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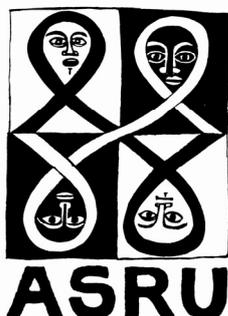


CENTRE FOR
SOCIAL SCIENCE RESEARCH

**EXPERIENCES OF HIV/AIDS
DIAGNOSIS, DISCLOSURE AND
STIGMA IN AN URBAN
INFORMAL SETTLEMENT IN
THE CAPE PENINSULA:
A QUALITATIVE EXPLORATION**

Lauren Kahn

CSSR Working Paper No. 94



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December 2004

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Experiences of HIV/AIDS Diagnosis, Disclosure and Stigma in an Urban Informal Settlement in the Cape Peninsula: A Qualitative Exploration

1. Introduction

This paper explores the personal experiences of five HIV positive individuals situated in an urban, informal settlement in Cape Town, South Africa. In-depth interviews and a focus group were conducted and analysed to facilitate an integrated understanding of how individual and social processes intersect and shape experiences of HIV positive individuals. Specifically, experiences of diagnosis, disclosure and stigma are investigated, and explored as they play out in the context of the family, the peer group, intimate (sexual) relationships, and within the broader community context.

The findings will be used to highlight the manner whereby the experiences under investigation are shaped by a complex interplay of factors and processes simultaneous operating on both individual and social planes. On the one hand, experiences of HIV diagnosis, disclosure, stigma and support will be shown to be shaped by locally specific as well as broader contextual factors, sounding a warning against an uncritical transposition of findings from western contexts to the South African case. On the other hand, it will be shown that personally-specific factors influence these experiences by producing variation in strategies of disclosure, and reactions towards the discloser (including both support and stigma) within and across relational contexts and geographical locations, as well as over time. Furthermore, it will be argued, on the basis of the findings, that stigma and support are dynamic rather than static in nature, and are actively confronted and negotiated by HIV positive individuals in a productive and instrumental manner – rather than imposed upon passive individuals. From this, it will be argued that there is a need to refrain from overly simplistic or generalised statements related to HIV disclosure strategies and HIV-related stigma.

2. Brief literature review: HIV/AIDS-related disclosure and stigma

HIV disclosure has received increasing attention over the last decade, both in the media and as a topic of research. Potential advantages of disclosure by the HIV positive person include access to social support, psychological and physical health benefits, more appropriate medical treatment and the reduction of stigma. On the other hand, there are also possible disadvantages and risks associated with disclosure, both to the person with HIV, and to significant others. Risks posed to people who disclose their HIV diagnosis include discrimination, violence and rejection (Greene *et al.*, 2003). Accordingly, empirical evidence indicates that for individuals testing positive for HIV, “disclosure of serostatus ranked second in degree of stressfulness behind testing and receiving a positive diagnosis” (Duffy cited in Schmidt & Goggin, 2002: 41).

On a broader level, HIV-related stigma and discrimination have been described as “...the greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating impact” (Parker & Aggleton, 2002: 5). In the context of South Africa, survey evidence shows that there are clear stigmatising tendencies among some South African population groups (Shisana & Simbayi, 2002; Maughan Brown, 2004).

It is also important to note the widely recognised link between poverty and AIDS (e.g. Whiteside, 2001, 2002; Desmond, 2001; Poku, 2001; Cohen, 2000), a situation which in South Africa is exacerbated by post-apartheid migratory patterns. Since the post-apartheid relaxation of restrictions upon labour migration, many Black South Africans who were previously affected by apartheid influx control laws have made the transition from rural to urban areas in the hope of securing a livelihood and/or reuniting with their families (Ndegwa, Horner and Esau, 2004). Not only do these areas have high HIV-prevalence rates, they *also* have higher tendency levels of HIV/AIDS stigmatisation. Specifically, it has been documented that poor, unemployed and uneducated people were more likely to stigmatise than employed people, people of a higher socio-economic status and educated people. As such, the people most vulnerable to poverty, and likely to become infected with the HI virus are also the people who are most likely to suffer stigma and discrimination (Shisana & Simbayi, 2002).

Much contention exists, however, surrounding both how to conceptualise and, in turn, how to measure stigma (Link & Phelan, 2001; Stein, 2003) which makes this phenomenon an elusive object of research. In particular, traditional approaches characterising stigma research have been criticised, firstly, for their

individualistic focus, which has served to obscure the social origins and consequences of stigma. Secondly, social scientists working along a traditional vein have been criticised for prioritising “their scientific theories and research techniques rather than the words and perceptions of the people they study” (Schneider cited in Link & Phelan, 2001: 366). As such, it has been argued that stigma research has been conducted “from the vantage point of theories that are unformed by the lived experiences of the people [under] study” (Link & Phelan, 2001: 365).

3. Aims and Methods

The current study turns its focus upon the lived experiences of the people under study, and aims to explore disclosure and stigma in a manner that facilitates an understanding of both individual and social processes, and how these intersect and shape experiences of HIV-positive individuals. The study draws upon the experiences of HIV positive people, all of whom were living (at the time of the study) in Masiphumelele, a low-income, informal urban African township in the Cape Peninsula. In particular, the study focuses on their experiences of initial diagnosis with the HI virus, disclosure within the family, the peer group context, within intimate sexual relationships, and subsequent experiences of support and stigma.

Five HIV-positive individuals participated in the study. They had participated in an AIDS outreach programme, run by the University of Cape Town in the year preceding the study, and were recruited as the study participants through this institution. Participation was voluntary, and participants gave informed consent. In accordance with ethical considerations surrounding confidential and anonymity, the names used in the study are pseudonyms. The participants were involved in one focus group in which all were present. Following the focus group, each participant was interviewed individually. Although the participants were Xhosa-speaking, the focus groups and interviews were conducted in English (the language of the researcher) as most of the participants were proficient enough in English to do so. Two of the participants were more proficient in English than the other three; they assisted in the focus group by translating to the others when necessary, and re-translating their responses into English. One of the participants required a translator in the individual interview. She chose another one of the participants to stand as translator, as she did not wish to have another ‘outsider’ involved due to the personal and sensitive nature of the discussion.

