

Stigma, identity and resistance among people living with HIV in South Africa

Jane Goudge, Bulelwa Ngoma, Lenore Manderson, Helen Schneider

Abstract

AIDS-related stigma can cause delays in testing, poor treatment adherence, and greater numbers of new infections. Existing studies from low- and middle-income countries focus on the negative experiences of stigma, and few document resistance strategies. In this article we document the diverse journeys of people living with HIV in South Africa, through ill health, testing, disclosure, and treatment, and their responses to stigma. The research questions of focus are: Why are some able to resist stigma despite poverty and gendered oppression, whereas others are not? Why are some people able to reach closure, adapting to diagnosis, prognosis and finding a social context within which they resist stigma and can live with their illness? The illness narratives reported here show that the ability to resist stigma derives from a new role or identity with social value or meaning. Generation of a new role requires resources that are limited due to poverty, and exacerbated by unstable family relations. People who are socially marginalised have fewer opportunities to demonstrate their social value, face the greatest risk of transmission, re-infection and failure to adhere to medication, and require particular support from the health sector or community groups.

Keywords: stigma, resistance, identity, HIV/AIDS, South Africa.

Résumé

La stigmatisation associée au SIDA peut entraîner des retards de dépistage, une mauvaise adhésion au traitement et un nombre accru de nouvelles infections. Les études disponibles des pays à faible revenu et à revenu moyen se concentrent sur les expériences négatives associées à la stigmatisation, et peu abordent les stratégies de résistance adoptées. Dans cet article, nous étudions les différentes expériences de personnes vivant avec le VIH en Afrique du Sud, dès le moment où celles-ci tombent malades, se font dépister, divulguent leur état sérologique, où elles se font traiter, et leur réponse à la stigmatisation. Les principales questions que pose cette étude sont les suivantes: Pourquoi certaines personnes sont-elles capables de résister à la stigmatisation en dépit de la pauvreté et de l'oppression basée sur le genre, alors que d'autres ne le sont pas ? Pourquoi certaines personnes sont-elles capables de tourner la page, de s'adapter au diagnostic, au pronostic et de trouver un contexte social dans lequel elles peuvent résister à la stigmatisation et vivre leur maladie ? Les récits de la maladie rapportés dans cet article montrent que la capacité à résister à la stigmatisation découle d'un nouveau rôle ou d'une nouvelle identité associée à une valeur sociale ou à une signification. La création d'un nouveau rôle nécessite des ressources limitées du fait de la pauvreté, exacerbée par des relations familiales instables. Les personnes marginalisées d'un point de vue social disposent de moins d'opportunités de démontrer leur valeur sociale, et sont confrontées aux risques les plus élevés de transmission, de réinfection, et d'incapacité à suivre le traitement, et ont besoin d'un suivi spécifique par le secteur médical ou les groupes communautaires.

Mots clés: Stigmatisation, résistance, identité, VIH/SIDA, Afrique du Sud.

Jane Goudge, PhD, is a Senior Research Officer at the Centre for Health Policy, School of Public Health at the University of the Witwatersrand, Johannesburg. She joined the Centre in 1998 and since then has conducted research on a range of health policy and system issues including access to health care and why people drop out of treatment, the affordability of care, social protection, and health care financing.

Lenore Manderson, PhD, is Professor of Medical Anthropology in the Faculty of Medicine, Nursing and Health Sciences, and Faculty of Arts, Monash University, Australia, and an Honorary Professor in the School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, South Africa. Her research spans questions of social exclusion, inequality, diversity and chronic health problems in Australia, Southeast Asia and South Africa. She is a Fellow of the Academy of Social Sciences in Australia and Fellow of the World Academy of Art and Science.

Bulelwa Ngoma (MA Psychology) is a researcher at the Centre for Health Policy. Her areas of research include: understanding why patients drop out of ART programmes, and improving the provision of chronic care for ART patients; self-management in chronic diseases – patient knowledge, perceptions and processes; operationalising health as a human right and implementation of the Patient's Rights Charter in the health sector; non-governmental organisations working with people living with HIV/AIDS in Gauteng province; the social diagnostics of stroke-like symptoms and healers, doctors and prophets in Agincourt.

