

5. Epidemic logic and its alternatives

Elizabeth Reid

Ndimbël na tchay fek loxoy borom (Wolof proverb)

A critical approach to the HIV epidemic requires that the production of health and the production of knowledge become sites of contestation and re-articulation. Epidemic conditions rationalise and augment regulatory power regimes. They create a logic of crisis which structures and justifies the regulation of social relations and social production. This logic re-inscribes subordination in the practices of beneficence and may insidiously assert authority beyond any justifiable mandate.

Epidemic logic rationalises power as control, regulation and hegemony, in the production of health, and power as intrusion, extraction and appropriation, in the production of knowledge. To give but one example, as late as 1989, the head of the AIDS programme at the Centres for Disease Control in Atlanta, USA, stated at a National Press Club Luncheon in Australia: "History will condemn us if we do not search out every infected individual".

This is the epitome of epidemic logic: the magisterial 'we', the assumption of righteousness, the disassociation and distancing of the expert from those affected, the 'search and destroy' metaphor and mentality, and the construction of the Other as a person to be regulated on moral grounds. The discourse of contagion and warfare claims to carry its moral and practical justification on its surface.

To open up sites of the production of health to democratic contestation is to allow the re-articulation of how illness and information are managed, crafted, controlled; how identities are fractured or constituted. It makes possible the diffusion and recrafting of power relations, for they can only be contested from within; there is no without. It allows the reconstitution of the nature of relations between and amongst all those occupying these sites. To form linkages between the medical and epistemological management of the HIV epidemic and the medical, legal or epistemic construction of gender, race, class or other forms of differentiation is to provide a coalitional framework for a strategic politics of advocacy, action and activism.

Regulatory practices in the production of health and knowledge

The ambivalent status of informed consent in the process of hospitalization provides a point of entry into the mapping out of how power is organized and circulated within an epidemic logic:

“hospitalization dismembers the subject ... Informed consent, in institutional terms, is obligatory, i.e., one will not be admitted to the hospital without it. The power relations and forms of subjugation typified [by] but not limited to hospitalization are organized around a certain ironic construction —that of a form of power to which subjugated bodies give their informed consent, because they have no other choice” (Singer 1993: 103).

Hospitals are the paradigm of medicalised space: sites for the production of life and health, and for the defeat of disease and death. Entry into a hospital is a metaphor for entry into any regulatory medical or research space. Crossing the threshold is a mandatory act of submission. The denial of consent acculturates the person entering to an interventionist or regulatory logic of power. The person submits. The desire for the benefits of entry, including treatment, access to technology, and knowledge, outweighs the loss of active participation.

Entry into regulatory regimes strips the person of agency and of choice. The location of decision-making and expertise in the magisterium strips the person of presence. Interventionist power regimes are formed and sustained by the subordination of the Other. Medicalized regulatory regimes, and extractive research regimes, not only render the Other subservient but fundamentalise the body or mind.

With the HIV epidemic, this stripping away of life starts at the ‘moment’ of disclosure, the announcing (‘l’annonce’) to a person of their infection status:

“les échecs et les réussites de l’annonce (du double point de vue du médecin et du patient) sont avant tout ceux de la prise en charge, de l’accueil du patient au long cheminement du conseil et au suivi thérapeutique” (Gruénais and Vidal 1994: 152).

This could be translated as: “Disclosure would make sense if it has a positive impact on care, counselling and treatment”. The setting of disclosure in Africa is almost invariably a medicalized space: a hospital or a doctor’s surgery.

Disclosure becomes the practice by which the infected individual is stitched into the logic of regulation: a lifetime of treatment, counselling, interrogation, the traffic in patients. There is little or no space here for life, for the stitching of the person back into living. The thickness, moral complexity and trauma of the processes of disclosure are reduced to a ‘moment’, an announcing; the pathos to a pathology; the fullness of being to a tainted organism, the ‘seropositive’.