The focus group discussion centred upon the participants' general perceptions of and attitudes towards disclosure to family members, sexual partners and within their community more generally. As focus groups tend to encourage consensus and normative responses (Alexander & Uys, 2002), the participants were also interviewed individually. The individual interviews were geared towards eliciting narratives surrounding the participants' biographically unique, personal experiences of diagnosis, disclosure, stigma and support. The focus group and interview material were analysed in a manner that served to retain a sense of each participant's personal meaning frame, rather than fragmenting accounts into discreet themes. In the interest of producing an analysis that recognised the simultaneous operation of personal and social processes, however, the individual case studies have been juxtaposed in a manner that may highlight continuities and, alternatively disjunctures across the individual cases, and between the group discussion and the individual interviews. The trajectory of the paper will follow, and explore the participants' accounts of diagnosis, disclosure, stigma and support, as they move through contexts varying in relational intimacy:

1. Familial context
2. Peer group context
3. Intimate relational context
4. Broader community context

Table 1: Relevant personal details of study participants

<i>Respondent</i>	<i>Gender</i>	<i>Age*</i>	<i>Diagnosis</i>	<i>Years since diagnosis*</i>
Neliswa	Female	40	March 2001	3
Sindiswa	Female	20	February 2003	1
Zolani	Male	29	March 2002	2
Nobuntu	Female	23	April 2001	3
Zoleka	Female	29	March 2002	2

Note: * At the time of the interview.

4. Results

4.1 Familial Context

The ‘familial context’ as a context of disclosure has been well-researched. In western contexts, nuclear family members (e.g. parents, siblings, children) are viewed as some of the most likely potential recipients of disclosure of HIV status, while the extended family (such as grandparents or in-laws) are far less likely to be considered high-priority disclosure recipients (Greene *et al.*, 2003). However, *family* “is a broad term, varying in specificity by culture” (*ibid*, 2003: 72). In this regard, it is important to note that black familial structures do not always conform to western notions of the family as an (urban) self-contained nuclear unit, a point which should be held in mind as the analysis proceeds, and to be returned to in the discussion component of this section.

The participants were involved in a focus group prior to being interviewed individually. One of the first questions posed to the group referred to their feelings around the importance of disclosure. As a group, the participants strongly advocated disclosure in the context of the family as an important factor whereby initial support may be mobilised.

“It’s important if one of your family...yes...I think it’s very important [for them] to know. When I’m...getting sick, they must know why I am getting sick...and then maybe they can help...”

“I think...the family is number one...The family can help you through the bad situations... You must tell them, I think, because I disclosed to one of my family, my mother...she knows me. And I don’t tell so much the others but I told my mother...and she told me I can stay long time...”

Families were described as containing and safe places in which the participants felt accepted. Disclosure in the context of the family was viewed as providing “the best” place for initial disclosure, an important foundation of support to prepare before disclosing to others beyond the familial context: “It’s the best thing, start with your family...then go outside”. Additionally, the participants emphasised that disclosure within the familial context was an important means of mobilising an understanding network of support should they become physically sick.

In the context of the group discussion, the familial context was consistently held up as serving a support function by all of the group members. However, collectively-expressed sentiments often diverged from individual accounts. The following case studies will show converging as well as diverging experiences in relation to initial diagnosis, and first experiences of disclosing within the familial context. These case studies also point towards the complexity, dynamism and variation in experiences of disclosure and stigma within the context of the family, and warn against simplistic statements about these issues.

CASE 1: NELISWA

At the time of her finding out her status in 2001, Neliswa (aged 37) had three children and was staying with her stepmother and stepmother's children in Masiphumelele. She had grown up without her biological mother, and her father had passed away years before her diagnosis. She tells of the harsh reaction she experienced from her step-family when she disclosed to them initially.

“In the first place I disclosed to my family. It was very hard because I've got my step-mother and I felt at...first...so angry and sad because they were funny to me...They made the funny things and they didn't even eat my food; they didn't even want me to wash with the basin. Or something like that, you know? Even the teaspoons, cups and things. They were very funny and I was so sick at that time because I was so angry and stressed”.

Neliswa links her experience of physical weakness at the time of disclosing to her family with the difficult emotional experience that coloured her disclosure. Her disclosure is figured as one that was experienced both psychologically as well as bodily, or physically. She maintains that her suffering at this time was further exacerbated by the fact that she was financially dependent upon her step-family at the time of her diagnosis and disclosure.

“I was only working one day a week, a month, you know so... I was so suffering. And one day when I...came home from my work, she [step-mother] said to me, ‘I want you to go out of my yard and take your children also to go out. We didn't need you’. I was crying and wondering because I didn't even know where I [was] going to...stay with my children”.

She was faced with becoming homeless and unable to provide for her three children. She emphasised how her situation – an HIV positive diagnosis, lack of financial independence, and her uncertainty surrounding what her future held,

due to her HIV status and her family's negative reaction to her disclosure – was given greater force due to the fact that she was a mother. Her situation thus had great implications not only for herself, but for her children too, and posed a challenge to her filling her role and meeting her responsibilities as a mother: “Oh, I was *crying* – I was thinking about my children's future. That was my first thought”.

As such, a variety of interacting factors within her personal situation rendered Neliswa's initial experience of diagnosis and disclosure as one coloured by feelings of helplessness, personal impotence and uncertainty about her future ability to fulfil a role of provider for her children or herself.

While the initial psycho-social climate in which Neliswa experienced diagnosis and disclosure was harsh and rejecting, Neliswa's desperation to find and mobilise a supportive environment for herself and her children led her to explore other potential sources of support beyond her immediate geographical location: she first approached a friend and then later, when this yielded positive results, other members of her family in the rural context of the Eastern Cape.

“Then I [went] to my friend from Eastern Cape... I [talked] to her, said ‘please give me a place to stay with my children because my mother throw me out’. And my friend gave me the room. She gave me the big room; she told me ‘go and collect your kids and come and stay here’”.

She asserts emphatically, on my questioning, that people in the rural context of the Eastern Cape show a different reaction to HIV than those in the urban areas; they are more accepting, understanding and knowledgeable of the virus, and are also more supportive:

“Yes, they understand everything. In the Eastern Cape there are people – they are not so hard.

Interviewer: So in the Eastern Cape do they give more support?

Yes, because I've got also my brother – he's still in the Eastern Cape because he's looking after the cattle and goats there at home. So sometimes he [comes to] Cape Town. And he's got a lot of understanding, because the time I told [him], “ah, my brother, I'm HIV positive”, he was crying and said ‘*Oh god!* I know what – I'm going to everybody – my family, my sisters, my brothers about you. I don't want anybody to hurt you again – because I know when you are

HIV you must always be happy'. So they've got a lot of understanding".