Helen Schneider (MB ChB, MMed) is Associate Professor at the Centre for Health Policy and Professor Extraordinarius, University of the Free State. She leads a programme of research health policy and systems with a particular focus on HIV/AIDS.

Correspondence to: jane.goudge@gmail.com

Letter by Nokuzola Mfiki: *'I can no longer continue with life. This community is laughing at me, humiliating me and my children because they say I have AIDS. The bodies of Mfiki and her four children were discovered in a field near her home.*

Daily Dispatch, Eastern Cape, South Africa 8 Aug 2008

She was always saying bad things about people with HIV, but I told her it would be nice if all the people who talked badly about HIV showed us their HIV-negative results.

Paulinah, aged 33

Introduction

AIDS-related stigma has highly damaging consequences, limiting the impact of public health interventions through delays in testing and poor treatment adherence. The result is a greater number of new infections, poorer health and, occasionally, as with Nokuzola Mfiki, suicide (Mawar, Saha, Pandit & Mahajan, 2005; Skinner & Mfecane, 2004). A considerable literature documents the experience of stigma (Duffy, 2005; Reidpath, Brinjath & Chan, 2005; Simbayi, Kalichman, Strelbel, Cloete, Henda & Mqeketo, 2007; Varas-Diaz, Serrano-Garcia & Toro-Alfonso, 2005), measuring levels of stigma and resulting health outcomes (Kalichman, Simbayi, Jooste *et al.*, 2005; Mills, 2006; Nyblade, 2006). However, there is insufficient understanding of the complex pathways of experience that generate differing responses including resistance to stigma (Garcia & Crocker, 2008; Rohleder & Gibson, 2006; Soskolne, 2003; Squire, 1999; Whittaker, 1992). We need to understand better the social and economic circumstances and resources, in different settings, to help people with HIV to neutralise stigma and develop new identities (Cornish, 2006; Jewkes, 2006; Reidpath, Chan & Gifford, 2005).

As is true for studies in industrialised settings, existing studies from low- and middle-income countries predominately focus on the experience of HIV-related stigma, with less attention to people's resistance strategies (Dageid & Duckert, 2008; Makoae, Greeff, Phetlhu, *et al.*, 2008; Poindexter, 2005; Rohleder & Gibson, 2006; Soskolne, 2003). In sub-Saharan Africa, studies of HIV-related stigma are predominately among populations where ARV treatment is not easily or freely available (Campbell, Foulis, Maimane & Sibiyi, 2005; Kahn, 2004; Lindsey, Hirschfeld & Tlou, 2003; Olenja, 1999; Pool, Nyanzi & Whitworth, 2001; Rohleder & Gibson, 2006). Although control of symptoms will not remove stigmatising processes (Parker & Aggleton, 2003), stigma may lessen where treatment is available (Castro & Farmer, 2005), and strategies to resist stigma may be more possible as a person regains his/her physical health.

In this article, drawing on research conducted in Gauteng Province, South Africa, we document the diverse journeys of people living with HIV after the national roll-out of ARV treatment, through ill health, testing, disclosure, and treatment, and their responses to stigma. Using the illness narratives of five participants as an heuristic device, we explore why some people are better able than others to develop new positive self-identity, and why some are able to resist stigma, despite poverty and gendered oppression, while others are not. We also explore why stigmatised individuals choose a particular mode of engagement with others, and the effects of this on their ability to resist stigma. Why are some people better able than others to adapt to diagnosis and prognosis?

Methods

The data derive from a study on the health system constraints and opportunities to scale up the ARV programme in South Africa. One component of this study was to explore the relationship between patient factors, health system factors, and adherence outcomes. Structured exit interviews ($N=713$) were conducted with randomly selected patients at four public facilities in Gauteng Province. These participants were asked whether they were willing to be interviewed again as part of an in-depth study, reported here. Those who agreed were grouped according to gender and self-reported adherence. Sixteen participants for the in-depth interviews were then selected on a random basis from these groups. Although the original intention was to include equal numbers of fully adherent and poorly adherent participants, due to the difficulty of tracing patients, only two were poorly adherent, both women. People diagnosed with HIV, but who were not taking treatment or who had refused treatment, were not included in the study. (We have since initiated a second study with patients who have withdrawn from an ARV treatment programme.)

