

## **27. Seeking to optimise care for HIV positive women and extending the gendered rights' discourse —conceptualising the dilemmas, with illustrations from fieldwork in rural South Africa<sup>1</sup>**

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### **Introduction**

It seems important in an encounter of this kind, where we have the rare opportunity as social scientists to take stock, not simply to report in a seamless fashion on recent work, as is customary in medically dominated conferences, but, instead, to emphasise the very different discursive frameworks and intellectual agendas that we as social scientists bring to the field of STDs and HIV/AIDS (Schoepf 1991) —and in which our potential contribution has been marginalised (Seidel 1994); and, against this backdrop, to identify and articulate certain dilemmas which hitherto have remained largely unreflected, partially silenced, or remained semi-digested experiences.

The competing discourses and their various effects have been discussed in more detail elsewhere (Seidel and Vidal 1997; Seidel 1993a, b; 1996c). The dilemmas are theoretical, discursive, political, methodological and ethical. These are not only abstract intellectual concerns: they have material and practical implications (Seidel and Vidal 1997); and impact on women in particular ways.

Many interventions and policy decisions have not been well informed. In the place of 'quick, ugly fixes' (Obbo 1994), what is needed is a reflection on the origin and status of what passes for knowledge, and on our 'ways of knowing' (Schrijvers 1992), and an analysis of the social relations of power, to include gender relations. Much of the emphasis of health promotion has been on the 'health consumer' as an individual. This neo-liberal discourse is deeply problematic in that it ignores the crucial importance of social actors and new social forces in bringing about change (Escobar 1992). It also ignores the different experiences of women and men, and hence of the historical and social construction of gender.

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This introduction seeks to provide a critical framework through which the research questions and ethical concerns underlying this South African-based work and dilemmas that arise from the possible applications of findings from a pilot study on confidentiality, care and gender (Seidel and Ntuli 1996; Seidel 1996a; Seidel 1996b) may be more clearly conceptualised and addressed.

**The centrality of rights' discourse  
— but what happened to care for women?**

It had been argued, notably by Mann, that an emphasis on *rights* offers an extremely powerful analysis of societal dimensions of vulnerability to HIV and a guide to action (Mann 1996); and one which could put some people at odds with government and other sources of power, including health bureaucracies. This is now a more widely shared view, and one that highlights the importance of NGOs and advocacy groups, including women's rights groups, in the building of civil society, and as agents of social change.

Prior to the AIDS epidemic, progressive health professionals in Southern Africa emphasised the essential political link between human and democratic rights and the physical and mental health of entire populations. These are crucial insights for us all, North and South.

Another important link, in terms of ethics and rights, is that between prevention and care. This was emphasised by TASO, Uganda, the first indigenous AIDS Support Organisation in Africa, as early as 1987 in lobbying the first Director of the AIDS Control Programme. Their voice was not heeded at that point because it was a minority voice. It had been decided by the North to prioritise prevention, and condom use, with no linkage to care provision, or in-depth research. The ethical link between prevention and care has been stressed more recently by clinicians and NGOs (de Cock *et al.* 1993). The non-prioritisation of care, and of research (Huber 1993) into the social contexts of transmission is extraordinary and disturbing.

The single emphasis on prevention may be interpreted as an effect of the North-South divide, that is, the distinction between resource-rich and resource-poor countries in which this resource gap and counselling women about condom use were seen as largely non-problematic (Worth 1989; Bledsoe 1990). It also served to obfuscate *the gender of care*, in part through the convenient inflation of a 'culturalist' myth about the endless capacities of the African extended family and their 'coping mechanisms', with little gender specificity or gender equity concerns; and, lastly, it also ignored the clinical manifestations of AIDS in women (Berer and Ray 1993; Denenberg 1990). These skewed perceptions and silencing constitute an ethical and conceptual scandal.

