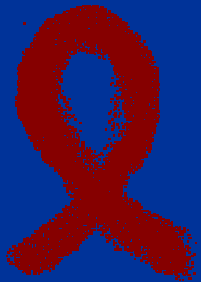


Genres of HIV talk

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HIV support in South Africa

- 37 semi-structured interviews, 45-90 minutes, in 2001
- Recruitment through HIV CBOs around Cape Town
- 29 women, 8 men
- 34 HIV + 3 unknown/negative status
- Themes covered: medical (conventional and traditional), social service, NGO/CBO, family and friends, media, religion, government support experienced, expected and required
- 8 followup interviews, 2003-4
- Content and narrative analyses performed

Problems of using conventional social support measures around HIV

- Lack of research on new social support structures
- Qualitative differences between support modalities
- Historically particular histories of support and of research

Value of a qualitative approach

- For a field with little general qualitative data
- For a field characterised by social stigmatisation and political neglect

Participatory Action Research – the best solution?

- Resource lack
- Potentially disempowering entrainment into ‘participation,’ away from other activities

Content findings

- **Specialised HIV medical support** highly valued and strongly demanded
- **Good knowledge** of existing medical treatments
- **Complex accounts** of accessing and implementing available medical treatments
- **Counselling support** valued post-diagnosis for status acceptance
- **Support groups** valued for a year post-diagnosis for information and social and emotional support
- **Family and relationship** support generally positive for at least 1 family member once disclosed to
- General **religious support** valued
- **Media representations** valued as with support groups

■ Problems with the content-based approach

- Neglect of language
- Extensive narrative data
- Explicit narrative focus by interviewees

- **Michael:** Firstly, eh, sh, should I start my story from '97 /is that where you want to start?/ yah I mean I started to know my status, started to, I mean started to know in '97.
- **David:** My story I think it will be very short because er I've just known myself that I'm HIV positive just last month.

Value of narrative analysis

- Apparent universality of narratives
- Interdisciplinarity of narrative perspectives
- Narrative focus spans theory and practice
- Narrative theory bridges modernism and postmodernism
- Narrative analysis allows multi-level approach (from clauses and conversational turns, through content, to cultural narratives)
- Narrative research allows some relationship to politics

Who the hell wants to protect subalternity? Only extremely reactionary, dubious anthropologic museumizers. No activist wants to keep the subaltern in the space of difference . . . You don't give the subaltern voice. You work for the bloody subaltern, you work against subalternity

Gayatri Spivak, 1993

Problems of narrative analysis

- Universalist assumptions about narrative
- Reifying equation of life and narrative
- Commodification of 'lives' and 'stories'
- Incommensurability of narrative-analytic methods
- What are the implications of narrative research?
- What is a narrative?
- In this research, narrative was defined weakly as temporal, spatial and/or causal sequences, with particularity of style and/or object

Approaches to narrative analysis in social research

- Focus on narrative syntax: Analyses the structure of personal event narratives (Labov) defined by narrative clauses, or functions within stories (Propp), or genres across narratives (Jacobs)
- Focus on narrative semantics: Analyses the content of experience-centred stories that map the violation and restoration of canonicity (key/fatal moments) (Bruner, Denzin)
- Focus on narrative micropragmatics: Analyses the positionings and performances of identity stories (Abell et al.), often as co-constructed (Georgakopoulou, Riessman)
- Focus on narrative macropragmatics: Analyses the gathering-together of interpretive communities that may potentiate social action, through story genres (Plummer), or the direct effects of narratives, usually in popular media, or the playing-out of metanarratives in smaller narratives (Malson)

Why the macropragmatics of genre?

