Confidentiality and HIV status in Kwazulu-Natal, 
South Africa: implications, resistances and challenges

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This article provides a contextualized comparison and analysis of the former Kwazulu and the new Kwazulu-Natal policy documents on HIV confidentiality, the differing practices within the region, and their implications for support and gender. It is based on interviews with key players in the regional NACOSA (National AIDS Convention of South Africa), and participation in meetings between August and November 1995. The main division is between those influenced by other rural African models, especially the Zambian concept of 'shared confidentiality' as a way of ensuring support, and who have gone on to develop more community-based practices to destigmatize the disease, in contrast with the stronger emphasis in the new document on individual rights, assuming a more urban constituency, and where 'shared confidentiality' is much more circumscribed. One of the difficulties of the new policy in which 'confidentiality' is interpreted as 'secrecy', is that it would seem to foreclose and neutralize lay and community support, as distinct from the earlier and unacknowledged policy of former Kwazulu. It also seeks to provide an enhanced role for professional counsellors. This psychologizing of the infection and the distancing from 'community', and from women's groups, is surprising in a country in whose townships 'community' remains a powerful motivating symbol, and where NGOs and peer groups have been identified everywhere as central to effective HIV/AIDS related prevention, care and support for behaviour change.

Different policies and practices operate around confidentiality and HIV status, and these have material effects on support. While different African national policies and, in particular, varying hospital-based practices around confidentiality and their constraints have been the subject of insightful studies, regional policy controversies in developing countries have received little attention; especially what these mean in terms of care, support, gender and advocacy, and how such links may be conceptualized. The new policy on confidentiality for Kwazulu-Natal, the region at the epicentre of the ascendent HIV epidemic in South Africa, is a case in point, with the varying practices, justifications and frameworks.

This article is based on interviews with key players, documentation and observation carried out between August and November 1995. It examines the former Kwazulu policy, the differing emphasis in its successor for the new region, their respective influences and constraints, the underlying social constructs, and the divergences in practice. It goes on to analyze the concerns, and resistances to the new policy; and, in the conclusion, explores possible links between forms of peer group activism and research.

The Kwazulu policy

After the official ending of apartheid and the first non-racial elections in April 1994, former Kwazulu was joined with Natal, predominantly urban and resourced, to form the new hyphenated region of Kwazulu-Natal. Kwazulu had drawn up a policy on HIV and confidentiality shortly before the election. The small group of health professionals concerned liaised with legitimate pressure groups and AIDS organizations with specific rights' concerns in the emergent new South Africa, most importantly with NACOSA (the National AIDS Convention of South Africa), an umbrella body.*

Kwazulu health professionals were influenced in particular by a rural African model of AIDS home care, that of Chikinkata, Zambia.² It was in Chikinkata that the notion of 'shared confidentiality' (the sharing of sensitive information within a given
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The KwaZulu operational policy document, approved in March 1994, was drawn up over a period of some 12 months by a small working group (PC, J. Stuart 1996). The document gave a definition of medical confidentiality as a form of professional secrecy (not standard terminology), but one, nevertheless, which permits an opening towards limited disclosure under certain conditions (easing the destigmatizing of the disease) and where such moves are prescribed as counsellor-assisted but patient-led:

‘Confidentiality in this context means confining the knowledge of a patient’s HIV/AIDS status to as small a number as possible of specified people. It is a professional secrecy with a focus on HIV/AIDS. It does not imply that patients should keep their status secret. Through counselling they should be encouraged to share knowledge of their HIV status with others when ready to do so in order to obtain support. This will help to reduce isolation, rejection and stigma.’

The new policy

The creation of a new region called for a new policy. What is interesting is that this was done with no reference whatsoever to any earlier policy document, despite the fact that members of the new working group were familiar with and had commented on the KwaZulu document circulated to them. It was as if the document did not exist, or had never existed.

A number of explanations are possible for this ‘silence’. These include a bracketing of recent history, a current government-prompted, if controversial, practice. The underlying political idea is to build a new South African rainbow nation (Desmond Tutu’s resonant phrase), and to construct this nation, assisted by this new unifying nationalist discourse, on the basis of forgiving and forgetting the past. This practice is best exemplified in the workings of the first phase of the Truth and Reconciliation Commission. This dissolving of history has been seen as problematic by some eminent South African historians, and is a theme running through current drama and satire.