Epidemiological discourse has had other effects. In choosing to focus, as a first step, on a category of working women — 'prostitutes', a Eurocentric and moralistic category (Pheterson 1990), as 'high risk groups' — and on pregnant women as sentinel groups, among the first

to be tested, a simplistic dichotomy has been set up between 'good' (married) and 'bad' (more independent) women, which has ignored women's real situations and needs (Hamblin and Reid 1995; Hadden *et al.* 1995). Through this discourse and its effects, women are being positioned as 'vectors', or as potential educators and carers for men and children, and of the community. This may be seen as an extension of their 'natural' role as mothers, part of 'naturalist ideology' (Guillaumin 1978). While motherhood is an important relationship, and, in most of sub-Saharan Africa, and especially among grassroots populations, it conveys important status (Preston-Whyte 1993), this construction is reductionist in that ignores women as social and political beings outside and irrespective of their biological function (that is, it ignores *social gender* as opposed to *biological gender*) (Mathieu 1985; 1991). The title of an important article that sets out to redefine the needs of women and sets out to undermine this discourse is entitled: '*Neither madonnas or whores*' (Carovano 1991).

What these epidemiological interventions also mean is that there is no specific care provision for women who are the most affected by the epidemic (Berer and Ray 1993; Seidel 1993b); and that in a heterosexist ideology, women are being further instrumentalised into providing unpaid care for men and children, and entire 'communities', irrespective of their own health and serostatus.

It is these fundamental divergences between medical and social sciences cultures and agendas, and the sidelining of *gender and development discourse* (Kabeer 1994) that account not only for very different conceptualisations of risk but also for very different research designs, ethical practices, and modes of evaluation.

### **The politicisation of medical culture in South Africa**

In South Africa, a country in transition, the strength of AIDS activism is that it has been able to draw on and extend the official rights' culture. Liberal notions of human rights are being extended to include gender rights (Peters and Wolpe 1995; Mabandla 1995), and different sexualities, fracturing the limited liberal and enlightenment discourse (Capitan 1988; 1993). At the same time, there is an ethical concern that women alone should not be the prime 'targets' for IEC, as this would seem to justify their blaming for HIV spread (Strebel 1993; 1995). Other South African work has given particular emphasis to gender-based violence (Armstrong 1994) and the particular socio-economic conditions, especially of STD spread, in which homelessness (Evian 1995) —not a membership of an epidemiologically defined 'risk group'— constitutes an important 'risk environment' (Zwi and Cabral 1991). This constitutes a break with epidemiological discourse on AIDS.

With differing emphases, the official rights' culture and rights' discourse has stimulated a broader conceptualisation of risk, particularly in the townships. This understanding of the multi-level factors has extended to include a widespread concern with male

violence, and with women and child abuse. This could not be conceptualised within the medico-moral discourse. Advocacy groups have sprung up in many communities, linked to existing NGOs and women's groups, including in Kwazulu-Natal. The ubiquity of rights discourse, at least in the cities and townships —but not extending to rural areas— means that these abuses are not conceptualised exclusively within conventional structural terms of poverty and deprivation and joblessness, although this legacy will continue to resonate in every area of activity. Although these discourses derive from different productions of knowledge, what they have in common is a concern with power and its multiple sites, including gender relations, gender construction, and the political interests of gender (Jones and Jonasdottir 1988). A problem with conventional medical culture is that gender is not an analytical category.

It is this same focus on gender, within a broader rights' framework, to encompass women's rights, and involving special interest groups, that has helped to put sexuality, sexual health and gender-sensitive HIV intervention programmes on the agenda (AHRTAG 1994; Gordon 1995; Heise and Elias 1995).

Our main argument here is that the accessibility and legitimacy of rights' discourses, and the foregrounding of the gender in development paradigm, provide insights into and help to conceptualise vulnerabilities to STDs and HIV (Seidel and Vidal 1997). These discourses, together with more adequate conceptualisations of the many sites of power, assisted by social and political theory revisited by those who have been marginalised by them, help to illuminate the processes of stigmatisation and marginalisation. It is not only women's symptoms that have been ignored but women's specific needs for information, care and support.

### **Public health discourse as a false universal: conceptualising the pilot project concerned with gender and prioritising care for rural women**

This pilot project in rural Kwazulu-Natal was conceived in early 1994, during a workshop in which a formative evaluation of a home-care programme was presented and discussed (Soldan *et al.* 1994). This programme was a first for South Africa, inspired by exchanges with Chikinkata, in rural Zambia; and located in a very under-resourced region that encompasses remote homesteads and difficult, mountainous terrain.

The principal recommendation of the evaluation, received as pragmatic and common sense and non-problematic, was that in pre- and post-test counselling sessions, patients should be encouraged to name a care-giver. There were persuasive public health reasons for this decision: it would facilitate the work of nurses who were not able to educate the 'family' because of medical confidentiality.

