

School of International, Political and Strategic Studies

# State Society and Governance in Melanesia

**DISCUSSION PAPER** 

Discussion Paper 2011/4

# READING GENERALISED HIV EPIDEMICS AS A WOMAN

### INTRODUCTION: READING AS A WOMAN?

In 2003, Catherine Campbell (2003: 1) asked a question central to developing effective responses to the HIV epidemic: "Why do the best intentioned attempts to stem the tide of the HIV epidemic often have so little impact?" I shall explore this question in the settings of generalised HIV epidemics. A key defining characteristic of these epidemics is that as many or more women as men are HIV infected. In Southern Africa, prevalence among young women aged 15 to 24 years is on average about three times higher than among men of the same age (UNAIDS 2010). In 2009 UNAIDS estimated that women made up 59 per cent of those living with HIV in South Africa, 59 per cent in Swaziland, 57 per cent in Botswana, 59 per cent in Malawi, 58.5 per cent in Kenya, and 61 per cent in Uganda (UNAIDS 2011). A similar pattern is emerging in Asia, where the proportion of women to men living with HIV rose from 19 per cent in 2000 to 35 per cent in 2008 (UNAIDS 2009). In PNG, in 2009, UNAIDS estimated that 58 per cent of those living with HIV were women.

Our way of talking about an issue—a discourse—is also our way of thinking about the issue and shapes the way we act—our response (Cranny-Francis et al. 2003: 93). The dominant discourse of HIV epidemics is one of rational individuals, of knowledge deficits, of groups and categories, of risk and of reach. But, as Campbell and others have noted, the best-intentioned responses to the HIV epidemic have had little impact. This raises the possibility that the responses of the dominant discourse were arrived at through a particular reading of the epidemics.

In this paper, I want to read generalised epidemics as a woman might (Cranny-Francis et al. 2003:120) and to rework the discourse on such epidemics to articulate and include a specifically feminine voice. In using the phrase "reading as a woman",

ELIZABETH REID my aim is not to develop a singular different voice, a universalised, essentialised feminine persona. Rather, it is to explore, in the words of Lorraine Code (1995:155), "whose voices have been audible, and whose muffled, in the articulations of prevailing theories; of showing whose experiences count, and how epistemic authority is established and withheld". I argue the need for continuity between the way these epidemics are read and women's multiple voices, experiences and subject positions. The answer to Catherine Campbell's question lies at least in part, I contend, in the absence of these women's readings, and in the absence of their incorporation into the dominant discourse. It also lies in part in the absence in the response to these epidemics of the programmatic insights to which a woman's reading gives rise.

To set out to read these epidemics as a woman is to contend that current readings are not value free, universal or complete. It commits one to interrogate the realities that have been constructed within the dominant discourse, to probe the meanings and values that are propagated by it, and to query what is socially normative within it. It accepts the existence of differing points of view, interests and perspectives, of different ways of doing things and, because there is a relationship between the position or situatedness of subjects and the knowledge produced, it implies the existence of different knowledges. Reading the epidemic as a woman challenges the dominant discourse to reflect and take into account the spatial, cultural and social locations within which women live their daily lives, the workings of power and patriarchy in their lives, and the gendering practices of societies (Reid 1992).

It is not the objective of this paper to critique the dominant discourse. Every discourse is problematic, makes assumptions that it cannot justify, and omits frameworks and questions that may prove relevant to its concerns (Grosz 2005:179). The concern here is with ensuring HIV discursive practices and knowledge better capture women's ways of relating to the world, and also children's. This requires a gendered analysis of the dominant discourse. A gendered

analysis requires an analysis of the operations of power in society (Cranny-Francis et al. 2003:94–95). The first part of the paper provides this gendered analysis; it outlines features of the dominant discourse that are critical as counterpoints to or points of departure for a woman's reading of the epidemics. The second section sketches a woman's reading of the epidemics; it does not set out to supplant the dominant discourse but to vary, expand and enrich it.

My intention is to provide readings, ways of understanding, which are effective in stemming these epidemics. Given that in these gendered HIV epidemics so many of those infected are women, I contend that working from women's readings of the epidemics can lead to other, perhaps different, priorities and programmes, to strengthened and diversified ways of responding to the epidemics. Some of the programmatic insights that arise from a woman's reading are discussed in the final section.

### THE DOMINANT DISCOURSE

Central to the dominant discourse on the HIV epidemic is the Cartesian notion of autonomous, individual reasoning (Lloyd 1984: 44–45, 49–50). The dominant discourse portrays the individual as someone who acts on rational assessments of situations. Behavioural and attitudinal changes come about as a result of an individual's rational and conscious choice about whether to abstain, be faithful or wear a condom (ABC). It is hypothesised that individuals who do not act rationally in an HIV setting have a knowledge deficit, and the lack of relevant information inhibits behaviour change. To address these putative deficits, airport briefings on HIV transmission and prevention are held for overseas workers before their departure; HIV awareness workshops proliferate; drama groups take their HIV plays from village to village; HIV testing and counselling centres are constructed one after the other. However, this Cartesian self is at variance with the HIV realities of most women's lives, and of many men's lives as well. Providing information has not led to significant HIV-related behavioural and attitudinal change. However, there are ways of theorizing this other than to postulate that the behaviour is irrational or arises from a knowledge deficit. This is particularly relevant to cultures where personhood is collectively constituted and responsibility is social conceived.