A second explanation is that a policy emanating from the former KwaZulu, irrespective of merit, was not seen worthy of note because of its bantustan and hence its origin and association, and on account of the urban-rural divide and the corresponding social and professional hierarchies. Thirdly, there are also more banal, general and pragmatic explanations, like pressure on the chairperson to produce a new succinct policy in the name of the new regional NACOSA.

The new policy document was drawn up following a meeting convened by the Head of Counselling from Pietermaritzburg AIDS Training Information and Counselling Centre (ATICC) operating within the broader framework of the KwaZulu-Natal regional NACOSA. The new regional policy of KwaZulu-Natal does not provide a definition of confidentiality, but, instead, sets out the boundaries. The idea of shared confidentiality – if that term is, indeed, appropriate in this new context – is much more circumscribed:

‘All persons have the right to confidentiality surrounding their medical condition. Therefore information surrounding a person’s HIV status may only be revealed to other health care workers with the consent of the patient’.

Sexual partners may be informed under specific conditions, much as in the earlier document, as influenced by STD guidelines, with limited results as elsewhere. More significant is the very succinct paragraph relating to disclosure and support:

3.3.3. Patients should be counselled on the issues surrounding informing family and friends of their HIV status. The decision to inform such persons remains with the patient/client.

In terms of communality and overlap, both documents, for example, refer to the AIDS Charter. This
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is a key reference, politically and symbolically, in respect of rights’ advocacy. The Charter was drawn up in 1992 by the Centre for Applied Legal Studies, University of the Witwatersrand, in Johannesburg, and subsequently adopted by NACOSA and by the new National AIDS Programme. The leading exponent of this Charter and former Convenor of the AIDS Consortium (a Johannesburg-based umbrella for all AIDS NGOs), now a Judge, also was invited to comment upon and helped shape the first Kwazulu document.

If the new regional policy document had been designed for a purely urban constituency, it would have a great deal to recommend it. For its critics, the problem is that it seems to assume an urban constituency, as if by fiat, when viewed from the perspective of a heterogeneous region which also comprises huge areas of tribal trust, as well as heterogeneous townships and informal settlements. And, whereas confidentiality is an important and legitimate concern in both documents, the new one is more explicitly premised on the individual. It is through this urban lens and in line with the AIDS Charter that confidentiality has been uniquely conceptualized and these guidelines set out.

Difficulties here are not seen to arise from any problems in principle with natural rights; and it is important politically to make this clear. The reservations and altogether predictable concern are with the meanings attached to an individual at particular moments in rural societies.

A further complexity relates to interpretations and the now more dominant practices that exclusively seek to professionalize confidentiality within the client-counsellor relationship. In this encounter, the counsellor puts her/himself forward as the sole mentor. However, more pragmatically, it is likely that a client’s overriding concerns following a positive HIV test (as Ugandan and other informal data suggest) are with the uncertain future for themselves and their children, where economic survival and safety are paramount and where technical, disease-related questions and psychological questions are way down the list. Sympathetic and longitudinal research on these priorities involving peer groups as discussants, and with a gender dimension, would be useful.

Discussions to formulate the new policy were informed primarily by urban experience and spurred on by the rapidly expanding counselling services in search of a full professional status and authority, with competing centres keen to establish themselves in the market. This may be a key explanation as to why there has been limited public debate around the appropriateness of this urban model for Kwazulu-Natal.

Although many would argue that standardization in an emergent profession is necessary and inevitable, and especially in view of the importance accorded to pre- and post-test HIV counselling by the WHO and in the national AIDS strategy, in practice this development is likely to mean the exclusion of lay counsellors who may be the only remaining link with community. The main thrust of the critique of the new policy focuses on these shortcomings: possibilities for advocacy and change are conceptualized and argued not in community terms, but exclusively in terms of professions and individuals; and they do so marshalling technical arguments and language, which may be used to mask particular interests and agendas. Such developments are seen by their critics as formalistic, over-technical, and potentially demobilizing, at a time when community-building (with media encouragement and celebration) is a national priority.