But what of the gender dimension? Public health discourse is not gender-specific: it fails to differentiate between men and women who

are HIV symptomatic, or who have AIDS. But in practice, the apparently gender-neutral proposal to name a 'care-giver' and 'educating the family' both mask the political realities of caring, and differential access to material and symbolic goods, including decision-making. It also failed to take into account the largely informal data, some of which was available at the same meeting from testimonies of women with AIDS, and from elsewhere (Temmerman *et al.* 1995), that some women who share their experiences are rejected and beaten, and made homeless (Seidel and Vidal 1997). In other words, this principal recommendation framed within public health discourse was problematic in that it took the man as the norm. It completely passed over women's experience.

A more detailed investigation was important; and this is the genesis of this pilot research undertaken in 1995. Although rural women have been explicitly prioritised for STD and HIV interventions in the South African Reconstruction and Development Programme (1994), very little work has been carried out concerned with and in cooperation with people with HIV/AIDS in rural contexts, in South Africa or elsewhere (Preston-Whyte 1995). This lack of data invites a series of reflections.

The main research questions that exercised us were these:

1. What are the discourses that construct gender, and their effects, in relation to care in our fieldwork area?
2. Through what agencies, in what conditions, and in what time-scale can more gender-sensitive agendas be introduced, questioning the dominant social construction of gender and gender ideologies, and thereby accessing or extending rights' discourse and knowledge in a participatory fashion, with the awareness that vertical programmes do not work?

### **The pilot project: narratives and the choice of gendered parameters**

The policy-related project in KwaZulu-Natal was formulated as a pilot study of confidentiality, gender and care, working in a deeply rural area, in Hlabisa, in a region whose economy is shaped by labour migration. Findings have been briefly reported in correspondence to the *Lancet* (Seidel and Ntuli 1996; Seidel and Coleman 1998).

The objective was to elicit gendered experiences of disclosure from a sample of women and men, diagnosed as HIV+, after receiving pre- and post-test counselling. There is a policy operating in Hlabisa to assist towards disclosure (Seidel 1996d) —and of receiving and, no less importantly, of expectations of care, since many were still well.

This kind of information is emphatically not available from questionnaires or KAP type surveys favoured by the WHO. But it is not only a question of methods, but of conceptualisation and different productions of knowledge. Access to respondents was negotiated through nurse-counsellors in order to respect confidentiality. The local peer support group also facilitated access and acted as initial hosts. To elicit this highly sensitive information, and to be able to

discuss it with interviewees to seek further information in a form of dialogue, to which we hope to return, an innovatory methodology was designed (and pre-tested elsewhere in the region), influenced by dynamic storytelling work in South Africa (Watson 1994; Seidel 1994), using two mini-narratives, or 'vignettes', *Joseph and Thandi's story*, and *Zanile's story* respectively. After the telling of each story, questions were constructed around gendered parameters. We were specifically concerned with gendered attitudes to care (for example: in Joseph and Thandi's story, who would care for the wife in the village? for the girl child? boy child? And the reasons for naming/not naming a particular person as carer).

Discussion of the key answers, which involved explanations, not merely yes/no or closed responses, called for a reflection around the gender of care and of care-related decisions (e.g., Who decides if there is enough money to travel to the hospital?). Responses involved reactions, repercussions, explanations (often justifications), with the first set of narratives relating to a semi-fictitious but realistic situation —the category of 'faction'. Questions were also attached specifically to TB, STDs and HIV and in whom the main 'factional' character in each of the two narratives, respectively a man and a pregnant woman, would be likely to confide about their TB, STDs and HIV, and why.

Then, in a second order narrative, the interviewee was invited to respond to the same basic questions around disclosure and care not in respect of Zanile's or Joseph's or Thandi's likely decisions, options and priorities, but in terms of their own experience. In the second order narrative, they would reply in the first person, describe the reactions, care or rejection experiences and by what sex, in the present, recent past, and projected future. Finally, we set out to elicit some initial idea of their hopes and precise needs, including but not only narrowly 'informational' as in a predominantly medicalised view, in a 'rewriting'/'retelling' by them, of the 'best' scenario for their situation. The stories were told in accessible Zulu and the questions translated and put by Neli Ntuli, research worker and nurse-counsellor based at Hlabisa Hospital, in joint interviews.