In these medicalised spaces, treatment, particularly HIV anti-viral treatment, becomes the point of living, not a means to living. Death ceases to be an existential moment. It becomes an outcome of failure

to take or access certain kinds of action. Many HIV infected people, in Africa and elsewhere, accept and operate out of these regimes.

Stories of living as an HIV infected person ('le témoignage'), the articulation of personal anguish and desire, are reduced by regulatory regimes to the voicing of suffering. Those infected become ventriloquial, telling the words that have been demanded by the system. Speaking of women, Gayatri Chakravorty Spivak says:

"I start from the assumption that men and women occupy different positions in the making of culture. Any discussion of culture that does not take this into account is symptom more than explanation. Women are silenced or ventriloquial, not-quite subjects who hold up the culture or, if conscientized, resist" (Spivak 1995: 152).

Those infected and those responsible for the production of health also occupy different positions in the making of epidemic culture.

Regulatory practices render the infected ventriloquial. They have no involvement or voice in planning, in establishing an ethical framework for disclosure, in determining how their stories will be used, their purpose, or their placement in processes. The autobiographical voice is appropriated and used by the magisterium. The relationship between the storyteller and audience is denied. It is replaced by that between the appropriators and the audience. Payment of the infected for such services renders explicit the reductionist, puppet-like and exploitative nature of the performance (Reid 1998: 6).

In a regulatory logic of power, the interrogated, whether patient or research subject or informant, is acculturated to extractive practices, to authority as a form of insistence on disclosure of self-knowledge. The 'consent' is constituted by regulation and authority, for power differentials undermine or render vacuous bargaining power. The informant is invaded: knowledge is extracted on demand, appropriated.

The HIV-infected person, however, whilst marked as subordinate and marginalised, is at the same time a highly valued commodity within the system: a source of research funding, disciplinary recognition, employment for the magisterium. The institutional setting of the subjugation of the HIV-infected person in Africa makes more stark the intrusive and regulatory practices of commodity creation.

"The beds are full. There are no drugs for the treatment even of the simplest opportunistic conditions. There are no gloves or other protective supplies. There is often no water on the ward. The staff are reluctant to care for the patients. There has been no training. Their fears have not been acknowledged. There are no staff support services or even recognition of the cumulative impact of their feelings of helplessness, pain, loss and grief. No provision made for the effect of the recognition of self in the sick. There is little chatting, laughter or consolation in the ward...

Yet, every morning there is a bustle of activity, of interaction between patients and staff. The only funding available in this hospital is for research. This is how the senior medical staff use their expertise and training. Each morning, blood is taken, urine cajoled, spinal fluids and vaginal secretions

extracted. There is but a rudimentary attempt to explain the bustle, the invasion of their spaces and their bodies, even less of an effort to gain consent”.

The person has been dismembered and reconstituted as body. Regulatory practices penetrate the bodies and minds of their subjects, generating relations of dependency and numbing the capacity to resist. The site of the production of health becomes a regulatory regime that signals a kind of death. The subjection strips the person of the ‘living’ that the practices seek to sustain.

But the dismembering is not limited to the patient or informant. In regulatory regimes, the regulator / extractor is as much reduced and constituted by the regime as is the Other. He or she is trapped into manipulating systems of values, patterns of behaviour, and disciplinary archetypes which recycle the regimes, reinforce privilege and authority, and fray the social threads which link them to society.

This stripping away of life is essential to regulatory regimes, for life is the locus of an affirmative power that contests and reconfigures power as regulation, domination and control.

Oppositional activism

In epidemic times, invasive and regulatory practices are advocated as acceptable, even protective. They come to seem normal. Yet, at the same time, regulatory practices create sites of possible resistance, sites of opposition and dissent. But the space of the practice is the space of the regulator, for the opposition is to practices that they have designed.

For example, even in resource-poor countries, extensive surveillance systems have been installed. Not only are they demanding of scarce human and financial resources, they have had quite serious social and psychological consequences. HIV surveillance systems induce the paralysis of fear, as data from Kigali bears witness (Bursansulitse 1994). They also induce paranoia through the realisation that we can be controlled, stigmatised, and scapegoated by what others claim to know about us collectively.