For those involved in the new policy, and many associated with NACOSA generally, including those in urban forms of AIDS activism, an important concern shaped by Johannesburg agendas has been with workplace rights and checking abuses of confidentiality by employers and some GPs in private practice; and with pre-employment screening, due to become a restricted practice in 1996.

Despite its important and obviously legitimate concern with the urban workforce, what the new policy lacks, precisely because of its single focus on the individual, is any vision, or even a clear indication of process and social agency, whereby the practice of confidentiality (tantamount to ‘secrecy’) could lead to the building of support for people with HIV/AIDS with community participation, where as many people are without work and where most women are part of the informal sector, have the higher incidence of HIV/AIDS, and, with children, are the most at risk.

In the opinion of a number of health professionals in Kwazulu-Natal, especially those originally involved in providing, organizing and evaluating home-based care in the region, this form of confidentiality leads to social isolation, whether in the town or the country. This in turn leads to a premature ‘social death’:
People always think that someone with HIV in the town has a lot of options and facilities available to them, and those in the townships, or in the country, have less, or none at all. This is probably true. But what I've found is that a person with HIV here in Durban who has no work, and of course more than 50% of people won't have jobs here, will just stay locked in their room and not go out, not even for food. They are frightened to tell anyone about their HIV because of the stigma. And they've been advised never to tell anyone by their counsellors. And that adds to their fear, and they go downhill very rapidly. We see these people every day. They are 'socially dead, prematurely dead.' (Convener of the Care Commission, regional NACOSA, former Manager of Durban ATICC, and Director of AIDS Consultancy and Training, PC, August, Durban 1995)

The question of support and 'community' is raised here, and this has very different dynamics in social and political space. In the townships, it is a highly emotive term and virtually an organizing principle based on a history of political action. In some cases, it may be idealized in NGO rhetoric, and manipulated in various ways by different interest groups, including NGOs themselves, and researchers.

‘Community’ also has gendered representations, but as used in the South African context, as elsewhere, is rarely differentiated in terms of sex. ‘Community care’ and ‘care within the family’ generally mean additional unpaid work for women, irrespective of their own health and HIV serostatus. In terms of support, it is not simply a question of different networks ‘within the community’ available to one sex and not to another, but of which networks are available to which women and which men, and the variables involved. Furthermore these support networks need to be explored in liaison, wherever possible, with existing organizations of people with HIV/AIDS and with NGOs and women’s organizations, which, in urban and peri-urban South Africa, are increasingly mobilized against violence, especially towards children and women.

It is not only attitudes to HIV but also potentialities for support networks for people with HIV/AIDS that are embedded in individuals own histories and experiences – although the stigma around HIV/AIDS, still very strong and not to be underestimated, may suggest different patterns, and naive ‘culturalist’ assumptions about unlimited availability of extended family support (very limited in this region marked by large-scale migration of men and women, malnutrition, and ‘low intensity war’) need to be challenged. Support, and particularly support for women in rural areas who have less access to resources of all kinds, is more likely to come from peers than from family (PC: R. Coleman, November 1995). The considerable distances between homesteads, the limited communication and hilly terrain, and minimal NGO activity, make rural support difficult.

In 1995, the Diakonia (Ecumenical Centre, Durban) counselling scheme was initiated, in which parallel voluntary and overlapping support groups bring together concerned individuals from Clermont and the immediate environs, including from informal settlements, on an eminently social basis, and where individual serostatus is not known or broadcast to others. Those who attend are mainly men, of different sexualities. Such gatherings held in private homes, which may involve some prayers, are assisted by a person with HIV/AIDS from a regional group, hither-to a man, who will tell his ‘story’, followed by a stream of questions and discussion. More voluntary participation is encouraged for these forms of advocacy work.

The basic counselling team (although ‘counselling’ here is not seen only in narrow individualist terms because of their political history) actively involved in Clermont in mobilization and advocacy at this point (January 1996) is drawn from respected community activists, not health workers and began to operate only part-way through 1995. It consisted then of one very committed woman, a founder member of the Union of Domestic Workers. She has very modest funding and no transport. In early 1996, she was joined by a young, male, former volunteer worker.