The dominant framing of HIV epidemics assumes both agency and rationality: that the individual is autonomous, able to define and determine him- or herself and to act independently of social norms and institutions and cultural values and of the social and intimate relationships that weave their lives. Individuals who fit this paradigm, who are rational and autonomous in the way theorised, may well be able to deliberate on the information provided, reach a conclusion about its relevance for their lives and values, and act on the conclusion. For them, the directives function as aide-mémoires to behaviour, as guidance in practical reasoning. However, the HIV epidemic has shown that there are few women and not so many men who fit these Cartesian constructs.

This Cartesian account posits power as a quality, namely autonomy, which resides in individuals: actors are autonomous, take decisions and act in accordance with them. Localizing concepts of power in individuals may have arisen from the fact that further sexual transmission of HIV could end if men decided to use condoms for protection. regardless of their sexual orientation or that of their sexual partners. The fact that men are not using condoms in this way should, in itself, have given rise to a re-examination of this account of power. The absence of such a re-examination has contributed to the neglect of analyses of power in the settings of transmission. The power and politics which structure women's relationships, and children's, within HIV-transmission settings remain undertheorised, lost in discourses of vulnerability and risk (UNAIDS 2008:Ch 3). A paradox of the dominant discourse is that it is also marked by an under-developed discourse on men. Women, young people and the marginalised are designated as particularly

vulnerable to HIV, but not men (UNAIDS 2005:15).

The focus of the dominant HIV prevention discourse is on the site of HIV transmission conceptualised as the performative sphere of sexuality. This is where enumeration (frequency of the sexual act, for example) (Aggleton 2004) and classification of the performers (homosexual, heterosexual, sex worker, for example) (Plummer & Porter 1997) take place. It is a mechanical and reductive focus: the site of transmission is reduced to a site of penetration. Sexuality is appropriated as a knowable, measurable, containable and classifiable object of analysis (Grosz 2005:197), perplexing concepts for female sexuality, perhaps more appropriate to the practices of male sexuality. As Grosz (2005: 209) contends, there is something countable in the thoroughly decidable nature of male sexual response and activity. This masculinised paradigm is observable in the enumerations, classifications and quantifications practiced widely in HIV epidemiology and social research.

The discreteness and specificity of the concept of "sites" of transmission encourage linear logics: there is a site of transmission and beyond that there are social, economic and cultural contexts in which the site is placed, which are themselves layered. For example:

HIV transmission is fuelled by a variety of factors, including most importantly, the local context created by local norms, myths, practices, and beliefs, as well as social, economic and human security realities (UNAIDS 2005:18).

A reading grounded in the realities of women's daily lives should be able to capture the fields and flows of gendered and structural forces in a less linear manner. These forces are inextricably implicated in, rather than fuelling, the settings or spaces of transmission to women.

Another consequence of starting with the concept of a "site" of transmission is that it has rendered the epidemic invisible. If the epidemic is read in the sexual acts—the sites in which transmission takes place, it cannot be

seen. Early HIV campaigns in the Trobriand Islands elicited responses such as:

We don't know what HIV looks like, so how do we know if it is here in the Trobriand Islands? (Lepani 2004:9)

When we got the AIDS awareness, we are all afraid of AIDS, so we are asking, do you have any ideas to help us see this thing, to help us with our feelings about AIDS, to help us understand about AIDS so we won't be afraid?

(Lepani 2007:14)

When an analysis begins with a site of transmission, the opportunity is lost to learn to see the epidemic in what we might call the spaces of transmission, to see it in its driving forces: in the lack of valuing of women; in cultures of rape, intoxication, gendered violation and abuse, shaming and blaming; in the lack of networks of mutual support and caring; in state neglect and structural violence, and others. Instead it is seen in terms of the consequences of transmission: the emaciated bodies and affected minds, the death toll, the ubiquity of coffin-making businesses. Too much time passes before the epidemic's consequences emerge into view.

A reading grounded in the realities of women's daily lives will also challenge the compartmentalisation of responses into irreducible categories: prevention, stigma and discrimination, care and treatment, and impact. This partitioning obscures interconnections and synergies. Women understand, for example, that protection from HIV infection must take into account the desire for conception, the quest for romantic love, the circumstances of a person's life. They understand that behaviour may change not with HIV information but with reflection on the consequences of infection, on its impact: women see men starting to protect themselves when they think about what would happen to their children if they were to become infected. Women are more aware of these interconnections; they read them from within relationships, families, and communities. And from the outside.

The dominant HIV discourse is also directive, framed in terms of interventions or

directions of flow: information to individuals, interventions for sex workers or drug users or truck drivers. The flow goes from experts and institutions to targets. What is sought, and measured, is that the "targeted" groups or individuals change their behaviours in the ways specified. Because of the target groups chosen, this has led to an HIV programming focus on sex, and hence on condom use, outside of heterosexual marriage or stable relationships. It is acknowledged that what marriage means varies across cultures, and extra-marital sex may be differently understood by men and women (Eves and Butt 2008: 7, Hirsch and Wardlow 2006, Hirsch et al. 2010, Pollock 2003). For men, it may be considered a condition for social acceptability, a constituent part of male friendships or a migrant labour practice, rather than "infidelity" (Wardlow 2007). However, prevention strategies have not included the advocacy of condom use in marriage. HIV social research overwhelmingly investigates condom use outside of marriage; only a few studies look into condom use within marriage or stable relationships. Yet women's experience of the epidemic arises from within marriage and trusting relationships, and outside of them. The majority of women are infected in marriage and other stable relationships. Women are infected by, and infect, men who are not protecting themselves, inside/outside of these relationships. Women are raped inside and outside of these relationships. It is the nature of the sexual relationship rather than whether it occurs inside or outside of marriage that is the focus of a woman's reading.