Practices of surveillance and mandatory testing have become sites of mobilisation, of defiance. Increasingly now, particularly in Africa, the morality and the effectiveness of such practices are being questioned. Those attending the Women’s Forum at the IXth ICASA Conference, Kampala, Uganda in December 1995 strongly rejected the exploitation of pregnant women for surveillance purposes. They demanded consent and disclosure for all testing. The site of resistance became a site of demand for ethically grounded epidemiological research.

For the patient or researched subject to oppose or move out of regulatory regimes is an act of contestation of authority, of resistance to control and manipulation. It is an asserting of power as defiance, as dissent. This resistance is cast in the language of the demand, and constructs self-in-opposition. Its sites are the demand for treatment drugs, for financial support, the strategies of groups like ACT-UP. The

life force is opposition to regulation, the contestation of marginalisation, deprivation or subordination.

Opposition, resistance and dissent define these practices of activism. The treatment imperative is countered by the demand by those infected to know and adjudicate the grounds for deciding for or against any given treatment. The research imperative is rejected, countered by the demand that knowledge and the use that is made of it remain under the control of the knowing subject.

“Communities of Australian aborigines refused to allow HIV and STD surveillance or any HIV medical and social research to be carried out in their communities on the grounds that the results were being used to stigmatise and scapegoat them. They demanded that knowledge be constructed exclusively by and used only within their communities” (Commonwealth of Australia 1991).

Power as resistance or opposition is the claiming of space within regulatory regimes that deny any sense of agency. It is a reworking of power against the grain of regimes of control. Care and concern are refused as gifts to be given. They are practices to be claimed.

The discourse that emerges from this contestation of power as regulation and extraction or appropriation reworks the discourse of power to include power as resistance and opposition. It works to disempower the magisterium. The sites of contestation, paradigmatically organisations of those infected and affected, become cultural positions, ideological spaces which give rise to the possibility of certain discourses. They constitute a base for forms of dissenting and demanding activism. These practices of dissent allow the transformation of the dismembered body into the linguistic actor, but in structures of oppositional social exchange. Identity is created in constituencies and strategies of opposition.

Enabling practices in the production of health and knowledge

“After a period of withdrawal, reflection and discussion amongst themselves, the Australian aboriginal communities approached the government and the research community and offered to enter into partnership with them. They proposed that together they find ways in which the integrity of the Aboriginal community and their desires would be respected at the same time as all concerned could better understand how the HIV epidemic had and could affect their communities. The result was the establishment of a code of ethics to govern all HIV research in Australian aboriginal communities” (Commonwealth of Australia 1991).

Enabling practices draw on the transformative promise of cultural practices that are not hegemonic, not subjugating. They are a resource for building communities and partnerships whose organising principles are affirmative, which work within difference and diversity with respect, recognition and inclusion. Enabling practices require the assertion and the acceptance of the person, or of the collective, as agent. Self-esteem and self-knowledge are demanded from all involved, not just the affected.

Within enabling regimes, the situation of being HIV-infected is being significantly reconstituted. The infected or affected person is constituted by affirmative agency, rather than by opposition or dismemberment. The isolation of illness is displaced by an insistence on the maintenance of a sense of constituency and community with others. In these regimes, knowledge and information flow diffusely through neutralistic networks, not from magisterium to patient.

In such regimes, care and concern do not in themselves justify intervention, even interaction. Such practices can be as appropriative, controlling or subjugating as any regulatory practices. It is the nature or quality of interactions that frames the ethical discourse, defines the partnerships and which determines the efficacy and sustainability of practical outcomes.

Sites of enabling practices become the occasions for significant social analysis and social transformation. The perspectives, desires and experiences of all involved contribute texturally to the understanding so that a life-affirming health is produced and the complexity of living within the epidemic recorded.