More typical examples of support networks in South African cities are those set up by and for gay men, more public in Johannesburg, but present also in Durban and Cape Town, although marginalized because of homophobia. These Johannesburg networks, largely white but also including some black activists from TAP (Township AIDS Project), Soweto, offer the warmth and renewed commitment of a gay community response. It is these activists working with progressive health professionals who have set the NGO AIDS agenda and shaped policy.

Initially, the epidemic in South Africa did primarily affect gay men, but it is now clearly a heterosexual
epidemic, or perhaps, two epidemics. In Kwazulu-Natal, those disproportionally affected by the virus are young black women between the ages of 15–19. The majority of these women are living in a very different set of socioeconomic, sociological, political and environmental conditions in Kwazulu-Natal, in risk environments\textsuperscript{12} with high levels of violence in urban, peri-urban and rural areas. They constitute another vulnerable category, with extremely limited support networks, where these exist at all, and with very limited options.

In these circumstances, how appropriate is the single focus on confidentiality and the individual in Kwazulu-Natal? Particularly in the deeply rural areas of the former Kwazulu, and where there is no NGO presence, or NGO culture and where, as a mass of international experience now shows, behavioural change and support for persons with HTV/AIDS and the destigmatization of the disease call for a measure of collective or community action and advocacy involving peers.

**Critical voices and constraints**

The emphasis of the new policy on the individual and on the practice of maintaining confidentiality virtually at all costs (‘Your status is your secret’) are seen as highly problematic by a number of health professionals, mainly from former Kwazulu, with experience of rural areas, and, in other cases, from Natal. The main critical voices are those who have been directly involved with home-based care, most of whom have been trained as nurse counsellors, together with other professionals concerned with health promotion.

Despite the openness of the regional NACOSA, participation in its primarily Durban-based professional meetings rarely includes people from rural areas\textsuperscript{13} or from many grass roots or community organizations, with the important exception of representatives from the Valley Trust, from the Valley of the Thousand Hills, between Durban and Pietermaritzburg. This is because of transport costs, the distances involved, and work overload, as well as poor communications with rural hospitals like Bethesda in Uombo, more than 7 hours by car, where motivated AIDS Action Teams comprised of nurses have been set up but which are isolated and under-resourced.

The distances, costs or workloads involved, the question of language rights, and the striking different interactional norms that may lead to some silencing, are not the only or, indeed, perhaps not the main reasons for the non-public or limited public airing of this policy debate, despite very clear divisions and differing experiences. Because of the former political status of Kwazulu as a type of bantustan, progressive health professionals in the region, black and white, are politically embarrassed to be seen to be speaking up in a very public arena as if in defence of a former Kwazulu policy. They do not want this interpreted as a form of covert political support for the Inkhata Freedom Party (IFP), as explained to me by a prominent but non-directive health worker involved in PHC training and IEC, now playing a leading role in the regional NACOSA. Also, consensus behaviours are favoured and rewarded within this small NGO.

This means that dissatisfaction tends to be expressed privately, or in c\textsuperscript{ô}teries. Yet, as mentioned earlier, and here there is a certain paradox, the Kwazulu policy document was widely discussed with key convenors of the national NACOSA in Johannesburg, where no such embarrassment was present. The physical proximity of Durban (the principal city of Kwazulu-Natal) to the former Kwazulu, but which for many Natal-based professionals is totally unfamiliar and virtually foreign territory, and the continuing tense political situation in the region, may be explanatory factors.

Nurses and nurse-counsellors whose work is primarily hospital-based in towns and cities, few of whom are professionally concerned with support systems or advocacy, are aware of potential law suits for transgression of confidentiality guidelines. For this reason, rather than out of conviction that this is a valid policy, they will now seek to follow them more attentively, although, inevitably, there is still gossip.

Further afield, in rural areas, with inputs from an AIDS service organization (ASO) and activists from Natal, new social actors (or ‘agents of transformation’), assisted by committed but non-directive health professionals, are developing practices which explore ways of building peer support and of destigmatizing the disease.