Study participants were interviewed twice over 6 months. The first interview elicited an illness narrative, an open-ended self-determined account of their illness. Each participant described the history of their illness, testing, adjustment to diagnosis, experience of disclosure, interaction with existing social networks, the development of new ones, impact of HIV on their livelihood, and interaction with health workers. The second interview explored these issues further, with the 6-month interval allowing documentation of further adjustment. All interviews were conducted in the participant's preferred language, either by Bulelwa Ngoma (isiXulu), or by both Harry Nyathela and Bulelwa Ngoma if the participant's preferred local language was Sesotho. Harry Nyathela, publicly open about his own HIV-positive status, is an experienced HIV counsellor. All interviews were recorded, translated and transcribed verbatim.

The narrative approach allowed us to explore how participants made sense, retrospectively, of the diagnosis and prognosis of HIV and the events that followed (Kleinman 1988; Mason 2006; Mohatt, Plaetke, Klejka *et al.*, 2007; Riessman 1993). Narratives of illness and other dramatic events are often structured around a familiar trajectory, characterised by narrative closure. The shared cultural framework of narrator and interviewer allows for exposition, analysis, confirmation and concordance in interpretation. Given the chronicity of conditions such as HIV, like other lifelong diseases, closure refers not to the resolution (or cure) of the illness, but to adaptation to diagnosis, prognosis and social meaning. Frank (1995) differentiates the strategies of chronic conditions in terms of quest (the search for cure), chaos (in which there is no medical or personal resolution), and restitution, wherein the narrator finds a personal logic to their illness and its trajectory.

The in-depth interviews were analysed with the assistance of ATLAS.ti (version 5.0), with passages coded using both *a priori* and emergent codes. The *a priori* codes were determined by the research questions, and referred mostly to different points in the participant's journey after diagnosis. The emergent codes mostly referred to different types of experience and responses reported by participants. The *a priori* code 'identity' refers to the notion of finding a meaningful role, i.e. a role that has social value. 'Adherence' refers to self-reported adherence to medication, including consistency of timing of medication. Three researchers read the transcripts: one coded each narrative, the others reviewed and validated the emerging themes through discussion. Given the analytical importance of the journey through the experience of illness and stigma, from quest, chaos, through to restitution (Frank 1995), the narratives needed to be presented as whole stories. Unable to include all the narratives, the research team decided to include contrasting narratives, thereby illuminating a greater range of experience. Once a network of the conceptual categories had been generated, one researcher identified particular narratives that illustrated the key categories. Where possible, the selection of the cases favoured those narratives that provided the richest and most illuminating descriptions of the individual's journey. Several participants, less skilled story tellers, provided briefer descriptions of events and their own emotions, with less explanation as to why they responded or acted as they did, making interpretation more difficult. One researcher made the initial selection of cases; this decision was reviewed by others in the research team and differences of opinion were resolved through discussion. Five stories are presented below.

Ethical clearance was obtained from the University of the Witwatersrand. All participants gave their informed consent.

We have used pseudonyms in this article, as in all publications, to protect the anonymity of participants.

Results

Illness narratives

Julius

On leaving school, Julius (33 years) trained and practised as a spiritual healer within the Church of Saint John (pseudonym – Christian fundamentalist). Through this church, he joined a traditional healers' organisation, participating in a programme in which nurses taught its members how to look after people who have HIV/AIDS and TB. After a long period of illness, Julius tested and was diagnosed as seropositive, with a CD4 count of 16. At this point, he started ARV treatment. His family, who had cared for him during his illness, were very supportive when they learnt of his diagnosis:

My mother and younger sister would wash my clothes, cook me food, clean where I slept, and did everything for me. Being accepted by my family has meant a lot to me. I don't think I would have made it without them in my life.