## Findings

What emerged quite strongly from this albeit small purposive sample of eight women and seven men —the exemplary study of male sexualities in the mines (Moodie 1990), and a sensitive study of sexworkers in KwaZulu-Natal (Abdool-Karim *et al.* 1995), were also based on small numbers— and of particular interest to us here were three findings.

**First, the isolation of women**, who, if married, are far removed from their own biological families in a patrilocal arrangement; and the isolation of unmarried women who expected little support, other than for tuberculosis, even from their own mothers, pointing to a lack of solidarity between female generations.

The married woman in the narrative would be blamed for passing on HIV to her largely absent husband, a migrant worker, despite the number of his own sexual encounters in the town, certainly by her mother-in-law, who would be in control of the home, of household decisions and expenditures, the husband's absence, and that *'she would probably hate her'*.

Yet it was supposed that the same mother-in-law would be the carer for the despised daughter. It was difficult to draw out the implications as to the likely quality of care. Perhaps this was obvious. And some men respondents showed marked impatience when we sought to engage further discussion on gendered issues.

***Secondly, the genderisation of care was expressed in fundamentally biological terms: a woman was seen as the 'natural' carer —by both women and men:***

*'Because she has suffered: she has known pain through childbirth. She knows what suffering is'*

It follows that all men, married or single, can anticipate receiving care from a mother, girlfriend, or wife.

Only one respondent, a young, formally uneducated man, who had lived in a large township, suggested that a care-giver for a man or a woman could be a friend, and of either sex, but would be more likely to be a woman, indicating at least the potential acceptability from his broader perspective of a man as a carer.

***Thirdly, the lack of reference to 'community'***, a ubiquitous reference in the townships where it is a vibrant source of shared experience and shared political activism (although open to manipulation by various interests, including by NGOs and researchers). While some insisted *'the government should help us'* in terms of free medicine and treatment (which goes against the 'fee for service' philosophy now common to neo-liberal health reforms (Walt 1995) in both the South and the North), one man, who was already very sick with pulmonary tuberculosis had internalised existing economic structures and spatial arrangements of hierarchy and exclusion. His 'ideal' scenario was one in which special huts, or small villages, would be built for people with AIDS, like the huts built by white farmers for their labourers (where conditions are among the worst in the country). Here they could share basic facilities and live among themselves, women would care for their families, and people there would not have to worry about hostility from outside. This is a poignant illustration of how care ideologies are embedded in existing social relations and social structures, in this case both racist (apartheid labour policies and arrangements with exploited black labour on white farms) and heterosexist (the unproblematic assumption that it is women's function to care for men). It was an arresting illustration of the seeming 'naturalnesses' of such discourses and arrangements.

We included a question about the usefulness or otherwise of an organised support group, which took a long and participative

paraphrase to explain in Zulu. Most thought that a group of people like them, an ASO, could help, but transport and money for transport was a major problem, and many lived in very remote homesteads, at some distance from a road. Others, particularly women, commented that it would be depressing as they would talk all the time about illness. But they thought it could be good for them if they could do other things and have some source of amusement. For most, electrification would be a great advantage.

**The urban and rural divide and the dilemma of gender advocacy: transgressing boundaries**

The findings clearly suggest that women need specific support and care provision. How can these pilot findings be used to inform AIDS work and gender advocacy in the region in which rights' activism in the towns has no equivalent in rural areas, and where very different discourses are in circulation.

Networking is crucial; and this may lead to different productions of sense, through working dialectically and 'sideways' (Schrijvers 1992). The findings have been welcomed by the institutional hosts, by the rurality-based regional co-chair of NACOSA (National AIDS Convention of South Africa), who liaises closely with the regional PWA group, and has been a key player in AIDS health promotion in the region; and by a woman doctor at Hlabisa who has played a crucial role in encouraging peer support groups and community education (McCoy and Coleman 1995; Seidel 1996b; Seidel and Coleman 1998). Coleman's work has included taking the initiative and much of the organisation around the production of an important Hlabisa video made with people with HIV/AIDS who speak directly to camera.

Our shared concern is with the interpretation and possible application of these findings in such a way as to make existing programmes more gender-sensitive, as a development of the existing peer education and peer support schemes in the region.