As such, not only did factors in her personal life colour her experience of diagnosis and disclosure, but Neliswa's personal negotiation of these factors and subsequent experiences also coloured her perception of social reactions to HIV: she now conceptualises the boundaries of supportive versus unsupportive contexts in stark geographical terms.

CASE 2: SINDISWA

Sindiswa was working as an AIDS counsellor at the time of her diagnosis at age 19; her decision to test was motivated – and possibly even compulsory - due to the nature of her work. She maintains that her knowledge surrounding HIV buffered the force of the positive diagnosis: “But at that time I found out I was positive I didn't worry: because I know it all about the people who have HIV".”

Her family context had been complicated and dislocated prior to her diagnosis. Her father and mother were divorced, and she stayed with her father who she describes as having had “many girlfriends” and “my father get drunk so much”. She told of how she eventually left her father's home after, at a high-point in their conflict-ridden relationship, he had burnt all her clothes and told her to go and live with her mother. Her mother had re-married and did not wish for Sindiswa to live with her and her husband so Sindiswa eventually moved in with her mother's relatives in Masiphumelele.

As such, at the time of her diagnosis she was living with these relatives. She first disclosed to a close friend, who she calls her “secret friend” (i.e. a friend to whom she tells secrets) and then to her mother's relatives. She describes how, initially, her relatives were supportive and then how their attitude towards her changed and they began to spread rumours of her status through the community:

“At that time – I think it was June - there was bad time then; they [were] changing; they did funny tricks and are going speak out to the people: ‘she have AIDS!’. I told them I don't have a problem”.

Her relatives then told her to leave as “they didn't want to stay with people that have AIDS”. However, the force of their rejection was cushioned by the fact that the friend to whom Sindiswa had initially disclosed gave her continued support, taking her in to her own home. However, this supportive environment was threatened once again when members of the community burned her friend's house down as a reaction to her ‘harbouring’ an HIV positive person.

At this point, she was a member of a community support group, and Sindiswa negotiated this experience in a productive manner, drawing upon networks of support forged by her involvement in HIV/AIDS support initiatives. Money, clothes and psycho-social support were provided to her from these support networks. Mobilising these support networks in a positive way led Sindiswa to consider non-familial sources of support in a ‘familial’ light; she maintains that although her “really family” (i.e. biological family) had rejected her:

“I didn’t mind at that time, because I was knowing a family – because at that time, my family they didn’t like me; they are fighting me. But I get support from support group; they give me support.... After that ... *I’m free!*”

Although she had little support from her biological family for a period of time, her father has now apologised; she has disclosed her status to him, and moves between living with him in Khayelitsha and her place in Masiphumelele where she lives with her “secret friend”. In both spaces – a year after diagnosis - she feels supported. However, later in her account, it became apparent that the scars of rejection remain. Sindiswa recounted that her aunt’s daughter, on her mother’s side of the family now has AIDS, but that she does not want to help her due to lack of support they provided her – “because they didn’t want me because I have AIDS”. Sindiswa remains bitter that her mother's family have not yet apologised to her; her personal bitterness stands as a barrier to her providing support for one of the mother's family members now who has AIDS. The rift between her and this side of the family also remains.

CASE 3: ZOLANI

Zolani is 29 years old, the only male participant. He was diagnosed in March, 2002 at the age of 27. At the beginning of 2001, his sister had come to Masiphumelele from the Eastern Cape for medical treatment and had been diagnosed with HIV. She was already in the final stages of the disease at that point and passed away soon after. Zolani described the difficult experience of caring for his sick sister, and watching her deteriorate and die. At the same time, he was also providing care for her small baby. Zolani’s girlfriend and their four-year-old son had also been diagnosed with HIV during this time frame. Zolani’s girlfriend passed away three months after the death of his sister.

As such, Zolani was diagnosed following direct personal confrontation with the ravaging effects of the virus. His personal life had been deeply affected by the virus; even now that he has been diagnosed, his concerns are often directed away from himself and towards his young son. His other concerns are also

centred upon his broader family: “I’m the breadwinner at home; is only me working for the whole family”; both his and his family’s reaction to his positive diagnosis was shaped in light of its financial implications for the family. However, this did not seem to affect the capacity of his family members to provide him with social and emotional support.

While his sister’s illness and death had been exceptionally trying, Zolani maintained that this had facilitated his disclosure to his family – his mother specifically – when he was later diagnosed with HIV:

“Then it was not so difficult for me; then I went back [to his family in the Eastern Cape] and explained...made it so easy for me. I told her [*i.e. his mother*], you know, my sister died because of this disease; I’m also in the same situation as her. And it was very easy for her – she understands...”

CASE 4: NOBUNTU

Nobuntu¹ described her experience of being diagnosed with HIV as a difficult and lonely one, describing how, in the beginning, she “was sad, and did not tell anybody for a long time”. She was diagnosed in 2001, at the age of 20 while she was pregnant and only disclosed for the first time in 2003, two years later, when she became a member of an HIV advocacy and support group. She disclosed to some of her family members after joining the group, as becoming part of this group has made her “feel strong” enough to disclose. She described the process of making memory boxes and books (part of a psychosocial workshop series conducted within the group²), and writing self-narratives, as having facilitated her disclosure to her family members. She is the only participant interviewed who made her initial disclosure after a significant time lapse following her diagnosis. She used the box and books as an opening to broach the subject to her family: her translator remarked of this, “she says, at home, they ask her about the memory box and books, and she tells them”. She feels unburdened psychologically since becoming part of the support group, and maintained that “now she don’t even think about she’s positive”.

¹ Nobuntu could speak little English. Her interview was conducted with a translator present. As such, her words are presented in the third person.

² See Almelah (2004) for some of the tools used in these workshops.

CASE 5: ZOLEKA

Zoleka was diagnosed in August, 2001 at the age of 24. At the time of her diagnosis, she was extremely sick, unable to walk, and was accompanied to the doctor by her family with whom she was staying (in the Eastern Cape), and who were providing care for her. Her doctor had given her an HIV test, and her family had taken her home. The doctor decided not to tell Zoleka, but rather told her sister that Zoleka had tested positive. Zoleka believes that he did this out of a concern that, in her weak and sickly state, she would have been unable to bear this diagnosis; she believes he was preparing her family to support her emotionally when diagnosed. Fearing Zoleka's reaction, her sister had told the rest of the family but not Zoleka; instead, the family took Zoleka back to the doctor who diagnosed her with a positive status in front of the family. The family was a strong source of support for her; even before knowing herself to be positive, her sister had comforted her when she had voiced her fears of being positive.