This extra-marital discourse and programming focus has made the interpretation of new research findings on discordant couples morally fraught. Recent studies have shown that in some parts of Africa the majority of new HIV infections are occurring in marriage or stable relationships (de Walque 2007, Bongaarts 2007, for example). Interpreting this data within the dominant discourse has led to analyses in value-laden terms such as "infidelity", to disputes about whether or not marriage is a "risk factor" for infection, and contestations about whether the "infidelity" involved is male or female: " ... in

a significant percentage of unions, it is the woman who brought HIV into the marriage" (Herling Ruark 2007). This has contributed to the blaming of women with the use of the terms such as "female infidelity". The reductive focus on sites of transmission produces a "time-slice" approach, which takes out of the analysis the interplay of forces over time. At one HIV treatment centre in rural PNG, in three of the five discordant couples receiving care it was the woman who was infected (Bundu 2007). A simplistic analysis of complex situations could give rise to claims like the above: that these were cases of female infidelity, of women bringing the virus into marriages. However, on further investigation, it was found that each of these three women had lost a previous husband to HIV. Which marriage, then, is the focus of analysis? Women who bring HIV into a marriage may have been infected in a previous marriage or raped or unfaithful, or infected in a health-care setting or when earning a living. It could have been more than one of these, or some other story. The analysis should encompass this.

The centrality of the notion of the individual has also resulted in an understanding of social change in terms of HIV programme reach in which social change requires the total coverage or saturation of a group or a population. Programme objectives have been defined as, for example, all men who have sex with men reached with information and access to testing, or, every door in a district knocked on. In this understanding, success is measured quantitatively, and this has led to performance indicators on work plans which encompass every individual in a population. It has also led to the principle of scaling up being standardly interpreted as getting organisations already working on HIV to work with more people. Programmes driven by the imperative of material coverage can fail to take into account alternative theories of how social change comes about. Alternatives include more iterative social learning processes in which learning and social change is linked to reflection, participation and practice (Schon 1983, Wenger 1998, Guijt 2007, Pettit 2010). They also include what might be called

"memetic reach"—reaching people in ways, for example, that see old wives' tales become part of our cultural genetics and facilitate changes of social values and norms and cultural practices from within groups.

# READING GENERALISED HIV EPIDEMICS AS A WOMAN

To read as a woman is not to claim that all women read the same narrative of an epidemic. Women are situated in different ways within the epidemic: as living with HIV; fearful of being infected; loving/in relationships with other women, or with men living with HIV; as caring for people with HIV; as married, divorced, separated, widowed, or unmarried women struggling to remain uninfected; as younger, more mature, or post-menopausal women, and more. Women may be differently located culturally, socially, spatially, ethnically and in other ways. The experiences of women, and the knowledge they produce, will reflect these differences. However, it is still possible to share experiences of the world with women who share crucial features of this social positioning.

Reading as a woman is not what necessarily occurs when a woman reads the epidemic. Just as a man may read outside of the dominant discourse, so may a woman read within it. Wives who refuse to allow their husbands to use condoms may not be reading the epidemic from the perspectives of women struggling to protect themselves, but rather from the dominant discourse of extramarital or transgressive sex. They are not acting to save their own lives or to ensure that their children have parents. The notion of reading generalised HIV epidemics as a woman relies on the notion of the reflective experience of women as women.

### **READING REFLECTIVELY**

Reflective practice is similar to the practice of mindfulness. This is the practice of being mindful in one's daily life, of taking heed or care, of being conscious of oneself in the world. It deepens and enriches understanding. The concept of reflective practice can be glimpsed in Agnes's story, a story from the Highlands of PNG (Meier 2006).

I give HIV awareness classes. I have been doing this for four years now. I have lots of knowledge and science in my head. I am a professional, a nurse for 13 years, but it was Rose who gave me knowledge for my heart.

Sister invited me to visit Rose with her. We arrived in front of an old house with rotting grass on the roof. Sister went in and a voice from a corner of the dark room said: "Hello, Sister". I could not see Rose clearly but my stomach told me what I was looking at. I was looking at a woman in the last stage of the AIDS illness. I froze at the doorway. My legs refused to take me into this dark rotting house.

Sister went over to Rose, gave her a hug, and presented her with some dishes of food and medication. Why didn't Sister tell me we were going to visit an AIDS patient? I was frightened. Maybe Sister knew my heart and fears better than I knew myself. I could see Rose clearly now. Her bones were sticking out everywhere. She had wrapped herself in a dirty blanket. In all my years as a nurse I never saw a person looking so bad.

I could see the light in Rose's eyes as Sister talked to her. A wonderful thing happened to me at that moment. All my years as a nurse, wife, and mother came together in my heart and feelings. I accepted Rose as my friend. I gave her a place in my heart. I no longer had any fear of her AIDS illness.

I have gone back a number of times by myself to visit with Rose to help her in the way that I have been trained. It was not just I the nurse and Rose the patient. She and I spoke to each other from our hearts.

Such reflective transitions are by no means the prerogative of women alone. Yet

HIV work, and work on men's violence against women, shows that men may not be fully aware of the impact of their actions on women. When made aware, they are often troubled. The distress can be heartfelt. When, in Goroka, some raskols (street criminals) had been boasting about raping women, a community worker asked them: "What do you think happens to the women you have raped?" They replied with stories of women trying to get back at them, stories of women's payback, of women's acts of revenge. They told stories of women seeking compensation or laying charges with the police. The community worker said "No. I am asking how you think the women feel after they have been raped". The raskols were puzzled. The worker told them stories of how rape affects women, of how women who have been raped feel, of what happens to them. "Stop," the raskols said, "it is not good feeling this" (Lennon 2008).