**Resistances**

Reservations were forcefully expressed at a meeting of the regional NACOSA home-based care commission held at Amatikulu Primary Health Care Training
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Centre, in northern Kwazulu-Natal, in September 1995. All those present, other than the author and a representative from AIDS Consultancy Training, were black nurses, mainly from former Kwazulu.

These were some of the views put forward:

‘This confidentiality thing does not help us. It holds us back. We cannot care for patients’.

‘They taught us this thing when we went for training in counselling. Then we didn’t know any better and we listened to them. Now we know that this secrecy is not good for our patients’.

‘It is Eurocentric – perhaps it is good for white people. But we Africans are different – we care about others, we care about our neighbours. The first thing you do in the morning is to greet your neighbour. It is the first thing you hear in the morning. You spend time with them, and you share your problems with them. This secrecy is killing us. It is not our way. These white doctors have too much power’.

The debate is confounded, as mentioned earlier, by the fact that in translation, the term ‘imfilho’ is used in Zulu for both ‘confidentiality’ and ‘secrecy’. However, this is not the crux of the problem, as a Zulu-speaking counsellor with fluent English explains:

‘Some counsellors tell clients that this is their secret – and they must never tell anyone. This does not help. Confidentiality and secrecy are different things’. (Unpublished interview with Durban ATICC Counsellor following the first Counselling training course in Zulu, 1994).

In general, many largely monolingual English or Afrikaans-speakers may fail to understand the considerable difficulties involved in translation from English of IEC (information, education and communication) materials concerned with STD/HIV/AIDS. Large amounts of funding have been wasted because these have been altogether offensive or incomprehensible. Further problems have arisen because African languages have been skewed by the official Language Boards under apartheid, and there is an absence of specialized glossaries, with just a handful of trained linguists.

Insights into other resistances were also gained at a Workshop on Gender and HIV/AIDS in Durban, hosted by the Centre for Epidemiological Research in South Africa (CERSA) in August 1995. One matron from Edendale Hospital, the sprawling township near Pietermaritzburg, expressed anger that men in her community who knew their HIV status were allegedly infecting a number of women partners as they were not practicing safer sex. As counsellors, they were bound by confidentiality, and could say nothing; they felt angry and helpless.

This was the first public intimation from health professionals in the region that the policy was also problematic not only in terms of psychological isolation, of compromising optimal care by not being able to share information with home-based care-givers, but in terms of its gender implications. In practice it was not ‘even-handed’, because it further compromised women’s health, given the pattern of gender relations and the social construction of gender in the region. This gender concern has been a gap, or silence, in the discourse on confidentiality so far, and may be seen as a dimension of gendered ethics, where, in AIDS work as elsewhere, it is the norm for men’s rights in terms of heterosexism to take precedence over human rights. This constitutes a legitimate ethical concern.

Another site of exchange has been the columns of ‘Positive Outlook’, the journal run by Pietermaritzburg ATICC. Particularly noteworthy are lively exchanges between Greg Woods, Editor and also Head of Counselling, and Rosalind Coleman of Hlabisa Hospital, northern Kwazulu-Natal, an important exponent of ‘shared confidentiality’ but under the control of the patient, in which Woods reproduced and commented on extracts of a letter sent to him by Coleman. The main argument put by Woods is that due to the elite status of nurses in South Africa (unlike Nigeria, Uganda, or the UK, for example), their voices would be dominant in any exchange; and that, in view of this hierarchical relationship, genuinely informed patient consent to disclosure would in most cases be lacking. This is a valid argument with sociological weight. It is true that nurses’ training has been narrowly clinical, and informal data suggests that nurses are often directive and do not share their patients’ more marginalized experience. However, an important omission by Woods was any reference to the inevitable workload carried by nurse-counsellors in hospital and polyclinic clinic settings for whom counselling is an additional burden, often with unacknowledged burn-out.