Zoleka told of how she was unable to walk for almost an entire year, and the painful experience of being told that she would never walk again by her doctors in the Eastern Cape. They told her she would have to be confined to a wheelchair. She maintained that the idea of the wheel chair was worse than being HIV positive: “HIV, it is easy! But the wheel-chair...I wasn't feeling about the HIV, I was feel[ing] *the wheel-chair*”.

She then moved to Cape Town where she felt she could get better treatment in terms of health care. She now stays with her brother and his wife in Masiphumelele. She told of her miraculous recovery during which she re-gained strength and mobility³. She was once again able to walk, an achievement that had the doctors in awe, and her family and the Eastern Cape community in disbelief when she returned there recently. Now, 3 years after her diagnosis, she returns to the Eastern Cape occasionally to see her 8 year old daughter who lives with the father, to whom Zoleka was once married. The father supports the child, but Zoleka sends money when she can.

DISCUSSION

The picture of the family as a place of sanctity and source of support is not as clear-cut when one explores the individual accounts of diagnosis and disclosure. Disclosure to family members was often met with rejection, and was

³ It is not clear whether this was due to anti-retroviral treatment, which could promote such a recovery.

accompanied by experiences of isolation. In the case of Sindiswa, her privacy was violated by her family, who spread knowledge of her infection around the community, indicating how the family as a private and safe, containing place for initial disclosure cannot be assumed. However, the accounts also show that experiences of isolation and rejection were not accepted passively by the participants; rather, such negative experiences were actively negotiated as individuals sought out support and acceptance.

In particular, the accounts of disclosure within the familial environment point towards the need to recognise the complexity of familial structures in the South African context, and to note the socio-historical, political and economic forces that have brought about such familial structures. Simplistic conceptualisations of the family as a nuclear, co-residential unit akin to the Western nuclear family system (see Russell, 2004 for a critical discussion of black households in South Africa) need to be overturned when attempting to understand disclosure in the familial context. The accounts reflect a picture of ‘family’ as extending beyond the uniting factors of biology and marriage, and consisting of multiple units that are separated geographically. These units are figured as divergent in terms of the relative degree of support they offer to the HIV positive family member. Furthermore, the participants mobilised support, even after initial experiences of familial rejection, through shifting between these various familial nodes in a productive manner. Such shifts included crossing urban-rural divides, and moves within and across urban locations. Additionally, leaving the relative sanctity and support of the family located in rural areas is also sometimes necessitated by the need for medical attention, and financial resources that require a move to urban areas.

The findings in the current study support evidence from other parts of South Africa indicating that migration is “an important strategy for poorer households having to cope with the HIV/AIDS epidemic”, a strategy that may be geared towards economic survival (i.e. in-migration to urban areas aimed at seeking out employment), social survival (i.e. migration aimed at accessing support and care from extended family, regardless of whether the destination is rural or urban) or physical health survival (out-migration from rural areas aimed at accessing better health services in urban and metropolitan areas) (Booyesen, 2003: 31).

Furthermore, the accounts point towards the need to conceptualise stigma or, alternatively, support as not simply static contextual factors that are imposed upon passive individuals: rather, stigma and support are dynamic in nature, and are actively confronted and negotiated by individuals. Furthermore, stigma and support are represented not in a uniform but, rather, varied and often diverging manner as a product of unique factors at play in the personal lives of individuals. It becomes apparent – and will become more so as the analysis proceeds – that

an environment is not singularly supportive or, alternatively, unsupportive or stigmatising. Rather, both levels of support and stigma respectively need to be considered in terms of a continuum rather than mutually exclusive and discreet categories. Finally, the findings also indicate the presence of ‘communities’ of stigma and support that exist, both spatially and figuratively, that people living with HIV/AIDS negotiate and draw upon in an instrumental manner that serves their individual needs.

4.2 Peer Group Context

CASE 1: ZOLANI

In studies conducted in the United States, disclosure to friends about an HIV diagnosis has been found to be common, as “friends are freely chosen and distinguished by mutual trust and similarity” (Greene *et al.*, 2003: 73). However, this common-sense assumption did not appear to play out as simplistically in the lives of the Masiphumelele study participants.

Disclosure within the peer group context was figured in varying manners within the group. Zolani described experiences of social ostracisation, fear and hopelessness as characteristic of HIV positive people attempting to disclose to their peers within the community.

“My friends also...they can’t talk about it. If you talk about HIV, they scared of that. If you talk about it, they just go out [of the room]. They scared; they don’t feel...they are hopeless. I try to show them... Some of them are HIV; they told me, but they are scared to come out about their status. That’s why, if you talk to them about HIV, they going out; say, ‘I’m coming now’. You won’t see them; just left. They don’t want to hear anything about HIV and AIDS, ja”.

His account shows the difficulty he has in maintaining a positive personal identity as HIV positive in the face of much resistance – not only from the community in general, but from his own friends who are themselves HIV positive. His friends’ fear of acknowledging and “coming out” with their status means that they avoid the opportunity of connecting with, and forming support networks with other HIV positive members of their peer group. On the one hand, this stands as a strategy that Goffman’s classic text on stigma refers to as “passing” as “normal”, a means of managing “undisclosed discrediting information about self” by attempting to maintain a social identity that coheres with others who do not bear the stigma of, in this instance, HIV/AIDS that

disclosure would erode (Goffman, 1963: 58). However, the result is a form of denial and self-imposed isolation from the very people who might – potentially - offer the most support and understanding.

Zolani maintained that men, in particular, are resistant to getting involved in psycho-therapeutic support groups, and are difficult to mobilise in this respect. He described an attempt he had made to form a men's support group, which had failed to draw in many participants. He attributed his male counterparts' lack of involvement to the fact that men were not interested in engaging in the sorts of activities characteristic of HIV psycho-social support groups, particularly their discussion-based style:

“Because maybe they look for something different. Maybe some sort of money. That sort of thing. See, the men, they don't want to *sit* like this and *discuss* and just...”

“We are still looking for something that can make them strong, ja. Like, they can do something; they don't just come and sit and discuss...maybe they can *do* something”.