Since recovering his health, with the support of his family and members of the church, Julius has been able to continue actively to provide practical and spiritual support to others. His HIV-positive status has strengthened this role:

Some people at church come to me to seek for advice. I disclose to them so that they know that they are not on their own and I encourage them to do things correctly. This also makes the discussion flow because we are all on the same platform.

From this base, Julius has the confidence to engage with health workers as equals, reprimanding those who do not treat him with respect:

Some shout at us without waiting for any explanation. I don't like to argue, but if it carries on, I tell her if she doesn't wait for my explanation I will report her to the sister in charge.

His confidence, derived from his social support, also helps him to view his treatment positively and to adhere to the regimen:

I always take my treatment on time because I know the consequences of not doing so. If it were to happen that I miss taking the tablets, I think it would be easy for me to tell the nurses and doctors, so that they can help me not to repeat this in future.

Julius's only source of income is a social grant from the government, provided to those disabled by chronic illness. He

depends on this to meet his basic needs, including the cost of transport to hospital to collect his medication:

The disability grant helps me to look after myself, allowing me to do things like buying clothes, assisting around the house, getting transport to the hospital. If they cut mine [grant], it would really be a huge problem. I am not working. I really don't know how I would survive without it.

The significance of the grant for Julius becomes clear when he criticises HIV support associations:

I was very ill. I went to a support group and asked them to come to my house to talk about issues related to this illness. I waited and waited but they never came, so I stopped going there. I also went there to ask for a food parcel. They told me that because I was getting a disability grant, I couldn't get it. This didn't go down well with me because I knew that others received food parcels even though they were getting a grant.

Julius now has no links with HIV support organisations and, as a further means of self-protection, he limits his social engagement to the safe environment of the church:

I don't have friends. The people that I regard as my friends are my elders at church.

Phanuel and Paulinah

Phanuel (35 years) left school at 16 years of age, and worked as a petrol garage attendant. He and Paulinah, his wife (33 years), have three children. After one child was repeatedly ill, Phanuel and Paulinah tested for HIV. Both were positive. Phanuel was also diagnosed with TB and stopped work. His initial response to his HIV-positive status was one of denial and anger:

Phanuel: I became angry with my wife, and started fighting with her. She also blamed me for sleeping around.

Paulinah: He was beating me.

Phanuel: I drank alcohol a lot during that time, trying to forget about the situation. The only thing I kept thinking about was death. I was losing hope in life because my child had passed away. This carried on for a long time.

A counsellor was close enough to the couple to be able to intervene:

There was a nurse at the clinic who knew our situation. She made me realise there is still life, and I must focus on getting better, and on my family. She used to come to our house to talk. After the sessions with her I came to be at peace with my wife and our situation.

Both Phanuel and Paulinah have spoken out during stigmatising conversations:

Phanuel: When my friends talked negatively about HIV, I'd tell them it didn't seem right when they haven't been tested themselves. We would then start a huge argument and they'd turn nasty. I decided not to tell my friends about my status.

Phanuel has lost friends as a result of this decision:

I decided to do away with them and to focus on my family, to look after my wife, child and HIV. I don't have friends anymore.

In contrast, Paulinah was open about her own status, as a way of resisting stigma:

I decided to be open about my status with my neighbour. She was always saying bad things about people with HIV, but I told her it would be nice if all the people who talked badly about HIV showed us their HIV-negative results. But none of those who talk badly have been tested. After this, it was fine, she doesn't judge (me).

By being open about her status, Paulinah established friendships with other HIV-positive people:

My neighbour now has other friends who are also HIV positive, so when they come to visit her I sometimes go there. It is very healing to talk with other people who are in the same situation. You feel accepted and you realise that you're not on your own.

Even so, the attitudes of others in their community have forced Phanuel and his family to move to another area where they are unknown:

I could see our neighbours knew about our status because of the car from the support group that used to drop food parcels at our house ...we decided to move from that community to start a new life (Phanuel).

Phanuel is also not able to talk about HIV with his extended family – his mother, he explained, was 'not comfortable' – nor at his church. He and Paulinah decided to tell their pastor about their status, but because people at church 'talk negatively about HIV', they decided to tell no-one else. The hospital waiting room, however, is a social space where Phanuel can talk freely:

I have met people in the hospital, but we don't keep in touch as friends would. We don't judge each other. We talk a lot about AIDS and this is a very huge relief.