Aware of some of the difficulties and constraints of nurse-counselling, arguments from present and former Kwazulu health professionals are being
rehearsed in favour of a significant shift in the quality of interaction between health workers and the community. There is a desire to develop a more adequate model of counselling focussing not exclusively on the HIV test but on the broader social context, and, more significantly and coincidentally in line with the Diakonia scheme, on the need to train appropriate and trusted non-health workers as counsellors, and to train more community-based peer educators.\textsuperscript{18,19}

For some time, Hlabisa Hospital in rural Northern Kwazulu, in line with the former Kwazulu document and respectful of patients’ rights, has continued to adopt a counselling strategy ‘that favours the easing of patient disclosure towards support’, and promotes community education as a way of destigmatizing the disease. The team’s approach in Hlabisa, including Coleman’s important contribution to the process and that of Nomsa Wilkinson, responsible for AIDS counselling from the start, has been pragmatic, enabling, and creative.

‘We ask them at pre-test counselling, and say if your test is positive, would you like a home visit; and if they say yes, we write that down. We also explain to them that this is a lot easier if they can tell someone at home if they are positive so that when they get sick this person knows what to do and how to look after them. We also say that if the result is positive, would they like to meet another HIV positive person, and if they would like to act as peer educators, though we can’t promise that they’ll get paid for it.

And when they come back for the result, if it’s positive, we ask them these questions again, and write down their name in the home-based care register and how to find them, as often it’s very difficult, so they get a visit probably about three weeks later. And there’s another entry on the form for those who want to be peer educators. But we’ve had to stop home care visiting now – there’s no vehicle for one thing. And about meeting others, my idea is that we shouldn’t lose time, we shouldn’t lose the momentum. If they do want to meet with another HIV positive person, someone in the peer support group, then we should jump in a car and drive around straight away. But there’s no pressure on patients to agree to meeting others.’

(Interview with R Coleman, September 1995)

As an additional resource, which, it is hoped, will encourage further disclosure to build support in this profoundly rural area, a video was made in 1995 at Hlabisa at Coleman’s initiative. It features women and men diagnosed as HIV-positive (HIV+) speaking directly on camera, using their own words, and in home and local settings. Members of the support group narrate their own stories. These illustrate the benefits of disclosure to a partner or other family member(s), going beyond the Zambian recommendation that was more narrowly concerned with the home-care setting. The video, in Zulu, or with English subtitles, is entitled \textquoteleft Umuntu, Umuntu, Ngabantu\textquoteright (‘A person is a person with the people’). It is currently being evaluated by a researcher in Amatikulu PHC Training Centre for possible use in other parts of the region.

A parallel development to be further promoted region-wide has been that of ‘Positive Speakers’, with HIV+ women and men speaking at community venues. On occasions, and significantly, this practice has further exemplified the blaming of women for the spread of HIV:\textsuperscript{7,20} while men’s stories are listened to with attention, HIV+ women speakers have sometimes been insulted and even manhandled at the same meetings. There are other examples of HIV+ women encouraged by counsellors to inform their partners. Male partners have defined and dismissed the ‘problem’ as a ‘woman’s disease’, and subsequently abandon them, and any children, with or without physical abuse (Testimony, Ladysmith NACOSA, 1995). This accrued stigmatization of HIV+ women, hitherto only recognized in relation to the double stigma attached to gay men, need to be conceived, articulated and addressed in terms of the rights’ agenda, and women-based interventions.\textsuperscript{21} However, it will be a slow process.

It has been suggested that women’s stories of more independent women coping are also essential as role models (PC, A. Jaffe, Amatikulu). Yet ‘coping’, too, may be seen in terms of the dominant gender, within the same problematic frame of ‘community care’. A recent example of ‘women coping’ given by a medical superintendent of a hospital in Kwazulu-Natal was their new willingness, following counselling, to look after their husbands and family, and cited in that context as a model to emulate – quite irrespective of their own situation, and frequent woman-abuse. Is not this model double-edged? Given the broader context in which AIDS prevention globally has made gender construction, woman abuse, gendered rights’ issues, and sexualities more ‘sayable’, whose political gender interests are furthered by the projection of this role model?
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The Hlabisa peer education and support group (of whom only two members currently receive payment from the regional authority), liaising with committed activists from the regional PWA association and assisted by health professionals, are developing their own dynamic, despite enormous odds, under-resourcing, and the difficulty of the terrain. This very practice constitutes a critique of and a creative resistance to the new, more urban-conceived policy, in what is effectively a relocation (or dual location – hospital and community) and a broadening of the counselling function.

