by the quantity and quality of research produced there. As a result South African experience dominates the literature on HIV/AIDS in Africa in general, and on the response in particular. The literature on HIV/AIDS in South Africa is exceptionally broad and deep compared to elsewhere in Africa, and offers a treasure-trove of insights into the conjugation of politics and the epidemic. The relevance of the socio-economic context to understanding both the dynamics of HIV transmission, as well as its impact and the response to it, has been confirmed for the South African epidemic. There, the legacy of apartheid, particularly in the form of steep gradients of socio-economic inequality, has been identified as the driving force behind the epidemic and challenges neo-liberal assumptions that the epidemic can be explained in terms of individual behaviour (Schneider 2002).

In the New South Africa's vibrant democracy, HIV and the adequacy of the government's response has been widely debated (Vliet 2001). The debate has become increasingly politicised, driven by an active civil society with grassroots skills honed in years of struggle against the apartheid regime. After the advent of effective therapy for HIV in 1996, it was here that the issue of access to treatment was brought to the foreground of the international stage in 2000 (Bass 2000). The first ever International AIDS Conference, held in Durban that year, provided a dramatic stage for a confrontation between the pharmaceuticals industry, the South African government, and a coalition of activists from South Africa and around the world. The confrontation was carried out in a series of court battles between the government and the industry (around the right to import generic drugs) and the government and the activists (around the need to supply treatment to prevent transmission from mother to child). President Mbeki's comments to the effect that HIV did not cause AIDS only served to fan controversy (Fassin 2003). Both court battles were settled in favour of expanding access to treatment and, at the time of writing, the government is rolling out an even more ambitious treatment programme after losing a subsequent case against the activists.

The cost of ensuring access to treatment highlighted the glaring funding gap in the response to the epidemic, even in comparatively wealthy South Africa. While early attention focussed on the cost of treatments, increasing attention is being paid to health systems. The direct impact of the epidemic on health services, as staff either fall ill themselves (Goudge 2000) or 'burn-out' (Raviola 2002), when conjugated with the chronic under-funding of public health systems in Africa, has dealt a devastating blow to the ability of existing health systems to respond to treatment needs. South Africa's comparatively functional health care system paradoxically makes these problems more visible there. Worsening child health directly and indirectly due to HIV infection has strained resources further

and only added to the psychological burden of staff who must deal with unprecedented child morbidity and mortality (Pillay 2001, Walraven 1996). This happens even when most morbidity and mortality occurs outside of health care institutions, as is the case elsewhere in Africa (Ngalula 2002) – raising the concern that improving health care systems may only increase the burden they have to bear, in effect shifting it out of the domestic realm into the public sector, with potential impact on other diseases. The potential flow of resources into HIV/AIDS care and treatment raises major concerns about health equity (Ntuli 2003). Health sector reform will clearly need to respond to the realities of both containing the epidemic – through better diagnosis and treatment – and its multiple impacts (see above), although there has been relatively little discussion of this in the research literature. While the role of primary care needs to be rethought (Petersen 2002), broader, political issues will need to be addressed.

It is difficult to imagine that any meaningful reforms can be undertaken without reallocation of international debt, as debt servicing decreases health expenditures (Cheru 2002). The political nature of these issues poses the related question of governance – who will decide, and how (De Waal 2003). This issue is particularly complex in an era of globalisation, where aid donors and transnational corporations have greater financial clout than most African states (Poku 2002) and where local factors clearly play an important role in shaping both the epidemic and the response to it. The need for a concerted international response is clear (Thurman 1999), but risks becoming mired in American domestic politics (Brainard, 2003:776, Gow 2002) and while some Americans have been optimistic, claiming that ‘a new institutional order is emerging in the global fight against HIV/AIDS’ (Morrison 2003), the experience of the New Partnership for African Development (NEPAD) is not encouraging (De Waal 2002).

Three questions emerge from this largely South African literature. South Africa’s experience shows that the response to the epidemic, and the impact of that response, is eminently political, and that politics is rooted in local histories of engagement and struggle. This suggests that it may be difficult to ‘graft’ political responses onto terrains that do not have the same history of engagement and struggle. South Africa’s case militates against the consensus that universal, technical ‘development’ solutions will work equally well everywhere. This question requires further study. A second and related question concerns the issue of governance – what are the best mechanisms for making decisions about how to respond to the epidemic? If authoritarian solutions are more effective, as has been argued by some and as the case of Cuba would suggest, who is to decide? How? Finally, it is impossible to consider the response in isolation from the impact, as the case of health systems tells us. Social transformations wrought by HIV/AIDS, from changes in knowledge and attitudes to illness, affect those who must respond directly. This can be a vicious cycle, or it can be an opportunity for an effective politics of solidarity.