But what of regional rural discourses on gender relations? Although discussions on the high cost of *lobola* (bride-price to be paid by the groom) are commonplace throughout KwaZulu-Natal, including on Radio Zulu, questions of gender ideologies, of gender construction, of the gender of care, and gender rights are not. Most discussions come down to a defence, albeit in some cases a resigned defence of 'traditional' warrior culture, where warriors in the service of famous kings defended the 'Zulu nation', against the British invaders, are still celebrated, but now manipulated by and a hostage to divided IFP (Inkhata Freedom Party) ambitions in the region.

'You need to know our Zulu men and to understand our culture. Our men are hard. They are like that. You know about our warrior tradition? How can we change our culture?'

Some of us want to change lobola - it costs too much. People are greedy. But other say we should keep it — as our culture is all we have left. We have lost everything else’.

This is a summary of the somewhat ambivalent response when the researcher attempted to raise these issues informally with Zulu-speaking women in Hlabisa and the environs, irrespective of their educational background. However, more critical responses are provided from a small number of women discussants, community and health workers from the region, who identify as Zulus and as South Africans, and who have been more exposed to rights’ culture, including gendered rights. Their informal comments provide a gloss:

‘Yes, that is the culture here, that is true. People value their culture very highly. We are proud of it. But that is not the only influence’.

There is a dynamic sense here that the gender problems are both more universalistic and more particularistic. Mobilising this more dynamic discourse on gender, culture and identity, that is also produced and circulated within the region, through drama of the kind inspired by Boal’s *Theatre of the Oppressed* (Boal 1995) may be the most appropriate way forward in this context to develop this critical process. Academic or ‘outsider’ knowledge, both negatively connoted, is more likely to be viewed with suspicion in a setting where distrust of ‘outsiders’ of any origin was fostered by apartheid’s enforced separations, including ethnic divisions among black South Africans, and by other processes (Mare 1993); and suspicion of ‘outsiders’ remains very vigorous at all levels of society.

A comparable ambivalence in the construction of gender and regional identity, where this region, the stronghold of the ultra-nationalist and ‘traditionalist’ IFP, denotes ‘Zulu-ness’, has been acted out in AIDS education through school performances. Dramaide, hitherto a regional-based AIDS-related drama initiative in KwaZulu schools, seeks to encourage AIDS education through performance, and largely through dance. Some codes appear to be undermined, where schoolgirls perform dances conventionally performed by men. This may set the scene for a fracturing of dominant gender ideologies. Schoolgirl participants clearly enjoy this experience of greater freedom of movement, body displays (deemed appropriate for single but not for married women) and access to particular symbolic forms normally denied to them. However, without more sustained discussion and challenges, such performances may remain ‘rituals of rebellion’; and harnessed to political ends by the still dominant traditionalist culture (Dalrymple and Preston-Whyte 1996). The dilemma is that much of the dominant symbolism and references to ‘nationhood’ (and songs about saving the ‘nation’ from AIDS) inevitably may be interpreted as referring to and as grounded in the ‘Zulu nation’. This is a region with a clear IFP presence in the rural areas, mainly tribal trust land, where ‘traditional’ values remain very strong, and where any form of minority culture or challenge is profoundly silenced.

### **Possibilities of extending the research partnership**

It has been suggested that a new kind of partnership bringing together researchers, community activists and special interest groups may be in a better position to undertake research on gender violence (Heise *et al.* 1994) and, by implication, gender relations in various forms. This community-based insight has further implications for work on gender construction and for the extension of gender rights.

Another key development within the region, and exemplary in many ways in terms of non-vertical community education, has been that of Positive Speakers involved in talks and 'telling their stories' in community venues. This initiative, influenced by the Phillys Lutaaya project in Uganda (Amooti 1996), and a similar project in New York, has been given an impetus by work in and around Hlabisa, and the Hlabisa-made video referred to above. There is also an indication of proposed future networking with a group for rape survivors and battered women, but the origin of this proposal is not clear.

How can this process and important networking —probably the best source of support for women where limited family support is available— be assisted and sustained? And through what agencies? And in what time-frames?

The one and only 'traditionally' married woman interviewed in our very small sample who did admit that her husband was beating her (and this behaviour apparently pre-dated confirmation of their common HIV positive status) 'justified' his abuse in terms of unemployment and frustration, which has led to drinking bouts. The absence of a gender explanation is problematic in a broader and feminist perspective of rights which is present in South African urban contexts, and very strong among ANC (African National Congress) women activists.