Reflective transitions require mindfulness and an openness to change in one's ways. Agnes now has knowledge from the heart. Her HIV awareness classes will now be different. She need no longer rely solely on facts and diagrams, the knowledge and science in her head. She can speak from a lived and deeply felt reality. She has experienced the profound change from a nurse-patient relationship to one talking from the heart. Agnes now has stories of respect and dignity, of courage and grace, stories that might touch others and motivate them to protect themselves. It is not ignorance, a lack of knowledge, that is fuelling the epidemic so much as the lack of the desire to change. This is true in PNG and elsewhere. The will to change requires a capacity for reflection and the willingness to take the challenges of the epidemic into one's life and reflect on their meaning.

### READING CHILDREN INTO THE EPIDEMIC

A woman's reading would be a reading that includes children, children and their parents and grandparents, children as abandoned or as orphans. It would be about the way women with HIV become determined to stay alive to take care of their children. It would be about how men do not want harm to come to their children and that this goodness in men can lead to them change their sexual behaviour. It would be about how the impact on children starts as soon as one or both parents come to know they are infected and lasts long after their deaths, about the agony of discerning when and how to tell one's children, about the grave psychological, emotional and social impact on children of living in a family touched by the epidemic, about the deprivations and exploitations involved in growing up in HIV-affected communities, about the way the epidemic affects schools, and about the courage of children.

Christine, a Ugandan woman living with HIV, a teacher and a mother, talks with Henning Mankell about her daughter, Aida (2004: 24–25).

"When I am gone, Aida will have to take on a lot of responsibility. I am trying to live for as long as I can for her sake."

"Does she know about it?" Henning asks.

"Of course she knows about it."

"What did you tell her?"

"What had to be said. She will become the mother of her brother and sisters, and if my parents are still alive, she will become their new daughter once I am gone."

"How did she react?"

"She was distressed. What else would you expect?"

There are already millions of children touched by the epidemic. They have been reading the epidemic as children, yet their voices also have not been heard. In seriously affected countries, some 95 per cent of these children continue to live within their extended families. Together families and communities bear 90 per cent of the financial cost of caring for the affected children. Yet responses so far have primarily targeted orphans and children in isolation from the families on whom they rely for care and support and the community

responses that support these families have been overlooked (JLICA 2008). Programmes for these children and their families need to begin early, be provided through family-centred and community-based programmes, and continue into adulthood.

The Serendipity Education Endowment Fund (SEEF) in PNG has been designed in this way (Reid 2010c). It provides support to families touched by the epidemic to help them keep their children in school and able to complete their education. Parents living with HIV have to cope with illness, pain, fear, despair, discrimination and much more. Often they cannot continue with their gardens or work. It becomes impossible to keep their children in school. SEEF works with a number of partner organisations who work with people living with HIV. Through them, SEEF supports parents, carers and guardians of families of children whose parents are living with HIV or who have already died of HIV. SEEF contributes towards the children's school fees and other costs associated directly with their education. SEEF brings hope to families and the feeling that they can do something for their children. It gives them a reason for living and for looking after their health. It gets families talking to each other again, helps the parents feel that their children may now have a future. It gives these children a voice, and brings them together to support each other and enables hope.

# GENDERED SPACES OF HIV TRANSMISSION TO WOMEN

A woman's reading of generalised HIV epidemics is inextricably linked to the gendering practices of societies and the power that pervades their production and praxis. For women, the sexuality implicated in HIV transmission is heterosexuality; women are infected sexually in unprotected, penetrative sexual relationships with men. Among the millions of women infected sexually, there are only a few documented cases of woman-to-woman HIV transmission (CDC 2011). In the richness and diversity of women's sexuality and its expressions, it is in their heterosexual

relationships that they are infected. Hence a woman's reading of generalised epidemics is a reading about relationships with men, about the forces and factors that constitute the spaces of HIV transmission, and the social norms and values and cultural practices that result in women being so significantly infected.

What do we know about the spaces of transmission to women? Large numbers of young women (women through to their midtwenties) are infected because the immaturity of their genital tract makes it much easier for the virus to enter their bodies-much easier than in the bodies of older, pre-menopausal women, or of men, whether circumcised or uncircumcised. Women who live in violent and abusive relationships, particularly where there are high levels of male control, are more likely to be infected than other women (Dunkle et al. 2004, Jewkes et al. 2003, Silverman et al. 2008). Women who are involved in unprotected anal sex, whether it is consensual or not, have much higher rates of infection. Women report quite significant rates of receptive anal intercourse. In one African study 18 per cent of the female participants reported receptive anal intercourse (Grijsen et al. 2008). In one PNG study, over half the truck drivers along the Highlands highway claimed to have had anal sex with women (Millan et al. 2006). Most women living with HIV were infected by their husbands or regular partners (UNAIDS 2004, Hammar L. 1999, Aeno 2005).