As such, Zolani described the nature of support needed by men as being different to that of women if it is to yield positive outcomes. For men, it appeared that becoming “strong” required “doing” not “discussing” or “sitting”, being ‘active’ rather than ‘passive’. This is possibly a reference to traditional dichotomies of masculinity and femininity. This reference may be usefully informed by recent research investigating African masculinities in South Africa, and how dominant constructions have informed the African male population's response to HIV/AIDS, both in terms of prevention as well as in dealing with infection (e.g. Hunter, forthcoming; Beck, 2004).

The reference to money is also a possible reference to (African) men's responsibility of filling the traditional role of economic provider, fulfilling monetary obligations surrounding marriage, building a household, and assuming a head of household status (see Hunter, forthcoming). This reference also highlights the importance of acknowledging the close association between poverty and HIV (e.g. Shisana & Simbayi, 2002) in South Africa, and how the experiences of HIV positive people may be coloured by concerns surrounding economic survival and not simply concerns surrounding social integration within their communities.

Conversely, Zolani maintained that “the women, they don't have a lot of problems” as they provide support for one another. His view is supported by the

accounts of the female participants. While Zolani describes having difficulty forming networks of support with other men, the women, alternatively, appear to have less difficulty engaging with other HIV positive women, and describe actually being approached for support by their HIV positive peers. For example, Sindiswa told of how she had been approached by others in the community who had been diagnosed with HIV; she maintained that they felt able to approach her and disclose their status to her because they knew that she was HIV positive:

“They know I’m HIV; they are coming to me because they didn’t want the community to know...They feel happy, because I told them I’m HIV. They didn’t ask me, but I told them”.

DISCUSSION

While the men shy away from making connections with, and forming networks of support with other men due to a fear of disclosing their status, the women seemed to find support and a sense of comfort and acceptance in forming networks with their HIV positive peers. The accounts indicate that women tend towards an “in-group alignment” with like individuals (i.e. other HIV positive women) finding strength in a shared HIV positive identity, while the men still orientate themselves towards an “out-group alignment” with individuals who do not bear the stigma of an HIV positive identity, and in so doing, attempt to find a sense of belonging within a community that does not compel them to recognise their HIV status and its implications (Goffman, 1963). The result is a sense of displacement, as men can only maintain this position through a form of self-imposed denial; however, this also stands as a protective strategy against stigmatisation and discrimination.

4.3 Intimate Relational Context

The women described experiences featuring difficult relations with members of the opposite sex: at many points in their accounts, men figured as obstacles, particularly as sexual partners, to their negotiating a positive identity. There was clear evidence – which will be drawn out in the individual case studies below – that disclosure in the context of intimate heterosexual relationships was a contentious and highly emotion-laden issue.

These issues were clearly apparent in the focus group that preceded the individual interviews, in which disclosure to sexual partners arose as a complex issue. In the focus group, the participants were asked whether HIV positive people – *in general* – should be obligated to disclose their status to their sexual

partners. The group seemed divided in gendered terms on the issue of disclosure to sexual partners. More specifically, the women all advocated non-disclosure to sexual partners (although strongly emphasising that non-disclosure must be accompanied by enforced condom-use). On the other hand, the only male participant interviewed argued that disclosure to sexual partners was important, and that HIV positive people should be obligated to disclose in the context of their intimate sexual relationships. In order to understand these contrasting views, the personal experiences of the participants in relation to disclosure to their intimate partners will now be presented.

CASE STUDIES: FEMALE PARTICIPANTS

CASE 1: NELISWA

Neliswa maintained that her boyfriend did not appear to view her disclosure in a significant light.

“... And he said ‘So? What is funny?’. And I just said, ‘No!’. I told him I’m HIV positive, so as from now, I don’t want to have any boyfriends. So go to live your life now. So I’m going to look after myself, and look after my children”.

Furthermore, her boyfriend did not attempt to make contact with her subsequent to her disclosing to him. She felt that the lack of acknowledgement he paid to her disclosure is reflected by the fact that he still had not gone for his own blood test (at the time of the interview). She believes that other women were being infected by this man now (as she is aware that “he’s got a lot of girlfriends”), while he continues to avoid facing his own possible infection: “and he’s not looking ok, even now...It’s very, very difficult; it worries me a lot. Because I saw a lot of ladies got a lot of rashes; even he [is] not looking good”.

She maintained that she still has no boyfriend, and has not had one since her diagnosis. When asked if she ever wishes she had a boyfriend at present, she mused:

“Maybe, I say. Sometimes I say maybe God can give me the right one... the men who can understand my problem... Because the ladies always say the guys didn’t understand when I told them I’m HIV positive; they do not understand. They [say], ‘no, that is nonsense, we can’t use the condom; mustn’t use’. So I wanted somebody who can understand but – *Ja*, we must use the condom full time.”

CASE 2: SINDISWA

At the time of her diagnosis, Sindiswa was in a relationship with a man. She said that, when she found out that she was positive, she disclosed to him and “told him he must go to clinic to test... But at that time we [were] fighting because he didn’t want to go and test and he didn’t want to condomise. So I told him he must go away if [he] did not want to condomise”.

She maintained that the roots of her partner’s resistance to using condoms lay in the fact that he did not accept her positive status:

“I told him twice [that] I’m positive. But he didn’t believe that; he said, ‘you [don’t] look sick!’; I said, ‘if you have HIV, you [are not] sick all the time’. So then, he goes away from Masiphumelele. He didn’t stay here. I say, ‘if you don’t want to condomise with me, then stay away!’. After that, I find another boyfriend.”

Sindiswa then said that she both disclosed and enforced the use of condoms in her current sexual relationship from the outset of her current relationship; she also encouraged her partner to test himself. He found out that he, too, was HIV positive; his being in the later stages of the virus means that he was infected by someone other than Sindiswa at an earlier time. She described how he sought comfort in her when finding out his status, and found her a source of support and strength and someone who could share and understand his experience.

CASE 3: NOBUNTU

In the case of Nobuntu, when asked of her opinion surrounding disclosure in the context of sexual relationships, she said that, in her own opinion, “it’s not important to tell your partner” as she had told her husband and he had “run away”. She did, however, follow up this statement by emphasising that, even in the context of non-disclosure, it is important that condoms are used.

She described her painful experience of having been rejected and left by her husband, attributing his rejecting attitude to the fact that he too was HIV positive but was in denial of his status. Accepting her status would have meant accepting his own, which he was unable to do. He had left her alone with their young HIV positive child. She had tried to visit her husband late the previous year but “when she went to visit the husband, he did not want to see her anymore”. Later that same year, their nine-month-old child passed away, and Nobuntu had become very sick, possibly as a result of the compounded stressors she was

confronting. She was highly resistant to the idea of entering into another intimate relationship at the present time.