- Allows consideration of 'horizontal' commonalities in narratives across media (Todorov)
- Allows for generality across as well as within personal and cultural narrative fields
- Suggests that personal narratives are part of cultural politics as well as social change
- Allows consideration of the ambiguities, polysemy, authorial uncertainties and gendering of narratives through genres' constitutive instabilities (Derrida)

The 'speaking out' genre: from othering to owning

Intertextualities:

- Plummer's account of the intimate disclosure genre
- The sociopolitical salience and currency of 'speaking out' about HIV in South Africa
- Existing research on the 'othering' of HIV (Joffe) and the importance of social openness (Campbell)
- Frequent references to the necessity of progressing towards 'speaking out'
- Performances of 'speaking out'

What is the structure of the genre?

Progression from 'othering' and ignorance; through denial, recognition, shock, and negative reactions; towards acceptance and owning of HIV within a social context (interpretive community); ending with wider 'speaking out' and action.

- **Michael:** (After the first test) I didn't think any, you know the problem was that, I, I, I just ignore it, ignore the point of H, HIV and then we had that problem, we had the problem of, of us the people in South Africa. We took, it, we took the HIV issue light and we compare it to the places like the countries like, like America and I mean in States you know, something South African, I mean in States, then we didn't compare it to in South Africa that HIV can be here you know, I took it light and I ignore it just like that, no, this is not a truth that I'm HIV positive. I just ignore it and the doctor didn't give me the guide lines, how to live with HIV, I must do this and this.

- **Michael:** (After the third test) the results came back positive OK, the guy told me ‘No what you, say what you say to me, what you told me {that Michael tested HIV positive before}, it’s really like that’. OK I told him, ‘No I want to see it physically don’t tell me like that you know /mhm/ show me the paper, the papers you know, let me see it, you should see that the man is HIV positive’, OK it was fine. ‘How do you feel now?’ now I started to become shock now, I looked up the sky like that, I looked up the sky, the guy asked me ‘How do you feel?’. ‘No, I mean I’m just OK’ you know, but there’s that question in my mind.

- **Michael:** My friends now they are all, they are all love me, they are all love me that, 'yhu we've got a friend which is who's HIV positive and he's open about his status' and the they gain a lot from me /mm/ they gain a lot from me. So even if we are here they always come to me that 'where can we go?' yah I go to the taverns, I'm not drinking, I'm not smoking /mm/ then they drink buy for me a juice no then we start to discuss the issues based on HIV /mm/ I'm the one who's got experience about the HIV because I know it from myself you know, so that's why they like me they are too much supportive to me

Social ownership

- **Busisiwe:** Okay, what I would tell you my sister, the support that I get is that I go to my friends and to the elders and say 'I have this problem, what words do you have as advice?' Then, when s/he speaks s/he would say 'I believe you have to take the treatment because the medical treatment is good.' What I also encourage is that there is a lot of us who are HIV positive even in the shebeens where we drink, I personally know some of those people. I just wish those places be visited too. You see, let me make an example, if I can take my friend that I know, we were once close, and who is also HIV positive and bring her/him here, I would be afraid to tell her/him. So, I would take and come with him/her here so that s/he can see that I also have this. So, I accepted that I am HIV positive although it did trouble me. I heard from (clinic) that I've got it and it's been a month now. I exposed it by some means at home and they now know that I have it. However, there is nothing else I can say because I also told my boyfriend to accept it but if he doesn't want to take the medication, I for one do not know what else must I do because I do urge him to take the medication, he is adamant. What has helped me is my understanding that perhaps he is too shy to come for a test and treat it, things like these but I want him to take the medication

Imagined performance of HIV's social ownership

Ntomboxolo: Oh no, there's nothing wrong with the support group, it's like the best thing, we sit and chat. For instance if there's a new beginner, we as the old members, we would not be able to talk to strangers, then counsellor {facilitator name} would give us the go ahead, so that we can ask the new person for details.

The new member would greet us and ask how do we do?

The old members would respond, and then tell {facilitator name} that we cannot talk freely in front of the new faces, so {facilitator name} would say, 'Go on ask her for details', she does not talk, only we do the talking.

We would ask, 'Sister what are you doing here?'

She would probably say, she came to fetch the milk formula for the baby.

We would say 'This is not the place to fetch milk formula, why do you have to get milk formula?'

She would say, 'I do not breast-feed.'