Heterosexuality for women is complicated by consent and reproduction, fraught with the virgin/whore dichotomy, saturated with power, discomforting, desired, too often focused on the "other" rather than being experienced "in and through the other" (Irigaray 1985:31). It is in these uneasy gendered and relational spaces that HIV is sexually transmitted to women. These spaces are virtually inescapable for women in sexual relationships with men, for HIV-protective technologies or strategies are not under a woman's control, as they are for men irrespective of their sexual orientation. Women understood this long before the time of HIV because reproduction and sexual health are so rarely under their control. Protective faithfulness is not under women's control. Being faithful is an asymmetrical relationship: most HIV-infected women were being faithful to their husbands or regular partners when they were infected. Women can abstain from sex in contexts of respect, in cultures or relationships in which women are valued, but abstaining is not a strategy under women's control in contexts where subjugation, ownership, violence or the threat of violence operate (Eves 2006: 25, Haley and Muggah 2006: 170, 174, Lewis et al 2007: 6, 118, Haley 2005: 35).

The only current candidate for a protective technology for women, the female condom, can be seen and felt by their partners. It does not allow women to protect themselves in the way that condoms enable men to do. It is a protective technology for women who control their lives and their sexuality. This includes women in relationships with men in which they are respected and able to talk about sexuality and protection, and many women in sex work. Cervical barrier methods, such as the diaphragm, which are under women's control and which can be used without the fear of exposure and the threat of violence, are yet to be trialled for their HIV efficacy (Mantell et al. 2008). They are unavailable in PNG and difficult to obtain elsewhere in the Pacific. Reducing the number of concurrent sexual relationships is emerging as a protective strategy, limited in its effectiveness, but important to understand. A number of the peer educators and the women they work with in the Poro Sapot Project of Save the Children in PNG have decided to adopt it, along with female condoms, as a protective strategy.

For most women, the only way to protect themselves when having sex with a man who is not protecting himself is by confronting, resisting, negotiating, cajoling, battling in each sexual encounter with such a man. This holds whether the woman is married to the man, having consensual sex with the man, being raped by the man or men, or involved in various other forms of transactional or commercial sex. The inadequacy of these protective strategies and technologies for women casts light on why women throughout PNG, for example, have been paralysed with fear and filled with despair and hopelessness

by HIV awareness workshops, drama and billboards. Theirs is not a knowledge deficit but an agency deficit, an inability to protect themselves in their sexual lives. In spaces of HIV sexual transmission to women, there are men who are not protecting themselves. Central to a woman's reading, unless and until protection is under a woman's control, is the search for ways to work with men to help them strengthen their desire to protect themselves and care for others.

Women live within the epidemic as sexed and gendered subjects, and the irreducibility of sexual difference and the intractability of gendering practices require the production of gendered readings of the epidemic. This calls for new ways of thinking the feminine and the masculine, of understanding gendered subjectivity and of the relationship between the individual and her or his culture.

# UNDERSTANDING THE GENDERED SPACES OF HIV TRANSMISSION

In a woman's reading of generalised HIV epidemics, HIV transmission occurs in spaces, rather than sites, spaces awash with power, saturated with daydreams, desires and aspirations, amorphous spaces. Such a space is described by Dantip, a young woman from coastal Papua, Indonesia (Hewat 2008: 159):

On the ship I stood at the front just like that pretty girl in the film *Titanic*, and like her I was full of strong feelings. When I got off the ship and saw his face I felt in love .... We just sat on a hidden place on the beach and "played" and it was so delicious.

Vera Paiva (Boyce et al. 2007: 17) gives us the voice of a young Brazilian woman describing such a space:

The exact moment I was infected by HIV, I was not getting infected ... I was deeply in love, wanting to be with my love, in a joyful and long desired moment of body and spiritual pleasure, longing for all the moments we would share together ... from that magical moment, sharing hopes and sensitiveness.

This is not a description of the spatially locatable nor is it countable as the site of HIV transmission. Here the space of transmission is a confluence of states of being: of cravings, hungers, yearnings, desires, aching, touching, pasts and futures. It suggests a sexuality that has no centre (Irigaray 1985:79) but rather is multiply sourced, diffuse, fluid. It is a confluence "that upsets the linearity of a project" (Irigaray 1985:30) and in so doing resists the semblance of ejaculatory simplicity in discourses of transmission.

Another woman's voice is given to us by Mary Huang Soo Lee (2004):

I did not ask him to wear a condom. I knew he was infected but I wanted him to feel he was really loved.

This is the voice of a 28-year-old educated, employed woman in Malaysia who married a man she knew was living with HIV. Hers was a considered decision to have unprotected sex but it is not one of the alphabet choices in the portfolio of the rational man of the dominant discourse. Yet it is a voice that is heard in conversations with other women, one that needs to be captured in women's reading of the epidemic.

These are narratives of agency, of consensual sexuality and of regard for the other within relationships, paradoxically a privileged place from which to view the epidemic (Eves and Butt 2008: 18). Most women living within the epidemic are located elsewhere, fearful of, or living through, violence, abuse, rape, shame, neglect, drunkenness, dispossession, poverty, and the many other locations from which women experience the epidemic.

Understandings such as these of the extension, complexity and relationality of HIV spaces can capture the workings of power and patriarchy in women's lives in ways that a discourse of vulnerability fails to accomplish. How the machinations of power and gender affect women's lives may be illustrated by a story from Mexico City, Frida's story (Winn et al. 1996:4):

Frida's husband was infected. He could not bear the thought of Frida being the lover of another person and so he decided to infect her. Frida knew that her husband had intentionally infected her. She was not angry at him, or at life. She was not traumatised by the anguish, grief, loss of being infected. She had a curious calm. What she said was: "I am not afraid of him any more. We are now on equal terms".