CASE 4: ZOLEKA

Zoleka strongly advocated condom-use in her individual interview. She accounted having disclosed to her boyfriend over the phone, as he was living and working in the Eastern Cape at that time. She had not seen him for a long time preceding this as she had been sick, and had also had work elsewhere. He had reacted with fear and, following this, disbelief: “that day, he was afraid: ‘what’s happening; how long?’...But now he don’t believe me after I tell about this. But I don’t mind”. She asserted that she had not slept with him since she had disclosed her status to him, as he had not accepted it. She maintained adamantly that she was not involved – and had not recently been involved - in a sexual relationship at the time of the interview. She seemed resistant to discussing this area of her personal experience at greater length than this.

DISCUSSION

As noted earlier, in the focus group the participants were asked whether HIV positive people – *in general* – should be obligated to disclose their status to their sexual partners. In the group context, all the women asserted that HIV positive people should not be obligated to disclose their status to their sexual partners, on condition that they use a condom, however.

Despite this, all of the women maintained that they had disclosed in the context of (at least one) sexual relationships. Their negative experiences in this regard may be producing their hesitancy to advocate disclosure to sexual partners as obligatory for HIV positive people in general. Even Sindiswa, who is currently in a sexual relationship in which she has disclosed – with positive results – still advocated that HIV positive people should not necessarily disclose to their intimate partners.

The women gave accounts that illustrate the powerful – and often destructive – effect that disclosure can have in the context of intimate relationships, and the difficulty facing HIV positive women in finding a (male) partner who will accept their positive status in this context. Male partners were typically described as resistant to accepting – or even acknowledging the reality of - their HIV positive status, and reluctant to engage in sexual practices that acknowledgement would accord.

MALE CASE STUDY: ZOLANI

Contrary to the collective view of the women in the group – that one need not disclose to one’s sexual partner - Zolani maintained that one should tell one’s partner; he openly opposed the views of the women. Zolani emphasised that non-disclosure could result in a breach of trust and hence a broken relationship, should one’s partner find out one’s status from another source: one should disclose to one’s sexual partner as, otherwise, “maybe somebody else [is] going to tell her you HIV, and now she won’t trust you any more”.

Two cost-benefit logics appeared to be in operation. On the one hand, most of the women felt the cost of disclosure – i.e. possible rejection by an intimate partner – to be greater than the benefits of disclosure – i.e. openness and trust. On the other hand, the male participant weighed the cost of *non*-disclosure – i.e. loss of trust, with the possible breakdown of the relationship should one’s partner become privy to one’s status – as out-weighing the possible benefits of keeping his status from a partner. While the women viewed disclosure as a potential threat to a continued intimate relationship, Zolani perceived non-disclosure as a greater threat.

It became apparent in the context of Zolani’s individual interview that his views were a product of uniquely personal experiences that were not necessarily specifically gendered in nature. His specific fears related to the breach of trust that non-disclosure in the context of an intimate relationship may result in - should his status be made known to his partner by means of a source other than himself – appear to be a product of his initial experiences with HIV.

As seen in his initial case study, Zolani’s girlfriend had passed away from an AIDS-related illness at the time of his own diagnosis. Although Zolani had not officially disclosed publicly at the time of the interview, Zolani maintained that many of the people in the community believe that he is HIV positive “because...my girlfriend [had] passed away”. He has been labelled HIV positive – regardless of his ‘real’ status – by virtue of association, and not due to his having disclosed. He feels that he holds little personal control over who is informed of his status, as community speculation networks have taken this decision out of his hands:

“maybe someone knows about you, then lot of people know about you; and I think they spread [news of your HIV status] over the community...I’m sure they’ve got the information from *outside*; *I didn’t tell them...*”

His views surrounding disclosure to sexual partners seem to be an extension of this experience. He maintains that, on entering into a relationship with his current girlfriend, he felt compelled to disclose to her as he feared her learning of his status through community networks of information; in fact, he believed that it was possible that his current girlfriend was already aware of his status (prior to his disclosing) *because* of this information network. His impetus to disclose to his current girlfriend immediately was, in part, because of his fear of her hearing from another source, and then no longer trusting him.

“I think that she knew from outside. Instead of [her] get the information from outside, I must tell [her] myself; then she can decide what she want to do. Because I ... knew that she was getting information from outside. Because some of our friends are not right. that's why, if I meet someone, I must tell the truth. Because the people *outside*, they going to...”

“Some of them, they don't say the right things... They say the *bad things* about many: not all the members of the community, some of them, they love me; some of them, they don't love me. So they are going to say bad things about me. Yes. That's why, if I meet someone, I must tell her the truth.”

Zolani's reference to information from “outside” gives a sense of his perceived lack of control over his own private information; he is not in control over the boundaries separating his ‘inside’ or private information from ‘outside’ or public knowledge. This is in alignment with theoretical work surrounding disclosure of private information, such as an HIV positive diagnosis, which emphasises how individuals work to control the flow of their private information, due to a perception that they ‘own’ it, and the potential vulnerability that may consequently arise when control is lost (Greene *et al.*, 2003; Petronio, 2002). A “boundary metaphor” is employed to “illustrate the parameters that people set around their private information” thereby managing and coordinating the “dialectical tensions” between privacy and disclosure of an HIV status (Greene *et al.*, 2003: 10). Zolani, within this theoretical framework, experienced “boundary turbulence” when he was no longer able to assert individual control over the flow of his personal information i.e. his HIV status (*ibid.*: 10). However, he retained a subjective sense of control and personal boundary management by taking charge of disclosing within the context of his intimate relationship; by so doing, he wards against ‘outside’ forces, beyond his control, operating ‘inside’ the confines of his personal life.

He also asserted that community speculation – rather than actually being HIV positive and educated around the appropriate behaviour change this requires -

has actually driven him to change his sexual practices in a manner that serves to reduce negative speculation:

“Yes, before [I was diagnosed HIV positive] had lot of girlfriends. But I say, I don’t know. Since HIV positive, I stop: maybe they are going to say I'm trying to spread this. People, they've got different ideas. Maybe they [will say] ‘ah, that guys HIV, got a lot of girlfriends; he try to spread this disease’. But I always use a condom.”