This approach to the production of knowledge and of health assumes that all those involved bring their own life experiences, personalities and skills to the interaction. Within these interactive processes, the insider-outsider, patient-provider, informant-researcher, recipient-expert distinctions are not erased. Rather the nature of the interaction enables each participant to become both, with respect to self and the other, to better understand each other's and one's own desires, perspectives and expertise.

In writing of these enabling practices with respect to feminist research, Maria Lugones and Elizabeth Spelman argue:

“If white/Anglo women are to understand our voices, they must understand our communities and us in them ... [and] undergo the very difficult task of understanding the text of our cultures by understanding our lives in our communities. This learning calls for circumspection, for questioning of yourselves and your roles in your own culture. It necessitates a striving to understand while in the [un]comfortable position of not having an official calling card (as ‘scientific’ observers of our communities have); it demands recognition that you do not have the authority of knowledge; it requires coming to the task without ready-made theories to frame our lives. This learning is then extremely hard because it requires openness (including openness to severe criticism of the white / Anglo world), sensitivity, concentration, self-questioning, circumspection. It should be clear that it does not consist in a passive immersion in our cultures, but in a striving to understand what it is that our voices are saying” (Lugones and Spelman 1994: 28-9).

The same challenge exists for those who wish to understand the voices of those affected by the epidemic. Enabling practices require not only a change in the nature or quality of interaction but a reconstitution of self, of identity, by all involved, whether doctor, researcher or HIV-infected person. Enabling relations require identities robust

enough to be both confident and humble, for they require self-esteem, autonomy and acceptance.

Such interactions do not deny or ease difference but build on these differences thickly and constructively. These interactions can only take place in the listening mode. They require a harmony between what is said and what is practised. The relations themselves must be “empowering, inclusive and sustainable. It should encompass not only the person living with HIV/AIDS but the socio-economic environment in which they live” (Chipanta 1997). Enabling relations take time, for it takes time to create trust and for the dispossessed to understand that their own personal knowledge, experiences and insights are valued in the research or medical cultures.

These interactive and enabling practices of the production of knowledge and health require the generation of respect and trust across differences, often of privilege, education, wealth, social standing and infection status. Where these relationships are not generated, feelings of exploitation and manipulation result. Where they exist, true partnership becomes possible, and the relationship itself contributes to the production of health and well-being, to the structuring of purpose into life through a sense of contributing to the well-being of self and others.

Enabling practices: perspectives, knowledge and social transformation

Enabling practices which incorporate the perspectives of those living with HIV and AIDS and those researched as integral elements in the production of health and of knowledge are transformative:

— The interactions reveal the partiality of each individual perspective, especially the partiality of the perspectives of the privileged. Different perspectives arise from different social locations and carry an understanding of how other social positions relate to it. Social difference becomes a resource. All need to be expressed if social relations are to be transformed.

— Dialogue across difference creates the possibility of social transformation, for an understanding of what is happening to others is a pre-condition for the moral skill of empathy and facilitates more just and caring decisions and activism;

— The recognition of the knowledge, experience and insights of those traditionally silenced stimulates processes of validation, social inclusion and of the creation of self esteem; and

— The expressing, and challenging, of differently situated social knowledge adds to the social knowledge of everyone and can form a picture of society which is more complex, allowing a greater understanding of the reality and of how social transformation can come about.

Living with HIV and AIDS: identities in struggle

The quality of the relationships created in these enabling practices will depend in an important way on whether the HIV infected person can assert self as agent, and on the extent to which those infected are the locus of an affirmative power by which they live with, rather than are defined by, their HIV status. Enabling practices demand constructive, rather than oppositional, agency and active participation, and so create democratic contestation and rearticulation.

For living affirmatively with HIV and AIDS requires active processes of reflection, critique and self-transformation. Yet the struggle to construct and reconstruct self in the long post-disclosure journey is fraught with boundaries and stumblings. At least three critical transitions mark and shape this struggle:

- The transition from the trauma of disclosure to coming to live with that knowledge, taking up again the life that was being lived before and continuing on. This is a form of resistance to the constitution of identity as infected. It is a claim to life.
- The transition from living well to living with illness and the immanence of the dying. This requires a profound shift in the concept of self.
- The transition from HIV as a personal concern to HIV as a collective concern, the basis for constituency building and collective action.