It seems that there may be a difficult choice between a slow road —that involves in listening to women, and in this way showing that they are respected, and a faster, activist lane which stresses connecting with other NGOs and ASOs. In fact, there is already a kind of dual lane in terms of links with the national and regional PWA (People living with AIDS) associations; and where more frequent contact with PWA associations from the rest of the region, and beyond, is a great moral booster and opens up new perspectives of all kinds.

Apart from problems of unrest in the region however, the faster lane raises some ethical as well as organisational and financial problems. It could involve detaching the same small group of people away from the tiny but clearly expanding peer support group (PC Jaffe June 1996). And would most women have the same mobility as men? It is also a question of ownership of the process and sustainability —where 'outsiders' are frequently analogised as cancer and AIDS. If this initiative is not coming from a member of the existing ASO, will it be considered acceptable and legitimate, and will it work? A lot may depend on the delicate balance between 'community' input and the

involvement and the perception of 'outsiders' that would lead to a 'balanced community development' (Schaffer 1995).

Another related ethical and political dilemma concerns the ways used to silence gender questions and which also hold back the conceptualisation of male violence, including rape (Armstrong 1994), preventing it from becoming an advocacy issue locally. Family members try to 'hush' it up and not take it further (PC social worker, Hlabisa Court, September 1995; PC Z. Nxumalo 1996). Women in such situations have recourse to a series of survival mechanisms that are interiorised. Is there not an ethical issue involved in seeking to suddenly problematise this violence in deeply rural settings where no advocacy groups exist? The concern is that this could mean removing or undermining these survival strategies while there may be nothing tangible to be put in their place. (Is this not in a sense what happened to forms of knowledge when missionaries banned puberty rites in the 1930s?) Such a move could increase women's vulnerability; and it is this dilemma that would caution in favour of any fast, overtaking lane approach to this ideological and political work in this profoundly rural area.

At the same time, when women advance not specifically gendered explanations for male violence, or see it as unavoidable, it is not necessarily a form of 'false consciousness' in a marxist sense: women may be aware of the very circumscribed and subordinate nature of their lives, but are unaware of what to do about it, or have few options. Metaphors women use about themselves and which can be elicited can be very revealing in this respect. However, the 'power' that entails the experiential recognition of these meanings cannot be given from above: it has to be self-generated in political work with others. Some participatory learning techniques share these perspectives (Koning and Martin 1996; Pretty *et al.* 1995) in a national context in which community participation is valued (Shisana and Versfeld 1993). Different country examples and from different continents, including from South Asia and Latin America, suggest that such process can be assisted by issues by grass-root NGOs promoting innovative and participatory strategies (Kabeer 1994) —and more obviously by the creation of job opportunities where women have a greater measure of economic independence.

A particular example of community activism, one predicated on rights, is available from Clermont, a largely ANC township, near Durban. Women's organisations are particularly vocal and active in the township. Rooms have been converted adjacent to a church to serve as an informal drop-in centre where a range of information is available, on HIV, and which, at the same time, is also a centre for rights' education conducted by community activists. Encounters and exchanges of this kind could provide a political and heuristic space, disrupting boundaries. However, in much of KwaZulu-Natal at this political juncture, even to consider such exchanges, and their practical feasibility, the history of the political struggles between the ANC and the IFP (Inkatha Freedom Party) and the politicisation of spatial relations must remain part of the equation.

## Conclusion

To provide specific care and support for women, rather than women being instrumentalised to care for men, and positioned by 'naturalist ideology', calls for a profound change in political culture. Gender-sensitive programmes demand that an unequivocal gender lens applied to all facets of women's lives and decisions which affect them (Cancian 1992; Heise and Elias 1995). Such programmes also call for the scrutiny of such apparently sex-neutral concepts and phrases as 'community care', including their modes of costing and evaluation, where these are almost invariably gendered and involve gender interests. Public health discourse because of its assumed and false universality cannot take account of gender relations, and hence is profoundly flawed. While a gender and development discourse is present in urban South Africa (Preston-Whyte 1995), this cannot be assumed to be the case in rural areas, where there is limited HIV related research on women's support networks and care for women. Sociological research on sexual networking as carried out elsewhere in Africa does not in itself assist women.