Phanuel is working again, attends church regularly, and sees his immediate family, but no longer sees his friends.

Phosiwe

Phosiwe is 52 years old and was a factory employee. She had two children, but both died in the 1980s. For medical reasons, she had a hysterectomy in 1990. Her husband, who was not the father of her children, started an affair with another woman, who came to live with Phosiwe and her husband. Soon afterwards, her husband insisted Phosiwe leave. Forced from her home, Phosiwe stayed intermittently with her sister and an aunt, until she felt overwhelmed by their disrespect and insults, and decided to rent her own room. In 2001 she was admitted to hospital with TB of the spine:

I suffered a lot because I was worrying about where I was going to stay [crying]. My boyfriend asked a lady who we know to come and stay with me, so she could help me with the things that needed to be done. He couldn't do all the things himself as he was in and out of jail. He was a shoplifter and he was caught. He was trying to get money for us to survive.

Phosiwe was diagnosed with HIV in 2005. After her diagnosis, she withdrew and experienced a period of extreme grief:

I stayed (inside) for about a week, not saying anything to anyone. I kept on crying. My partner didn't see me crying because he was always out or was drunk.

As she recovered from depression, she began to resist internalising the stigma associated with HIV, and to ask for assistance:

I was feeling stressed for two months because my partner didn't care about me. But I could feel that it was eating me inside. I asked myself why I should worry about him. We all know that HIV is [a sickness] not for animals but for humans. Animals have their own illnesses that they worry about. I told myself that I must start accepting what was happening to me, and that I would be fine. I decided to tell my pastor and his wife. She sent her daughter to me, so that she could go with me to sign [as adherence supporter] for the ARV treatment.

Phosiwe disassociates her new 'good' identity from the 'bad' Phosiwe:

I've stopped drinking, fighting and being a bully. I don't need liquor, as it will affect my immune system. I just decided to go to church for spiritual upliftment.

Her partner denies the possibility that he may be HIV-positive. Phosiwe resists his denial with anger, and rejects his demands to have unprotected sex:

When he is drunk, he talks about HIV and insists that he isn't HIV-positive. He makes me angry. He doesn't want to go and have the test, but two of his girlfriends have passed away. When he is drunk he wants to sleep with me without using a condom and I don't allow that to happen.

Phosiwe is open about her status. She does not hide her need to take medication, and actively resists stigmatisation:

I am not scared of talking about HIV. I tell anybody who wants to listen, at church, in the train, anywhere. I don't want this to have a negative effect on my soul. There are those who still stigmatise. Last week a lady who I know saw me drinking my treatment. She gave a funny look, and I was, like, I don't care about you; as long as I am taking my treatment on time.

Phosiwe adheres to her treatment, and as a result benefits from a good relationship with the health workers:

I have never missed my pills. Once I took my evening pills late. The train was delayed and when I got home it was past 7 already but I took them anyway. I went to the clinic to tell them what happened. They said it was not bad, because it was only 20 minutes late. I get on well with the nurses, but when people don't take their treatment properly, they get angry and shout at them.

The social grant Phosiwe receives because of her HIV status supports both her and her partner. She also receives financial support from her niece, and has gained a purpose to her life by caring for her niece's child:

My niece plays a huge part in my life. She has asked me to come and help her in her house, cleaning and doing the washing, and she will give me money. My niece is the only person who does something for me now and again. Last time she bought me shoes and earrings. When I'm at [her house], I am at peace.

Losta

Losta (20 years) left school due to illness a year before she participated in the study. She had had two children, one of who died in an accident 2 years prior to the interview. She had separated from the father of her children, who was physically abusive towards her. Losta lost her remaining child to her parents, she presumes because they felt she was unable to care for him adequately:

My parents took my child and they are looking after him. My siblings all support my child as they are all working.

Losta had decided to test for HIV as she knew many others who were infected and were ill. Her response, as she represented it, was one of relief:

You know it was fine for me. Being positive didn't hurt at all. I was just happy I knew what the problem was.