These stories have programmatic implications. They can ground the response to such epidemics in the ways that women experience the world, and so throw light on how the response might be rendered more effective. A woman's reading in terms of gendered, power-saturated, relational spaces allows the development of more complex and synergistic responses. These take into account the various forces and factors constituting, pervading and shaping these spaces (Butt & Eves 2008). Some such responses will now be identified and discussed. They are responses that work with and against the shifting alignments of power and the practices of gender that create, constitute and structure the spaces of HIV transmission, care, treatment and support.

### ENTRY POINTS FOR SOCIAL CHANGE

Rape is a brutal violation of a person's integrity and facilitates HIV transmission. However, when HIV treatment drugs are administered to women, children and men within 72 hours of their being raped the likelihood of HIV infection is significantly lowered. A woman's reading would give immediate priority to providing these drugs for the victims of rape and incest, along with the training of health-care workers in the care and support of those victims.

However, a woman's reading also includes the practices, norms and values that create and shape rape and post-rape situations. Inherent in cultures permissive of rape is the lack of valuing of women. This, in turn, affects the effectiveness of post-exposure care strategies for the survivors of rape and incest; drugs can only be effective in situations where they are accessed. If HIV drugs are not to remain sitting on pharmacy shelves and pass their expiry dates, their availability must be complemented by programmes that

encourage families and communities to help their women and other victims to obtain the drugs. A story from the Highlands of PNG provides important insights (Meier 2005):

Thirteen year old Betty was raped by two young men on the way home from school.

When she reached home she told her parents. Her uncle had just attended a teachers' in-service training where a nurse from the nearby Catholic health centre had talked about the care of women and children who had been raped. He knew that there were now drugs available at the health centre which could be used to minimise the chances of HIV infection if the woman came or was brought to the centre quickly. He sent the girl and her mother to the Centre.

The Centre staff had developed a rape care plan which they followed. As a part of this, HIV prevention treatment (HIV post exposure prophylaxis) was offered. Betty and her mother were counselled and agreed to the treatment. Her mother helped her to follow the course of treatment. She has now finished the course of treatment and is not infected.

Girls, women, feminine men and others in PNG who have been raped rarely go to or are taken to heath care facilities. If they are, they are rarely admitted for care and emotional and social healing. The women may be brought to the outpatients clinic so that a certificate is issued for use in the courts. This is often days after the rape, usually after the failure of traditional compensation negotiations. The health-care facility, rather than being a therapeutic and comforting site for the woman, becomes a utility in men's search for compensation from other men (van Amstel and van der Geest 2004). As people see what can happen if women and girls are brought in early enough, they are challenged to change, to place concern for women before the desire for vengeance or compensation.

If families and communities are aware that the drugs are available, then the survivors

might be taken quickly to the health-care facility and admitted. There are always men, husbands, fathers and uncles, and families who want to protect and care for their members. The availability of drugs for those who have been raped or who are victims of incest may be one of the most effective strategies available for challenging and changing the gendered norms, values and practices that pervade generalised epidemics. Ensuring the availability of the drugs and creating a local demand for them set in motion processes that empower communities to change traditional and gendered practices and values. What might be called a reactive or responsive intervention, a response in reaction to need, in this case the provision of HIV treatment drugs for survivors of rape, in the process of complex implementation can catalyse processes of social change for families and communities and challenge patriarchal values, norms, and practices.

These empowering processes of change in community attitudes, norms and values can be supported by building community capacity to change and by stimulating the change processes (PNGSDP 2009a:164-166 and 2009b: 7-15). Community capacity to change includes the strengthening of community capacity to read and understand HIV spaces, strengthening community knowledge of itself, the way its practices, norms and values affect its members, and strengthening the skills required by the community if it is to change. A number of organisations in PNG are developing ways of working with communities to build their capacity to change (PNGSDP 2007).

There are other interventions that respond to situations of urgent need highlighted in a woman's reading of generalised HIV epidemics that also have the potential for fundamental social transformations. Heavy episodic drinking, alcoholism and other forms of alcohol and drug consumption that lead to drunkenness, betrayal and violence, are directly and indirectly implicated in HIV transmission (Fisher et al. 2007, Fritz et al. 2002). A woman's reading names this and looks for ways to address it. In cultures of intoxication, as those found in PNG (Baldwin et al. 2007), extensive social and peer pressure reinforce

these norms and constrain individuals who wish to drink less. Responsive interventions such as ensuring the widespread availability of detoxification and support programmes, including Alcoholics Anonymous, are urgently needed for individuals who wish to change and are able to use these programmes. However, these interventions must be implemented synergistically with programmes to help families and communities understand the complex linkages between cultural norms about drinking, drug taking and gambling, domestic and collective violence, impoverishment, and HIV transmission, among other things. This is another area, as in the case of rape, where the ability to change resides within families and communities and programmes are needed to strengthen their motivation and capacity to change.

Rape and drunkenness disfigure the lives of women. They are significant driving forces of generalised epidemics in many cultures and so must be addressed. A woman's reading gives them high priority as responsive interventions, but equally it shows that there are ways of addressing them that can assist communities to rethink their place in community life. Communities in PNG have established rape-free villages and decided that drunkenness is not to be tolerated. They have achieved this through a process of discussion and consensus building, based on an increased awareness of the consequences of these acts and a desire to live different lives.