We would ask, 'Why are you not giving breast milk to your baby?'

She would maybe say, 'I'm ill'.

We would ask, 'Which illness?'

Then she would not say.

And then we would say, 'Then we ask you to please leave the room if you do not want to tell us why you are not breast-feeding your child.'

Sometimes, other women ask the new beginners, 'At the time when they drew {tested} your blood, what were you told is in your blood?'

Then the other beginner would tell us, 'They told that I am HIV positive so that's why I can't give breast milk to my baby', then we would let her stay.

And then we would move on to the next one, let's say we have about three of them.

Then we would ask the third one, 'And you sisi {sister}, what are you doing here?'

Maybe she would just open up easily and say, 'I am HIV positive'.

So then we would ask, 'How did it feel when you were told for the first time in the clinic after they took your blood sample and told you that you are positive?'

Some women usually say, 'I felt alright.'

'Who did you tell?'

One would probably say, 'My husband,' and maybe the other one say, 'My parents.'

Do you get the picture?

Narratives of conversion and testimony

Intertextualities:

- Religiously-inflected popular-cultural stories of coming to terms with HIV
- Religious talk in the interviews
- Ubiquity of religious discourses and practices in South Africa
- Significant history of negative religious responses to HIV
- Established structure of conversion narratives

What is the structure of the genre?

From ignorance and rejection of faith; through crisis to conversion to belief; to finding a faith community in which to pursue ongoing struggles with faith, and testifying

Vuyani: So what I want, like I am interested in other people, understand who are like me, like counselling people, understand. To clarify as in, okay, if one has HIV like what kind of a person are you, how do you live like something like that, understand. Like, I have tried it, understand I have talked to many people, like trying to explain like what happens, for instance there is a woman that came to the clinic while I was there. This woman, she came and I could see shame she was thinking a lot, this thing was very deep in her heart. But I tried to explain to her that 'no man this is not the end of the journey, you know. God is able to give us more life, understand. So do not be like that, understand, it is the Devil that gave us these diseases, it is not God, you see'. So really this woman said 'no man brother I wish I could always be with you because why, you encouraged me in the sense that I feel strong with the words that you gave me, understand'. So I am saying that these are the things that we were told about before, that okay these things {diseases} will happen, you see, but we won't give up hope, we will always believe in God that he is alive, so he will cleanse us and rebuke all these things {diseases} that we have in life. So I am looking at reaching counselling and preaching to people, understand.

The prophetic HIV subject

- **Busisiwe:** So, I do (really) value that they {ancestors} give me brightness and drive away darkness. What I want now is to be shown things {about how to treat and/or cure HIV} . . . there is a need for a better treatment to be added or found. God can choose one person to explain the ingredients of the cure which is what I want . . . I have a sense of humour like the other lady {in the support group} who was joking about this. I realised that I could do it too. I can joke about it until a person understands it. So, people would see that I also have this and that I'm free and not anxious. . . . This must be done in a free spirit as one becomes free when s/he is preaching in the church hoping even that his/her prayer is ascending.

The ethical HIV positive subject

- **Michael:** God has made that Michael can, you might know yourself you HIV positive so that you can do things and protect yourself and involve yourself to the HIV/AIDS activities /mhm/ and you know all those things, I always thank God, to know myself, in time that I'm HIV positive, so that I can do things properly.

The normalisation of the HIV positive citizen

Intertextualities:

- Rights and equality talk in the interviews
- South African struggle and constitutional histories and discourses
- Failures to represent HIV within 'new' South Africa discourse

What is the structure of the genre?

From sociopolitical and personal exclusion; via collective assertions of citizenly rights and equivalence; to recognition of, assertion of and action as HIV citizens

- **David:** I must tell you that I was waiting for bad results because I've known myself, I've been, I haven't been safe. I mean I haven't been playing safe over the years, so I was really expecting bad news, so I was waiting for those bad news. And the results came and I was tested HIV positive. Okay, there's that little bit of a shock. Yes, there is, but it didn't change me. I I used to have dreams and I still have. Being HIV positive, I mean didn't change all those dreams. I'm still me and I'll always be me.