But she has been unable to tell anyone, either close friends or immediate family, of her diagnosis:

My mother would shout at me. She doesn't believe HIV exists and she talks badly about people living with it. My father is a quiet person, and doesn't behave like my mother. I don't want to hurt him. I don't know what would happen to him if I told him. One of my older brothers once told us that if he heard that one of his sisters was HIV-positive, he'd kill her. I realised that my mother and my elder brother would never accept a person who was HIV-positive. That's why I have decided to keep it to myself.

Losta has internalised stigma associated with HIV. Her closest friend had died recently from HIV-related illnesses and complications, yet neither had disclosed to the other:

We used to talk about everything, even about HIV generally, but not about us living with it.

She lives alone at her sister's place, while her sister has moved in with her boyfriend. Her social grant, which she kept secret from her family as this would reveal her HIV-positive status, has recently been terminated.

Losta is ambivalent about taking medication:

Sometimes when I don't feel like taking my treatment, I don't. I can't take my pills with water, and if I don't have juice, I simply can't take them.

Losta consequently has a poor relationship with the health workers responsible for supervising her; their perceived lack of sympathy means that Losta has not spoken about her lack of social support and other problems:

They shout at us when we don't take our treatment, just like they did today. I wouldn't be able to say all these things I have said to you to anyone of them. They are strict with us, so we're scared.

Thandiwe

Thandiwe (41 years) has completed a computer skills course and a security-training course, but she is unemployed. She lives in a government-provided house with one of her children, whom she suspects of drug abuse and who is also unemployed. Her

other child is studying with support from a government bursary. Her husband died 8 eight years prior to the interview. After 4 years of poor health, she tested positive for HIV. She received a social grant initially because of her HIV status, but this has recently been stopped. Before Thandiwe received the grant, she stayed with her sister. Thandiwe's relatives ostracised her when they learnt of her diagnosis:

My cousin told me my relatives are all laughing at me. I was thinking that they were going to support me but they don't want anything to do with me. Nobody was willing to come to the clinic with me to sign for treatment. I had to beg my cousin to do that.

Like Phosiwe, her sister's children insulted her, 'saying things like *if I die they won't come to my funeral because I have AIDS*' – and so she left to stay elsewhere. Her repeated attempts to maintain contact with her family have failed:

I tried to phone my sister when I was ill but she put the phone down without hearing why I had called. I don't have any relations with my siblings [crying]. Neither my sister nor my brother care about what is happening to me. It hurts a lot. It's like they are in America but we all stay in the same area.

Thandiwe does not blame herself for this; she asserts that the fault is theirs:

I don't know what their problem is. I am not happy with this.

Thandiwe has little other social contact due to her fear of stigma:

I don't have friends. I think they'd talk behind my back about my status.

Old friends have distanced themselves from her, and since disclosing her status, she has been subject to insults from a neighbour:

She swears at me each time she sees me and tells everybody about my status.

Thandiwe does talk to other patients at the clinic, and she is able to visit a local counsellor whenever she is in need. However, her emotional distress makes adherence to medication difficult:

When I am stressed I forget to take my pills on time. I remember maybe after 30 minutes later.

Losing her grant, too, has jeopardised her ability to attend the clinic regularly to collect her medication, and so to adhere. The clinic is some distance, and walking makes her very tired.

Experience of diagnosis, stigma and resistance

We have, through these case studies, illustrated various responses to diagnosis – anger, violence, blame (Phaniel), withdrawal, grief and depression (Phosiwe), and avoidance of others (Losta, Thandiwe and Julius). We have shown the cost of disclosure: neglect (Thandiwe), verbal abuse (Phaniel, Paulinah, Thandiwe, Phosiwe), accusations and blame (Paulinah), and physical abuse (Losta, Paulinah), reactions caused by fear of a potentially fatal disease, betrayal and the disappointment of fractured relationships, reflecting the associated stigma.