Public health and medical discourse may also have affinities with naturalist ideology and hence seek to perpetuate 'traditional' gender roles. An informal evaluation has been offered by a highly placed health professional in the region of 'positive living' of an HIV positive woman who, after receiving support and counselling, is now prepared to care for her husband. This is very double-edged. It carries with it the idea of potential psychiatrisation of women who do not conform. And, in general, it is also an indication and warning of how the political agenda of sexual and reproductive rights, in many contexts moved more to the centre by the epidemic and by AIDS activism, may be being subverted, and re-conceptualised within older medico-moral and 'traditional' discourses, constituting an overlapping of meanings (or vertical 'inter-textuality') (Fairclough 1992).

In evaluation for 'empowerment' (Baylies and Bujra 1995; Plaat 1995; KIT and WHO 1995), and in all work concerned with women's subordination and its effects (Elson 1991), this conceptualisation and scrutiny are usefully informed and assisted by critical social theory, by post-structural analysis influenced by post-colonial polyvocality and discursive theory; and by the kind of feminist epistemology and practice that addresses both gender and racist issues, and which seeks to analyse gender not as 'essentialism', not as a biological given —but as power relations between the sexes.

For this work to be effective, it also calls for advocacy work and activism, since a government or state cannot act as a social agency. And find ways of challenging masculinist representations that assume 'traditional', univocal forms, 'common sense' and 'naturalist' ideology —and which may be used to mask and to naturalise both gender and racist oppression.

It has been demonstrated throughout the world that sustained behaviour change is dependent on peer and community support. In much of South Africa the perception of the individual rights and

especially of gendered rights still remains weak in rural regions. It is men's, not women's experience that is not taken as the basis for theorising and enforcement (Binion 1995). Some townships women's organisations, like Clermont, have remained strong, and they contribute to and at times challenge different representations of gender within the immediate community. Together with some ASOs, and assisted by a core of progressive professionals, black and white, they constitute the new social actors. The possible 're-connections' and political opportunities are there. But it takes full-time participation, trust, and anthropological, not managerial or medical time-frames, and a shared language medium —and, no less importantly, an extended 'dialogic space' (Schrijvers 1992; 1993), in which the researcher does not disappear, in order to elicit these challenges, and to 'hear' them.

In the context of post-apartheid South Africa in which community-builders are celebrated and honoured, women are being called upon and mobilised as a rich potential resource for reconstructing violence-torn communities enabled by rights' discourses. Some of the dilemmas for women in caring roles, and the possibilities for total burn-out and unacknowledged workloads are contained in an unsolicited comment from a Zulu-speaking member not from KwaZulu-Natal, but from a Soweto-based ASO. It followed on a threatened attack on herself and her home, but which only served to strengthen her resolve:

'I thought I belonged to my husband. Then when I began this work I understood that I belong to the whole community' (PC, Community ASO activist, Society for AIDS Families and Orphans, Soweto, May 1994).

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Gill SEIDEL, *Seeking to optimise care for HIV positive women and extending the gendered rights' discourse – conceptualising the dilemmas, with illustrations from fieldwork in rural South Africa*

*Summary* — Since the start of the epidemic, African women have been positioned by governments, non-government and community-based organisations and mobilised to provide care for their families and 'communities'. Meanwhile, women's needs, particularly those in rural areas, their access to resources of all kinds, and the support networks available to women, have not been prioritised. This pilot study based in rural KwaZulu-Natal, South Africa, seeks to analyse the support networks available to HIV+ women within a gender-sensitive framework.

*Keywords:* HIV/AIDS • South Africa • women • gender • care • rights • discourse.

Gill SEIDEL, *Chercher à optimiser la prise en charge des femmes séropositives et étendre le discours de genre sur les droits - conceptualiser les dilemmes, avec des illustrations tirées d'une étude en milieu rural, en Afrique du Sud.*

*Résumé* — Depuis le début de l'épidémie, des positions spécifiques ont été assignées aux femmes africaines par les gouvernements, les organisations non gouvernementales et les organisations communautaires de base qui les ont mobilisées pour la prise en charge de leurs familles et de leurs communautés. Cependant, aucune priorité n'a été accordée aux besoins des femmes, particulièrement de celles vivant en zones rurales, à leur accès aux ressources et à la mise en place de toute forme de réseau d'appui disponible pour elles. Cette étude pilote, menée en milieu rural au KwaZulu-Natal (Afrique du Sud), essaie d'analyser les réseaux d'appui disponibles pour les femmes VIH+ dans une perspective sensible aux questions de genre.

*Mots-clés :* VIH/sida • Afrique du Sud • femmes • genre • prise en charge • droits • discours.