Finally, Zolani’s strong impetus to advocate disclosure in the context of sexual relationships may also be a by-product of his personal experience of being in a sexual relationship with someone who failed to disclose. Zolani maintained that he had not been aware that his girlfriend (who passed away due to an AIDS-related illness) was HIV positive while he had cared for her during her illness. He had watched her getting sicker and sicker, and had eventually gone to the hospital alone – “I didn’t say anything to her, because I did not want to worry her”. There the doctor had told him that his girlfriend was HIV positive. She had known this for some time, as she had been tested when she had become pregnant, but had not disclosed her status to him. When he found out that she was HIV positive:

“Oh, I didn't say anything; because she was staying with me at the time; I didn't say *anything*. I so sorry; can't blame her. So sorry. It was not easy. And the father was also not right at the time; was getting sick. And she started to get sick - she was walking; then, getting sick, she can't walk again. Sleeping all the day. Pain. It was not easy.”

His current tendency to frame disclosure in terms of love and trust may be a by-product of his experience of helplessness in the context of watching a loved one deteriorate painfully: “According to my understanding, if someone loves you, she loves you: under any... And you must tell her - tell her that [you are] HIV positive. And if she loves you - no problems, because the condom is there to protect her and to protect me”. He said that he had disclosed to his current girlfriend two days after meeting her, and how she loves him despite this.

4.4 Broader Community Context

4.4.1 Urban-rural variation in support and stigma

Responses to disclosure – ranging from support to rejection – were not simply framed within the interpersonal or group context in which they were experienced. Additionally, spatial or geographical references coloured the accounts. The participants often used spatial boundaries as a means of defining pockets of support and stigma alternatively. The stories point towards a very strong (familial) support network available to these HIV positive individuals in the rural Eastern Cape. On the other hand, urban areas are often figured in harsh and rejecting terms. It appeared that families in rural areas possessed both knowledge surrounding HIV/AIDS, as well a deep understanding of the implications of infection upon their affected relatives. Not only that, they also displayed open attitudes of acceptance towards the infected individuals, providing these individuals with a place of refuge, care, emotional and social support.

This is interesting in light of the fact that recent findings (Shisana & Simbayi, 2002) indicated that people in rural areas were less likely to display positive attitudes towards infected individuals, and were less likely to be knowledgeable about the HI virus. The study attributes the deficits in knowledge and positive attitudes in this sub-population to its receiving the poorest media and programme coverage of HIV/AIDS. However, this study also points towards the fact that greater personal involvement with HIV/AIDS, for example by knowing someone who is HIV positive, was linked to a greater acceptance of people with HIV/AIDS.

The findings in the current study underpin the importance of close personal involvement with HIV positive individuals in facilitating greater acceptance of this population. It is also possible that the strength of the relationship preceding HIV infection may also play a role in producing positive attitudes towards infected individuals: in most cases, those who provided the most acceptance and support were also those who were most closely related in familial terms (as opposed to being extended or step-families) to the infected individuals, or shared the closest bonds of friendship.

The findings in the current study also point towards the need to give credence to experiential or tacit knowledge and understanding possessed by people who experience the effects of the virus first-hand. This holds particular force when

considering the following account surrounding one of the participants' characterisation of the perceptions of HIV/AIDS held by others.

Zoleka employed spatial references when characterising perceptions of HIV/AIDS held by others. She described her (ex)-husband's worry about her living in Cape Town, an urban area, because of his association of this urban area with the HIV/AIDS virus: "He tell me...he thinks the HIV is here [Cape Town] and not in the Eastern Cape, so [he told me], 'please, please, don't leave Eastern Cape, because they've got the HIV in Cape Town'". She explains her husband association of HIV with the urban areas of Cape Town as such: "Because many people are come here, is dying with HIV. Still come here and die. He thinks HIV is here. And they go to Eastern Cape to die. My husband, he don't know about HIV; what's happening". This illustrates a social representation⁴ of HIV whereby people perceive the virus in terms of 'risk areas' rather than risky practices, which is, Zoleka maintains, a product of his limited knowledge about the virus.

However, this 'lay' representation needs to be considered in the light of epidemiological findings surrounding HIV prevalence rates. A national survey of HIV/AIDS in South Africa (Shisana & Simbayi, 2002) found that urban informal areas in South Africa (such as Masiphumelele) have the highest HIV-prevalence rate, while urban formal areas, rural areas (such as tribal areas and farms) showed notably lower rates of prevalence. Furthermore, the Eastern Cape showed the lowest provincial HIV prevalence rate.

As such, Zoleka's ex-husband actually represents the prevalence and spread of HIV/AIDS in quite accurate terms when he figures informal, urban areas as high-risk areas. Also, his reference to the fact that people go back to the rural areas of the Eastern Cape "to die" also reflects the findings of studies that indicate that people in last stages of AIDS often return to their rurally-based families to seek care in their final days of sickness (Booyesen, 2003).

The account stands as evidence of the fact that experiential knowledge – first-hand confrontation with the effects of the HI virus and AIDS-related death – can be as powerful a 'tool' of 'education' as formally-distributed knowledge and educative programmes surrounding HIV/AIDS. This first-hand experience is perhaps of a nature that cannot be denied.

⁴ See Joffe (1999) for an exploration of 'lay' people's responses to HIV risk, drawing upon empirical findings from South Africa and the United Kingdom, which employs a combined psychoanalytic and social representational theoretical framework.

While many of the participants gave accounts that indicated that others did not accept or acknowledge the reality of HIV/AIDS (for example, Sindiswa's boyfriend, to whom she disclosed after her diagnosis, did not believe her because she did not "look sick", Neliswa's boyfriend and Nobuntu's husband would not accept the possibility of their own infection; and Zoleka's boyfriend "did not believe" her) it is possible that, facing the death of close relations after AIDS-related illness, the reality of HIV and AIDS cannot go unacknowledged.

4.4.2 Intra-urban variation in stigma and support

Although there is tendency to separate supportive from unsupportive contexts, and represent them as standing in isolation from one another, the participants also emphasised variation in community attitudes towards HIV in a single context. For example, Zolani maintains that one cannot make a sweeping, all-inclusive judgement about the community in this respect:

"I think you must look what kind of people. Because some of them, they are going to say, 'oh shame'⁵; some of them are going to support you; they are going to love you. Others, they are going to say *bad things* about you! And...especially in *this* community".