### RESPONDING COMPLEXLY TO COMPLEXITY

Understanding the complexity of HIV spaces encourages the design of complex responses that address a range of the forces and factors present in HIV spaces. One such programme, the IMAGE programme in South Africa, combines a microfinance program for poor women based on a group lending model, with participatory training on understanding HIV infection, gender norms, domestic violence, and sexuality. Evaluations of the programme show that, over two years, physical and sexual violence by an intimate partner was reduced by more than half and improve-

ments occurred in all of the nine measures of women's empowerment. Reductions in violence were shown to result from a range of initiatives enabling women to challenge the acceptability of violence, expect and receive better treatment from partners, leave abusive relationships, and raise public awareness about intimate partner violence. Female participants were more able to talk about HIV and sexuality, more likely to have accessed HIV counselling and testing, and were less likely to have had unprotected sex with their last non-spousal partner (the protection status of spousal sex is not reported) (Pronyk et al. 2006, Kim et al. 2007, Pronyk et al. 2008).

Understanding the epidemics complexly creates the possibility of complex and more effective responses. The IMAGE programme grew out of an understanding of the interplay of forces of power, gender and deprivation that shape the economic, social and interpersonal lives of poor women. A programme was designed that responded synergistically to the complexity of the structural and interpersonal forces present and which strengthened women's agency. Similar analyses need to be made for men's lives so that less simplistic interventions can be developed in response. Complex interventions are urgently needed for men as well as women.

Another area in which the social and gendered complexity of the situation necessitates a complex approach is the prevention of HIV transmission from parents to their children during and after childbirth. The prevention of mother-to-child transmission (PMTCT) was developed in the dominant discourse as a simple stand-alone biomedical intervention: the administration of HIV drugs to a woman to prevent perinatal transmission from her to her child. A woman's reading, however, would open out from the site of transmission to the space of transmission. It would be a reading of complex gendered and social dynamics. In this reading, such programmes would be named the prevention of parent-to-child transmission (PPTCT) and would involve men throughout. The responsive intervention to interrupt transmission to children in the womb, during birth and during breastfeeding would be designed and implemented in such a way that husbands and partners would be

encouraged and supported to participate. It would take place in spaces where men are comfortable. That is, for most men, outside of antenatal settings. Both parents would be involved in decision-making and in ensuring that the socially difficult measures for breastfeeding were followed to the best of their joint ability. Involvement in such programmes can lead men to reflect on their own values and behaviours. The difficulties faced by couples would be lessened as communities became aware of perinatal transmission and how to minimise its likelihood. Communities would come to understand the importance of pregnant couples being encouraged to go for testing and being supported to minimise transmission to their children.

The objectives of these two programmes are to challenge the violation of women and to reduce HIV transmission during childbirth. These are particular objectives but the understanding of the situations in which they occur captured their social and gendered complexity and so made possible more effective responses.

# MOTIVATING PEOPLE TO WANT TO CHANGE

The dominant discourse, with its focus on rational individuals, on knowledge deficits and on reach, has failed to understand the importance of motivation: the importance of understanding what motivates people and whole communities to want to change, to desire to protect themselves from infection, to care about others and to want to support them. The dominant discourse moves from information to behaviour, from instruction to action, without considering, or pausing to work with, motivation. A woman's reading eschews such instructional, linear and directive stances, building instead on qualities in people and communities that lead to and strengthen motivation.

An approach that motivates people to change is exemplified in the work of the Poro Sapot project of Save the Children in PNG. Poro Sapot works with marginalised groups, in particular women and men in sex work, and men who have sex with men. The

project supports them to protect themselves from abuse, injustice and sexually transmitted infections and strengthening their sense of their own wellbeing. The approach is values-based, built on three key principles: recognition—the acceptance of each person as they are; respect—the valuing of each of them embedded in working relationships; and reliance—an understanding that the perspectives that the marginalised bring to their work are critical to its effectiveness. This respectful stance has created strong motivation for people to protect themselves, and created a sense of agency, which enables them to act on the motivation (Reid 2010a).

A woman's reading understands that, for women who want to remain in sexual relationships with men, the means to protect themselves is under men's control, whatever the means might be. This is why so many women are walking away from their marriages and relationships in order to protect themselves and stay alive to raise their children. Men who protect themselves do not infect their partners, male or female. Thus, on a woman's reading, priority is given to ensuring that men who are motivated to protect themselves can do so, they have the knowledge and support to do so, can develop strategies and skills for doing so, and that the technologies of protection are available and affordable. It also means that priority needs to be given to finding ways of motivating the many more men who are not protecting themselves. The following examples throw light on how people might be motivated to change their perception of themselves, to change their sexual and social behaviour, their attitudes, their values.

Experience has shown that helping men think through what might happen to their children if they were to become infected can motivate them to change their sexual behaviour. Building on men's sense of responsibility to and their love for their children can lead them to use condoms within and outside of marriage to try to ensure that at least one parent remains alive to support, nurture and guide the children. In such cases, the entry point for change of sexual behaviour lies outside of the site of sexual transmission, beyond the performative sphere of sexuality.

Another insight can be gained from Africa, where taking care of people with HIV can inspire the carers to want to change. In Zimbabwe, there was deep concern about the lack of change in men's behaviour and attitudes. One of the strategies adopted was to involve men in the care of the sick in their communities. Then men started speaking to each other about the need to ensure that no more families were destroyed by the epidemic. In Zambia, the HIV clubs established in schools involved young people, not in direct HIV awareness activities but in assisting households where people were sick. They swept the yards, cleaned the houses, ran errands, and carried out other tasks; they became a part of the lives of households. In other countries, where these clubs just brought young men and women together to talk about how to protect themselves, few lasted longer than six months to a year. Zambia was the exception. Being involved in care can create the motivation for self-protection and the protection of others.