Responses to stigma varied from passive acceptance to direct confrontation. Losta internalised a sense of shame that she would bring to the family. She felt unable to confront her mother or brother, and wished to protect her father from public shame associated with HIV, and so had not disclosed to anybody. Thandiwe, in contrast, despite ostracism by her family and considerable insults, resisted the idea of fault or responsibility (resistance thinking). Phaniel fluctuated between strategic avoidance and speaking out. Although he challenged the negative labels expressed by his friends (speaking out), he felt unable to disclose his status to the same friends (strategic avoidance). When others in the community knew of his status, he decided that the family should move to an area where they were not known (strategic avoidance). Paulinah, in contrast, revealed her status to her neighbour in order to confront negative labelling (active resistance), and as a result benefited from access to a group of HIV-positive people with whom to share experiences. Phosiwe resisted negative labels: *'HIV is a disease not of animals but of humans'* – and was publicly open about her status, happy to tell her story to anyone who would listen (activism).

Multiple disadvantaged and new identities

Gendered oppression is a common theme in these narratives: Losta's elder brother had reportedly threatened to kill any of his sisters should they be HIV-positive; Phosiwe's first husband started another relationship when Phosiwe could no longer have children; Phaniel was physically abusive of his wife Paulinah. In some cases the experience of more than one disadvantaged identity created greater levels of marginalisation, as in Losta's case (with gendered oppression from her boyfriend and her brother, compounded by her HIV-positive status). Yet despite desertion by her husband, neglect and stigmatising behaviour by close family members, Phosiwe was able to adhere to treatment. The effects of multiple marginalised identities appear not to compound necessarily (Meyer, Schwartz & Frost, 2008), and so the negative impact of stigma, resulting in delayed access to care and poor adherence to treatment, is not always predictable. Rather, individuals find meaning in certain domains of their

life through social roles that have value, and this provides them with the strength to resist stigma and so maintain their health and well-being. Phosiwe's 'new identity', derived from the assistance she is able to provide to her niece by helping with housework and childcare, gives her a secure basis from which to confront stigma. Julius' role as a counsellor within the church is strengthened by his HIV status, as he has a common experience with many of those who turn to him for support, and therefore the confidence to insist health workers treat him with respect. Losta, in contrast, has no role within her family, as her parents have taken away the responsibility of looking after her child, and she is unable to confront abusive health workers.

Motivational systems

Research on social stress has illustrated that people who consider themselves to be part of a larger whole, within which the needs of its members are equally important (an 'eco-system' motivation), are more likely to disclose, and to experience greater psychological well-being from doing so. Individuals more focused on their own needs (with an 'ego-system' motivation) are less likely to disclose and less likely to benefit when they do disclose (Garcia & Crocker, 2008). But as these narratives indicate, an event such as diagnosis with HIV is likely to shift an individual's attention towards his or her own needs (ego-system motivation). Phosiwe, for instance, withdrew from social contact for several weeks; Phaniel denied his status, and physically and verbally abused his wife. With the support of select individuals, both Phaniel and Phosiwe were able to express their emotions, make sense of them, and switch to more problem-focused/outward looking strategies to care for their health, and draw meaning from key social relationships. Phaniel drew on the support of his wife and a counsellor, became focused on the need to look after his family, and made strategic decisions as to when disclosure would lead to additional support rather than condemnation. Drawing on the support of her niece, Phosiwe decided to be open about her illness to prevent it 'eating her soul'. In contrast, Losta's social marginalisation, and possibly her relative youth, meant she had few resources with which to adjust to her status. Instead, in order to cope, she rendered the diagnosis meaningless:

You know it was fine for me. Being positive didn't hurt at all. I was just happy that I now knew what the problem was.

Yet her difficulties in taking the medicine suggest otherwise. Rather than a static categorisation of individuals (with either eco- or ego-system motivation), these narratives show individuals switching between inward and outward focus, with a minimum set of social resources being necessary to enable an outward focus. This in turn can yield further support.