Conclusion

The resistances to the new policy and the divergences in practice are palpable, with Pietermaritzburg ATICC, an important training centre for Northern Kwazulu-Natal, occupying and advocating one extreme of the secrecy-disclosure continuum (on a par with ‘My vote is my secret’, an analogy used by an HIV+ schoolgirl echoing and defending this position), and Hlabisa Hospital, Edendale and Ngwelezane favouring a counselling strategy encouraging limited disclosure under the patient’s control, linked to peer support and education, on the opposing side. Durban ATICC lies somewhere in the middle, concerned with the proposed exclusion of lay counsellors.

In some southern and east African gatherings, extreme positions seeking to rule out confidentiality altogether, and which bear no relation to issues of rights or of advocacy, have been expressed, including at the SANASO Conference (Southern African AIDS Support Organization) in Windhoek, Namibia, in 1993. Some of these arguments were couched in a form of populist culturalism claiming that ‘confidentiality is not African’. There are dangers of culturalist discourse where ‘culture’ is seen as unequivocal and unchanging.

Similar strategies have been used by others to argue that ‘human rights are not African’, and this has been extended as an argument for rejecting condoms on the basis of a particular construction of ‘cultural order’. Curiously, there are also examples of culturalist discourse used by anthropologists, taking up simplistic one-dimensional bio-medical data and in so doing stigmatizing particular cultures in the epidemic. Such extreme and problematic positions were not encountered in this study.

However, there may be traces of culturalist discourse, particularly in this immediate post-colonial context where certain forms of culturalist discourse and practices that were forced underground are being revived (like ‘virginity inspectors’). These discourses and some of the practices may seek to claim a wider audience, especially among ‘traditionalists’ in terms of a particular ‘Zulu tradition’ and among Christian conservatives in the politically charged context of this region where celebrations of ‘traditions’ connoting and reconstructing ‘Zulu-ness’ are hostages to rival political ambitions. This is the context, but emphatically not the arguments being rehearsed by the new policy’s critics.

The desire to redefine the source of advice or support, and hence the social agency, as narrowly professional, with counselling moving to a position of authority, is a significant shift. It will effectively remove lay counsellors and further sideline NGOs. The western counselling model is firmly implanted and being reproduced. How appropriate is this for the whole of Kwazulu-Natal?

These different perceptions and divisions in the region represent a range of experiences, subjectivities and interests. In general, NGOs are usually seen as the agencies to bridge the gap between counselling on the one hand, and community education, involvement, and rights’ advocacy, including women’s rights, on the other. However, the strictly limited activities of NGOs, whose funding dramatically dried up in early 1994, and their limited engagement in South Africa in AIDS-related work (despite more general assumptions, or inflated claims), is another difficult issue for AIDS activism and for the building of civil society.

By contrast, many urban health professionals in South Africa, with very limited experience of work, communities and environments in peri-urban and rural areas, tend to refer more to the West, particularly the USA. This means that they will be more likely to favour individualistic frameworks. While South Africans are, indeed, increasingly urban, these ‘positions’ have been shaped by South African history, ideologies and materialities.

The idea and practice of HIV confidentiality, including pre- and post-test counselling, represents a meeting point of conflicting and often gendered representations of infection, illness, the individual and the community. A less reductionist, more historical
and sociological view of this 'moment' would provide a conceptually larger space for diversities and conflict within a rights' framework, suggesting a different role for 'cause groups', including ASOs and NGOs, in civil society. It would also indicate particular directions for the critical social sciences, influenced by social movements' theory and by feminist epistemology, rather than continuing to foreground biomedical-led research. This would be consistent with the paragraph on STDS, HIV and sexual health in the Reconstruction and Development Programme, concerned particularly with disadvantaged rural communities and specifically women.

Although there is rarely a direct link between research and policy, it has been suggested that new models of participative research involving academic researchers and trusted community activists, with an interest in longitudinal studies of support networks using more sophisticated qualitative techniques, would be useful to those campaigning for more gender-sensitive policy and practice. This would be a particular challenge in KwaZulu-Natal within the rights' culture of South Africa.