### Summary and Gaps Identified

The literature reviewed in this paper indicates that the role of social and biological factors in facilitating the spread of HIV epidemics has been well described and that, for some of these, sufficient epidemiological evidence exists that we may speak of determinants - that is, factors that play a robust, quantifiable role at the population health level. However, what still remains poorly understood is why epidemics 'take off' in certain areas and not in others. The literature suggests that specific, local interactions between social and biological factors determine epidemiological pathways.

Significant gaps exist in our understanding of the relationship between HIV epidemics and social change. Understanding the impact of the response to the epidemic is quite narrow, with studies largely limited to measuring factual knowledge and behaviour change. Recently more attention has been paid to the impacts of the epidemic on specific parts of society: population structure, labour, the economy, the health sector, population health. The literature strongly suggests that the aggregate effects of these impacts will transform society. Social transformations due to the epidemic and the response to it are likely to shape the bio-social environment within which HIV epidemics wax or wane, and therefore are of considerable importance to future efforts to curb its spread and impact.

A striking overall finding has been the lag between the bulk of mainstream social science research and reports from organisations engaging in front-line HIV prevention. For instance, the relationship between HIV and gender, sexuality, conflict and violence was first widely documented in non-academic sources. On the other hand, critical social science - some of it still largely unpublished - early on warned against overly reductionist explanations and sought to explore the link between the epidemic and the broad political ecology of disease in Africa. This suggests that a more fruitful dialogue needs to be engaged between academic researchers, and evolving communities of practice being constituted around the front lines of the epidemic.

### What Drives HIV Epidemics?

Specific findings are that while a number of biological and social co-factors have been identified, evidence for a determining epidemiological effect exists for STIs, with strong evidence for lack of male circumcision, and younger age of first intercourse for women while a number of social conditions are identified as increasing vulnerability to HIV, none individually has emerged as a robust determinant of HIV prevalence.

Indications that interactions between biological factors and these social conditions (gender, migration, poverty and social inequality) can provide the necessary conditions for epidemics to 'take off' suggest a broader hypothesis: that local configurations of biological and social co-factors explain how epidemics are generated, and their subsequent growth and scope. These bio-social interactions

are locally contingent and dynamic; that is, they evolve over time, thereby shaping the ebb and flow of epidemics over regions. Understanding of these bio-social interactions requires that historical, political, economic, social, cultural data are considered alongside bio-medical and epidemiological evidence. This hypothesis maps out a research agenda that will require that social scientists and biologists work together to better understand how HIV epidemics evolve, how they may be contained, and the intended and unintended consequences of the social response.

### ***Gaps and Priorities***

Little is known about the epidemiological role of sexual violence, men who have sex with men (MSM), and common unregulated injection and surgical practices, such as those used to treat infectious diseases or interrupt unwanted pregnancies. (Of these new epidemiological pathways, MSM will likely receive the most attention, given the difficulties in studying sexual violence and the controversy that surrounds the iatrogenic hypothesis.)

Even less is known about how Structural Adjustment Policies, which compromised public health care on the continent from the 1990s onwards, may have shifted disease ecologies to favour HIV transmission. The relationship between macro-economic policy, social inequality, poverty and health also bears further scrutiny.

### **Is the Response Working?**

Specific findings are that social changes that occur upstream from the demographic impact can mitigate its impact. These changes reflect the multifaceted, societal response to the epidemic. The response may be consciously orchestrated as a matter of government or aid policy, occur more spontaneously as families and communities respond to awareness-raising campaigns or an illness at home, or emerge from discourses in the media, popular culture, and everyday discourse. These changes are part and parcel of cultural processes stemming from urbanisation, and democratisation.

The response can result in significant changes in sexual behaviour, as has been documented by decreasing sero-prevalence rates in some countries and groups. Even where prevention efforts have not translated into decreased sero-prevalence, countless surveys have demonstrated shifts in knowledge, attitudes, behaviour and practices. Children and youth are becoming increasingly sexually literate, and may be delaying onset of sexual activity in response to HIV prevention messages. These index the social and cultural ramifications of the epidemic, although little else is known about these.

Empirical evidence suggests that in many places responses to AIDS are extremely local; as suggested above, this may lead to new forms of bartering, or other informal relations that reconfigure local hierarchies or governance structures. Other impacts may restructure sexual economies in ways that alter transmission dynamics. General explanations of such phenomena may benefit from

explicitly considering cognitive or behavioural responses to aspects of the pandemic – at the individual level – that could cumulate in institutional transformations. Here the key point is that the societal impacts of HIV/AIDS are not a linear function of infection or prevalence rates; rather, infection, fear of infection, or responses to infection may disrupt the foundations on which social, political, or economic institutions and relations are built.