Further, research has shown that the longer young people stay in school, whether there is HIV education or HIV clubs or not, the lower the rate of HIV infection in both young women and young men. Being educated is, in itself, for young people, protective. The provision of universal free education is both a basic right and a transformative strategy. Uganda, Malawi and other countries offer universal free primary education as an HIV strategy. Agency and motivation are key concepts of readings that take into account the gendered and social dynamics of these epidemic spaces. Policies and programmes that strengthen them form part of the response.

Once motivated to protect themselves, people ask how to do it and listen to the answers. They set out to achieve it. Once motivated to reach out to those touched by the epidemic, caring families and communities develop. In a woman's reading, motivation is central. But a woman's reading understands that motivation must be coupled with agency. Women can be highly motivated to protect themselves or care for their neighbours, but be unable to do so.

# RELATIONAL SPACES: COUPLES, FAMILIES, FRIENDS, COMMUNITIES

On a woman's reading, HIV spaces are spaces where people interact and outcomes are determined by the nature of these interactions. A relational reading is constructed around interconnectedness rather than individual autonomy but guards the concept of agency (Davis & Fisher 1993). It recognises that people are socially embedded in marriages, families, lineages, communities, work relationships, friendship networks and church communities, and that these forms of relating are also a resource through which change can occur. These are relational spaces. Within them, engendered power sways HIV outcomes. HIV programming approaches can build on an understanding of the forces of power to counteract its potentially deleterious effect and strengthen its constructive expressions. The social units in which these forces shape outcomes can become the basic units of the response. The social units may be couples, families, youth groups, friendship networks, settlements, communities, any social grouping in which norms and values shape their members lives and which their members can decide to change these norms and practices.

In this understanding, couple-based programming forms a pivotal part of a woman's reading, especially in deeply gendered societies. Strategies include: the counselling, testing and mutual disclosure of couples as distinct from individuals; the care and treatment of couples; working with couples on HIV protection; disclosure of a child's HIV status to both parents; the involvement of both parents in the prevention of parent-to-child transmission; support groups for discordant couples, and other examples. Where only one person in a couple is involved in a programme, outcomes are often harmful: spouses are not informed of positive test results, women are forced to hand over or secretly share HIV treatment drugs, mothers of HIV-positive children are beaten, blamed and repudiated. Working with couples enables gendered power to be harnessed and used protectively.

Reading generalised epidemics as a woman brings to the fore the social norms and values and cultural practices that shape and determine an individual's behaviour and what happens to them. These traditions, rituals and practices are expressions of the will of the people; they arise from within and are constantly challenged, re-interpreted, amended and changed. Interactive and facilitative methodologies, such as Community Conversations in PNG and elsewhere, assist communities to reflect on, discuss and make decisions about how they wish their communities to function, what they want for their people, how they as a community can survive the HIV epidemic, can build the social capital of a community and create protection for its members (Reid 2010b). Where communities reflect on and address practices of rape, of intoxication, of domestic violence, of rumours, finger pointing and blaming, etc., individuals who want to live differently and protect themselves from HIV infection are much more able to do so. Where communities decide to challenge and resist abuses of power, harmful cultural practices are re-written, customs which lead to marginalisation and exclusion are opposed, dignity, self-esteem and safety become possible. Where social capital is strong, disputes are more likely to be settled, children to be cared for, people to work together for their common good.

# DEVELOPING WOMEN'S READINGS

There are many other insights that women can bring to generalised HIV epidemics. Because sexual difference creates different, perhaps irreducible, points of view, it is important that women's voices be heard and their insights considered. Reflective and relational readings are a way of understanding and describing generalised epidemics from different perspectives, ones that capture the realities and the variety of women's lives and experiences. For women, HIV sexual transmission occurs in spaces they occupy with their male sexual partners. These are spaces of constructed femininity and masculinity, of biology and physiology, of emotions, spaces

where power and gendered practices shape the interactions. They are socially constructed spaces. Similarly, HIV care and concern, and HIV-related vengeance and violence occur in these spaces, spaces that women share with men, their children, and other women.

Reading generalised epidemics as a woman is to seek for ways to work within these spaces so that women's lives and the lives of those that are important to them are transformed and protected. Because of the relationship between the situation of subjects and the knowledge produced, women's readings can give rise to different policies and programmes, and new and more complex strategies. Some of these have been discussed in the paper. Those discussed are only some of the programmatic insights that can arise with readings made by women. There are other perspectives, other readings, for there are many women, just as there are many men, in these spaces. For women to survive the epidemics, their readings must be spoken out loud, be listened to and taken into account. In this way we may be better able to respond.

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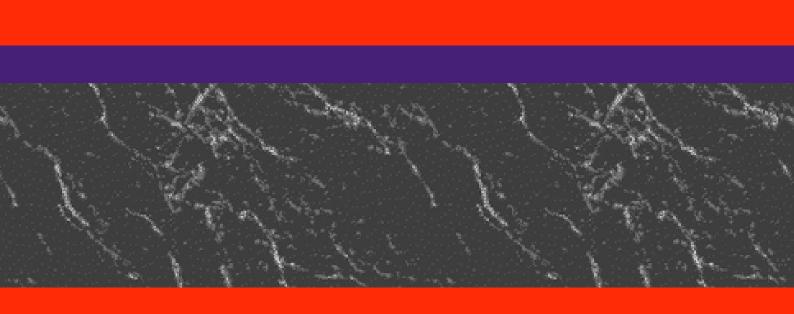
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ISSN: 1328-7854



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