He does, however, single out his own community - "*this* community" - specifically as one that, relative to other communities, is more inclined to stigmatise. He maintained that his community was a difficult one for a HIV positive person to live in, as "they need to get more knowledge about it" in order to be more understanding; this is a sentiment that is common to the group members. He draws on Khayelitsha, another community in the Cape Peninsula, characterised as a site of many HIV/AIDS awareness initiatives, as an example of a community in which HIV is more socially accepted:

"They are aware. I think Khayelitsha are doing well. Because anyone can stand up there and say their status...but here is not easy. You can try to show that – but instead of supporting you, they are laughing at you".

Sindiswa gave some insight into general community perceptions and attitudes towards HIV/AIDS in an account of community reactions to and attitudes towards wearing t-shirts advocating HIV; once again she sets up the community in which the group is located in relative terms to Khayelitsha. She maintained

⁵ Commonly-used expression of sympathy in South Africa.

that in Masiphumelele, wearing a t-shirt with the label ‘HIV positive’ visibly splashed across it was interpreted as an indication that the wearer was personally infected by the virus. She contrasts this with the attitudes of people living in Khayelitsha, explaining that people in Khayelitsha were not likely to label one as ‘HIV positive’ simply by virtue of the t-shirt one wears because HIV is publicly addressed and advocacy campaigns that involve both HIV positive and negative people are highly visible.

“In Khayelitsha, they didn’t think so [that wearing an ‘HIV positive’ t-shirt means that one is HIV positive]. In Khayelitsha there is many people that support; there are TAC⁶, many people that support the people with HIV”.

Sindiswa suggested that people in Masiphumelele were resistant to becoming involved in AIDS activism for fear of being labelled as HIV positive; as such, people were willing to get involved to some extent, but not at the risk of being stigmatised themselves. Referring to the general community attitudes towards wearing the t-shirts, Sindiswa said that “They like the one ‘Knowledge is to know; get tested’; they like that one. Because they are wearing that t-shirt. They didn’t wear the ‘HIV positive’ one”. Interestingly, Sindiswa said that the same people would, however, wear the ‘HIV positive’ t-shirt on a march, “because everyone wears the t-shirt then”.

A few points come out of this. Firstly, these extracts suggest that, while there may be a high level of stigma in the community, there are in fact people who are willing to – and are engaging in – HIV/AIDS advocacy. Furthermore, individuals negotiate the possible negative or stigmatising implications of their involvement by clearly defining their social advocacy role as distinct from their personal HIV status. However, in clearly political contexts – for example, political marches advocating treatment for HIV – individuals may drop concerns surrounding the protection of their personal identity in the interest of identifying with, and being identified with, the broader social cause.

It appears that the personal, the community and the political exist in complex relationships to one another. In particular, HIV/AIDS-related stigma and advocacy in the context of South African communities needs to be recognised as being contingent upon, and shaped, in a complex manner, by interacting personal, social and political factors.

⁶ Treatment Action Campaign – A political organisation advocating anti-retroviral treatment for people with HIV/AIDS, a campaign directed towards the South African department of health which was resisting a comprehensive roll-out campaign for all infected individuals.

5. Concluding Comments

5.1 Variation in Stigmatising Attitudes

The findings from the current study indicate (in line with findings from a recent South African national survey (Shisana & Simbayi 2002) cited in the introductory paragraphs of this paper) that sub-populations are still stigmatising people living with HIV/AIDS. However, the current findings indicate a need for hesitancy before labelling sub-populations as inherently ‘stigmatising’.

Firstly, there appeared to be variation in stigma, even within a group of people sharing the characteristics associated with stigmatising tendencies. This variation was evident both within and across urban communities, as well as rural and urban locations. Variation within and across relational contexts was also evident. In particular, the power of relational ties, as well as the extent of the disclosure recipients’ personal confrontation with the virus, appeared to play a strong role in reactions to disclosure to significant others. Secondly, variation in stigma in individual reactions *over time* was also evident. Certain individuals responded positively in the context of initial disclosure, while later displayed negative attitudes, and rejecting and discriminatory behaviour towards the discloser, or vice versa.

5.2 The intersection of the Social and the Personal in Experiences of HIV Diagnosis, Disclosure, Stigma and Support

The analysis also brought to light evidence that both locally-specific as well as broader contextual factors were exerting a powerful shaping force over the participants’ experiences of diagnosis, disclosure, stigma and support.

Social, economic, political and historical factors were at play in shaping experiences of HIV. Specifically, these included structures of poverty, socio-historical structuring of black families and households as straddling urban and rural locations, post-apartheid migratory patterns and, to some extent, constructions of gender. Acknowledging the role that these contextually-specific factors play in shaping experiences of HIV diagnosis, disclosure, stigma and support is, as such, a critical point that came out of the study, one that warns

against transposing findings drawn from a western context in an uncritical manner to the South African case.

On the other hand, these contextually-specific social factors did not function in a uniform manner in shaping experiences. Personally-specific or biographically-unique factors in the lives of the individual participants were simultaneously at play in producing their experiences. Such personally-specific factors produced variation in strategies of disclosure, and reactions towards the discloser within and across relational contexts. Furthermore, social and personally-specific factors did not simply act *upon* the participants, but were actively negotiated, often in a productive and instrumental manner.

These findings indicate the need to refrain from overly simplistic or generalised statements about HIV disclosure strategies as well as regarding HIV-related stigma. Directing a focus upon variation in experiences may serve as a useful lens whereby *exceptions* rather than *generalisations* may be brought into view. These ‘exceptions’ may yield valuable insight into how people living with HIV/AIDS negotiate *positive* experiences of disclosure, and why certain people *do not* stigmatise. As Alexander and Uys (2002: 301) note, it is important that HIV/AIDS researchers investigate instances in which outcomes are *positive* rather than directing an exclusive focus upon negative outcomes: “in this way, we will draw our research questions closer to our goal, and discover the positive experiences that can provide a foundation for effective leadership”.

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The Social Surveys Unit (SSU) promotes critical analysis of the methodology, ethics and results of South African social science research. One core activity is the Cape Area Panel Study of young adults in Cape Town. This study follows 4800 young people as they move from school into the labour market and adulthood. The SSU is also planning a survey for 2004 on aspects of social capital, crime, and attitudes toward inequality.

The Southern Africa Labour and Development Research Unit (SALDRU) was established in 1975 as part of the School of Economics and joined the CSSR in 2002. SALDRU conducted the first national household survey in 1993 (the Project for Statistics on Living Standards and Development). More recently, SALDRU ran the Langeberg Integrated Family survey (1999) and the Khayelitsha/Mitchell's Plain Survey (2000). Current projects include research on public works programmes, poverty and inequality.