Endnotes

NACOSA was set up jointly by the former Nationalist Government and the ANC — one of the first joint priority actions decided by the ANC prior to the 1994 elections. Initially, as a very heterogeneous grouping with diverse agendas, experiences, sexualities, and ambitions, there was considerable mistrust. Despite these difficult beginnings, NACOSA continues to function impressively as an NGO consultative and policy-making organization with its various commissions, and with regional bodies (Johannesburg, Soweto, Durban and Cape Town). However, in that it has no executive function, it remains a discussion and lobbying body.

The national NACOSA is based in Johannesburg. NACOSA played a key role in the formulation of a multi- and inter-sectoral national AIDS strategy in 1994. This strategy was formally adopted by Health Minister Zuma as the National Plan.

'Imphilo' in Zulu is used both to translate both 'confidentiality' and 'secrecy'. Interestingly, the new KwaZulu-Natal use of 'professional secrecy', as distinct from the standard 'medical confidentiality', is close to the standard French phrase: 'le secret médical'.

ATICCs were set up by the former nationalist government, only one in each main urban centre, with a main focus now on counselling and counselling training. Arguably, at that time, these were set up to assist whites only, as they are at a considerable distance from the nearest township; and post-apartheid residential arrangements are slow to change because of joblessness and income disparities. Although ATICCs are now staffed by black and white workers of both sexes and pay a greater attention to sexual orientation and to sexual behaviours, a number, including Durban, are still located in official and intimidating buildings.

While ATICCs now help to implement the new government's AIDS policy, its more prominent members also participate within the regional NACOSA where ATICC Managers tend to play an active role as executive members or convenors of commissions in addition to their daily workloads and other meetings. The more dynamic ATICCs like Pietermariitzburg and Durban also put forward their own strategic and business plans, with government and private sector funding.

The regional NACOSA also produces policy documents and regional objectives, but without any funding of its own is virtually dependent on the regional Department of Health and/or on private funding for its various activities and projects; and where the gender and, more recently, the research commission have sustained little interest and failed to thrive. This is happening in a context in which interventions are being planned on the basis of minimal qualitative research, and where this tends to be reduced to focus groups and questionnaires, often designed and conducted by the same group of people.

There are fears that NACOSA may be passed over and made to feel redundant now that the main opposition has passed into government. But the most active NACOSA post-holders continue to fight their corner; and in so doing are thrust into the decidedly uncomfortable and unequal position of lobbying their own DOH employers. For some, this contradiction has proved untenable.

COSATU commissioned an AIDS video. However, AIDS does not appear to be a priority, unions are not represented within NACOSA, and AIDS is not a mobilizing concern at present.

In late 1995, the setting up of regional sub-NACOSAs in Ladysmith and the South Coast may make some difference in the longer term, but at present they still tend to draw on the same small core of committed individuals, including from the ATICCs and key activists in the regional PWA Association who are becoming increasingly stretched.

Some researchers and commentators have tried to account for relative failures of health interventions on the grounds that they have encountered a 'cultural problem'. This gives rise to a form of cultural relativism and is highly problematic. Furthermore, this inflation of 'tradition' as a panacea to 'cure' HIV, or halt its spread, underestimates, or ignores, social and individual resources, as well as everyday practices. A claim by epidemiologists and clinicians, echoed uncritically by some social scientists, that societies that go in for male circumcision are relatively AIDS-free, would seem to blame those that do not. This argument is implicit in some of Caldwell's recent work and his synthetic mapping of AIDS in Africa, as analyzed by Seidell and Vidal; and they are reproduced uncritically elsewhere, including in Southern African publications, such as Insights. Also, in practice, this simplistic explanation ignores high seropositivity levels in countries like Côte d'Ivoire, where male circumcision is the norm. It serves to further reproduce and extend this fallacious argument giving further credence to the myth that 'Moslem men are faithful, well-behaved', etc. These uncritical frameworks detract from a more adequate conceptualization and potentially undermine health promotion strategies.

References

Confidentiality and HIV status

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Biography

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