Regulatory practices destroy the possibility of moving through these transitions but only this journey makes agency possible. It creates the pre-conditions for the active participation of people living with HIV and AIDS, as equals, in enabling practices and in the forms of activism that lead to social transformation.

In most African countries, the first two transitions are conflated: the person encounters his or her HIV status in the diagnosis of illness and so struggles to assimilate both infection and the possible immanence of the dying. The constituent elements of self shift profoundly and may be reconstituted either as the dying self or the self living but with the immanence of death.

The outcome of the struggle to make these transitions influences the nature of the relationship between those infected and their support groups. Where little agency or energy has been gained in the transitional space, the demands are often for the satisfaction by others, not themselves, of their needs, whatever they are, money, treatment drugs, legal aid, etc. Theirs is an oppositional stance. It is a demand by them for the imposition on themselves of regulatory practices. When this does not happen, there are recriminations.

The outcome of the struggle is also critical for those who share the person's life. This group is also composed of people in processes of change. They can be changing with or against the person infected. Those who share their lives, who love them (spouses, children, family, close friends...) face the same transitions as the infected person, and one more:

— The transition to life after the death of the person: living with grief and loneliness, the taking up again of life, the struggle to recreate the self without the other, the continuing presence of the epidemic.

There is a global discourse of the infected person as an individual without ties to lineage or community, and relating only to health care professionals. This discourse does not capture the nature of the relations between an individual and the group in many cultures. It leads to the neglect of those who are close to / live with the person, who themselves are profoundly traumatised by the knowledge of the person's infection and who are the infected person's closest counsellors and carers, and the midwives of the dying. Or would be, if helped to themselves make the transitions.

This discourse also leads to organisations and services for people living with HIV and AIDS excluding those that are close to them and neglecting their needs. For example, NAP+ —the Network of African People living with HIV/AIDS— moved from being a network *for* African people living with HIV to a network *of* African people living with HIV. There are few, if any, self-help groups for those who are close to those infected in Africa and little focus on care and services for them. Yet the construction of the infected self as agent depends on the active participation of the affected in the journey.

The relationship between someone infected and those who share his or her life can be symbiotic and supportive. If the infected person, and others, neglect this relationship, this can lead to disharmony and social dysfunctionality and to profound feelings of sadness and loss amongst all concerned.

Each transition is a site for the reconstruction, or destruction, of the self: personal growth may be arrested by the knowledge of infection or the self may remain changing, continually in the making. Being infected may overwhelmingly, perhaps obsessively, define identity and over-determine action: the constant search for treatment, support, etc., in ways that interfere with living. Or the person may come to live with the infection but not be determined by it. More likely, the person shuttles in and out of these possibilities and of places in between.

It is the changing self, self continually in the making by self, that is the site within which enabling practices are productive, energy is created and collective action and social transformation made possible.

The most important of the social circumstances that determine the self and that enable or constrain these transitions are found in our relations with others: love, concern, violence, acceptance and rejection (Griffiths 1995: 85-92). The person who has *come to live with* infection or with AIDS will be more able to enter into relations that require self-esteem and self-confidence, that require reflection and accommodation, in short, enabling relations.

Conclusion

The meaning of the Wolof proverb which starts this paper is that the act of helping should be matched by help offered; that, in undertaking a task, a person might need assistance but that assistance

must be to someone who is actively involved in the task himself or herself. A Sereer proverb states that someone being washed should help wash off the soap and water. These proverbs provide us with an initial means of distinguishing between enabling and regulatory practices. They argue that the helping act should not just be passively received but that instead the person helped should also be involved, that any act should actively involve all involved in reciprocal ways.