The citizenly subject

- **Yoliswa:** I think meeting {HIV organisation} had a very very big impact on my life . . . I stopped having the negative thoughts and, just started to be the old Yoliswa I used to be before I knew about my HIV status.

Drawing citizenly equivalences

- **Benjamin:** Next day it gonna be there in your family /mhm/ Because you're not gonna lock the gates and go to work /mhm/ and come and open the gates. /mhm/ One mistake there'll be HIV it's just like a death /mhm/ as we say most death is visiting families to families. So it's just like the case of HIV /mhm/ Don't put it as the issue of the teenagers. It starts from zero to sixty to beyond you see.

- **Zanele:** Even now I take myself as an HIV person because I don't know my status /mhm/ that is why I told myself that maybe I've got this HIV. So I, I'm on the side of HIV people. I don't say I'm not or I will not, I take myself as an HIV person.

- **Busisiwe:** Say, I tell my friend that, ‘girl, hey girl, have you heard of the big thing?’ that’s how they put it and I would say ‘people HIV is not something that should make you dislike me.’ I would go on to give an example and say ‘I’m like your sister because I’m also HIV positive so, do not treat your sister as if she is no longer a person, she is a person amongst others’

Problems of the pragmatic genre-based approach

- Lack of robustness and generalisability of the genres
- Neglect of smaller-scale phenomena, such as individual stories
- Failures of interpretive community in relation to some stories (Foster, Gobodo-Madikizela)
- Aspects of personal and social experience that cannot be narrated in all stories (Craib, Frosh, Kristeva)
- Material contexts limit genres' currency and effectiveness

Genres for post-political times

- Genres – including genres of self-narrative (Butler) - as forms of political discourse and action
- Genres' emotionality as particularised political strategies, rather than emotivist abdication of politics (MacIntyre).

Voices

Lumka Daniel

You are HIV Positive
YOU ARE – HIV POSITIVE
YOU ARE
YOU, HIV POSITIVE
YOU ARE POSITIVE
YOU ARE
YOU ARE
YOU ARE
HIV POSITIVE
I AM
I AM?
Nay, I am not
I am who I am
And
I am not HIV Positive
I may be living with HIV
That does not make me
HIV does not make me
I am who I am
And I still am who I am
And I live,
I live,
I live with HIV

HIV?
Humano
Immuno – def
Deficiency
V-Irus
HIV lives in me
I have not died
I am and HIV is within me
I am, I still am
There's no name for HIV
They can't find it
They can help me fight it
It is not detectable
It deteriorates,
Deteriorates my immunes
I was not born with it
God did not create me with it
Somebody got it
Somebody passed it on
Passed it on to me
Somebody whispered
You are HIV Positive

They cannot tell me, they cannot tell me
When I,
When I became, errr when I became HIV Positive
They cannot tell me
When I,
When I received the, errr the v-irus
They cannot tell me,
They cannot tell me who passed it on to me
The only thing they tell me
Is errr, my body's struggling
There's a battle in my immunes
Awakening my anti bodies
Ant-I bodies to battle with the v-irus
The trespassing curse
In my body
In my blood
They tell me,
They tell me,
You are HIV Positive
I feel like Judas in Passion of the Christ
Only that, only that I did not betray the Messiah
Only that, I did not sell the Messiah, nor my body
Only that, only that I have not killed myself

Maybe I have, maybe I did
By allowing them to change me
From who I am and who I am meant to be
To
You are HIV Positive
Who cursed me?
Why me?
Why now?
Why?
Should I kill?
Should I kill the cheater, the bastard, the moron?
If I was born with it, would I have to kill my parents?
Or would they have killed each other already by now?
Mhhh, errr should I kill the government?
Why wasn't there PMTCT?
Should we all die?
Am I?
Am I dead alive with the V-Irus?
I live
I am alive
And I,
I live with HIV!!!