### ***Gaps and Priorities***

Capturing the broader societal impact of these has been notoriously difficult. And yet, evidence suggests that HIV/AIDS is a motor of social change in Africa, much of that mediated through international prevention and treatment efforts. Concerns that behaviour change may not be sustained in the long-term, that prevention programmes may have unwittingly driven men to ‘protect’ themselves by selecting young girls as sexual partners, or that treatment programmes may stigmatise their beneficiaries, highlight the need for critical assessments that examine longer-term societal changes and their impact on social relations, culture, politics and economies. This social change has been difficult to capture as it falls outside of the indicators of prevention programmes. For instance, sophisticated AIDS prevention campaigns in the media have problematised the category of the adolescent, in effect making it available as an identity to young Africans in unprecedented ways; similarly, the culture of sexual openness that has permeated even out-of-the-way places in Africa on the heels of AIDS groups has created social spaces within which it has been possible to organise a homo-social sphere and, now, openly gay and lesbian groups. These phenomena point to a rapidly shifting social landscape that needs to be taken into account in continually refining our response to the epidemic – a lesson that is being learned now in the North, where HIV is now resurgent in communities where it had been controlled.

The vigorous and sustained response that exists within the households and communities that continue to bear the brunt of the consequences and care for the ill and those that survive them has remained largely off the radar screen. Better understanding of this grassroots response, particularly in high prevalence countries, would be an important step in developing strategies to support this endogenous response.

Practical experience in fighting AIDS is extraordinarily difficult to get. There is clearly a rich body of experience fighting the epidemic that exists throughout Africa at the community level. The bulk of care, for instance, is carried out by households and early research suggests that there has been an extraordinary robustness in the ability of communities to respond to the orphan crisis in southern Africa. However, much of this experience remains undocumented or, at best, relegated to anecdotal accounts within reports. There is a substantial ‘grey’ literature, which concerns programme and project implementation, often written for donor agencies. As a result, and understandably, this literature has been jargon-filled and

often lacks relevance with respect to the issues facing communities and societies struggling against AIDS. What has been documented is not being used. This difficulty has been acknowledged of late, with a growing emphasis on producing 'toolkits' and manuals that can assist in project design and implementation. Organisations like the Population Council, the International HIV/AIDS Alliance, FHI, and so on, are actually quite good at disseminating what they produce. The problem is that grassroots practitioners are too overwhelmed to produce any documentation whatsoever. The existence of this gap is borne out by programmes like Population Council's 'Horizons' project that aim to bridge it with operations research.

Important gaps remain in our knowledge about how HIV prevention, treatment, and advocacy efforts to shift disease ecologies (for example by reducing prevalence of sexually transmitted infections), create and sustain new forms of community, and catalyse a new political activism around health. Critical research to address these gaps can play an important role in harnessing HIV-driven social transformations to address broader issues in public health and social justice. Lack of understanding of these social transformations potentially compromises the success of continued HIV prevention and treatment efforts in Africa and globally.

Including communities, NGOs, activists and researchers in this dialogue will certainly help to improve sharing of lessons and disseminate 'best practices'. While these are short-term goals, they are nonetheless vital precisely because we are in the midst of an epidemic that is largely out of control. However dialogue can also be made to work towards broader, long-term goals. The sheer scope of this epidemic means that we should not forget that academic institutions will train generalists and specialists who must become leaders in the fight against AIDS throughout the continent – whether they be health care personnel, teachers, lawyers, engineers, mineworkers and so on (what Mary Crewe has called 'mainstreaming HIV/AIDS'). Just as the epidemic is transforming Africa, it should be transforming higher education globally. Evidence-based and theoretical research can add enormous value to the response to the epidemic. Just as an example, I would like to cite the Treatment Action Campaign, which this week successfully lobbied to make ARV treatment available to South Africans with HIV in their country. TAC's campaign drew on a practical history of social mobilisation (against the apartheid regime), but also on a blend of theoretical approaches developed in the social sciences.

Mobilising, and benefiting from that experience, will require critical dialogue between academic institutions and NGOs (including the activist groups that have done so much to challenge mainstream thinking about AIDS in Africa of late), as well as with the myriad community-level organisations (i.e. church based groups, youth clubs, self-help groups and so on) that actually bear the brunt of the epidemic and carry out the most critical aspects of prevention and care. Without this community voice, and in the absence of an institutional platform for developing

critical *and* engaged research, it has been difficult to develop perspectives that think outside, or are even critical of, how programmes are implemented in the field. As a result, much of the existing research is of little help to communities that engage with the difficult realities and critical choices that must be faced, and it has not been an inspiration for developing innovative approaches to addressing the challenges of the epidemic.