Enabling practices in the production of health and knowledge and elsewhere, have at least two defining characteristics. They call for the reconstitution of the mode of being present of all involved: the questioning of self, the reworking of authority, the acceptance of responsibility, a striving to understand, an openness to complexity, ambiguity, displacement. In the voices of Maria Lugones and Elizabeth Spelman quoted above, they require “openness, sensitivity, concentration, self-questioning, circumspection”. This reconstitution does not deny agency; it requires it, but a life-affirming, non-subjugating, respectful agency. The self to be reconstituted may be individual or collective: organizational, institutional, social.

Enabling practices are also defined by the nature or quality of the relationship, whether these practices are constituent of the production of health or knowledge, or of community, marriage or nation. They are essentially interactive in ways that draw in differences of desire, perspective, need or capacity, as well as commonalities, and acknowledge that all have a place in the thickness of the tapestry being woven: in social analysis, the production of health and in the processes of social transformation.

Enabling practices and discourse are based on and are generative of respect and trust, within and across lineage, gender, status, age, economic interest, class, etc. Because of this, they make possible alliances, constituencies and communities of difference where the quality of interacting is as important as its outcome and where the outcomes transform collectively and consensually, not imperially. The existence of these practices marks these alliances, communities and nations as sites of redistribution, equity and accountability.

This is the logic that the HIV epidemic requires. This is the logic that catalyses and sustains the cultural, social, political and economic transformations that confound the epidemic.

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Elizabeth REID, *Epidemic logic and its alternatives*

Summary — The HIV epidemic forces the opening up of certain types of practices as sites of contestation and re-articulation. Epidemic conditions rationalise and augment regulatory power regimes. Regressive practices of control and regulation, of intrusion and extraction, are legitimised and normalised. The contestation produces a distinction between regulatory and enabling discourse and practices. Regulatory practices lead to an activism of opposition by the regulated. Enabling discourse and practices are affirmative and transformative. They require, and strengthen, a sense of identity, individually and collectively, for they require self-esteem, autonomy and authority. Central to the concept of self is a sense of agency and of a capacity to influence and shape one environment. Coming to know that one is infected is the beginning of a struggle to construct and reconstruct the self, a struggle that is fraught with boundaries and transitions. Regulatory practices destroy the possibility of moving through these transitions but only this journey makes possible the active participation of people living with HIV and AIDS in enabling practices and enabling activism. These enabling practices and forms of activism create the kind of social transformations that this epidemic requires.

Keywords: epidemic logic • regulatory practices • enabling practices • identity
• living with HIV and AIDS • activism.

Elizabeth REID, *La logique de l'épidémie et ses alternatives*

Résumé — L'épidémie à VIH oblige à ouvrir la voie à certains types de pratiques où peuvent s'opérer des contestations et des réarticulations. Les situations épidémiques justifient et renforcent les régimes politiques autoritaires. Des pratiques régressives de contrôle et de régulation, d'intrusion et d'extraction, sont légitimées et normalisées. Leur contestation produit une distinction entre pratiques et discours régulateurs ou habilitants. Les pratiques régulatrices conduisent à un activisme d'opposition de la part des personnes soumises aux règles. Les pratiques et les discours habilitants suscitent l'affirmation et la transformation : ils nécessitent et renforcent un sens de l'identité individuelle et collective, car ils présupposent l'estime de soi, l'autonomie et l'autorité. Au centre de ce concept il y a une perception de la capacité d'être acteur, d'influencer et de modeler un environnement. Savoir qu'une seule personne est infectée, suffit pour débiter la lutte afin de construire et de se reconstruire. Cette lutte se mène avec des limites et des transitions. Les pratiques régulatrices détruisent la possibilité de traverser ces transitions, alors que seul cet itinéraire rend possible une participation active des personnes vivant avec le VIH/sida à des pratiques et des actions habilitantes. Ces pratiques habilitantes et ces formes d'action créent le type de transformations sociales requises par cette épidémie.

Mots-clés : logique de l'épidémie • pratiques régulatrices • pratiques habilitantes
• identité • vivre avec le VIH/sida • engagement dans l'action.