Social support

Social support played a crucial role in many of the processes described above. Social support provided by family members had both practical and emotional dimensions. Julius's family, for instance, cared for him physically when he was ill, leading him to reflect that he wouldn't have 'made it' without them. Phosiwe, in contrast, lacked practical assistance and suffered considerable distress as a result. Social support was also critical to the ability of these participants to build a new, positive identity. Julius's personal confidence and his role within the church built upon the constant support of his family and specific church elders. The social support of a counsellor enabled Phaniel to see the benefit of accepting his status, and to change his behaviour towards his wife. Phaniel's and Paulinah's mutual support, and the support of other family members, provided them with a buttress against insults from friends and neighbours. In contrast, Thandiwe, rejected by her family despite her attempts to enlist their support and her access to counsellor, was unable to respond to insults and verbal abuse of her neighbours. Losta's isolation from her family and friends, and lack of social support, hindered her ability to disclose her status even to her closest friend, or to express her emotions associated with her HIV-positive status.

The lack of stable accommodation, experienced by Losta, Thandiwe and Phosiwe, is the outcome of unstable family relations and poverty. All three participants spent time dependent for food and accommodation on people with stigmatising attitudes. These circumstances exacerbate vulnerability, hindering both disclosure and ability to engage in more active resistance strategies. In addition, both Thandiwe and Losta were penalised by the health system as a result of their lack of social support: Thandiwe had to beg a cousin to sign as her treatment supporter so she could obtain treatment, and health workers' verbal abuse of Losta is the result not only of her poor adherence but also her social isolation, exacerbating the situation further.

Government grants play a crucial role in bolstering social support from family and neighbours, providing financial access to basic requirements such as rent, food and clothing for the unemployed, and meeting the costs of transport to the clinic, so facilitating adherence. Interviewees who were coping relatively well (Phaniel, Julius and Phosiwe) were all receiving a government disability grant. Thandiwe's grant had been terminated and she was struggling to obtain sufficient funds to travel to the clinic to obtain her medication, and so adherence was a problem. Losta had also just lost her grant. Both Julius and Phosiwe expressed extreme distress at the prospect that their grant might be discontinued.

Discussion

Re-working the conceptualisation of stigma

Stigma has been defined as 'a deeply discrediting attribute' that reduces a 'whole or usual person to a tainted or discounted one' (Goffman, 1963, pp.12-13). Stigma is not simply negative attributes, culturally constructed, mapped on to some individuals by others, but requires a language of relationships between 'legitimate' and 'spoiled' identities. It has to be 'conceptualised as a social process, understood in relation to broader notions of power' (Parker & Aggleton, 2003, p.16). 'Legitimate' identities are those accepted by cultural norms, introduced by the dominant groups or institutions of society; 'spoiled' identities do not conform or have in some way broken the norms. Although stigma is a social process, there is disagreement as to how inevitable discrimination is as an outcome. Link and Phelan (2001) include discrimination as part of the definition of stigma, and Holzemer's model and description encapsulates stigma as a one way process (stigma triggers, stigmatising behaviours, types of stigma, and stigma outcomes) (Holzemer, Uys, Makoae *et al.*, 2007). Deacon (2006) distinguishes the social process of othering, blaming and shaming, from the outcomes of this process (discrimination). She argues that poorer groups can stigmatise wealthier and more powerful groups, even if the attitudes cannot be enacted as discrimination. This can be argued more strongly. The data presented here have shown that the marginalised engage in everyday acts of resistance and negotiation over the labelling of HIV identities, and creation of new HIV-positive identities. For example, by asserting their rights to respectful treatment by health workers, participants are de-linking stigma and discrimination.

Differing strategies of resilience and resistance

The existing literature on resistance strategies in the face of stigma describe similar strategies to those identified in this paper. In an analysis of South African women's narratives of living with a spoiled identity, Rohleder and Gibson (2006) describe how participants transfer negative social representations associated with HIV onto others ('splitting off'), just as Paulinah criticises those who do not test. In her description of women's resistance to stigma associated with childlessness, Riessman (2000, p.130) argues that resistance requires that 'women's agency be palpable ... where women advocated for themselves and their marriages'. This might include refusing to internalise a negative label (resistant thinking), taking a stand in an interaction (speaking out or active resistance), or seeking public discussion or confrontation (activism), which is closely aligned to the strategies used by others engaged in social movements (Poindexter, 2005). On the other hand, strategic avoidance,

such as hiding one's medication or avoiding social contexts in which confrontation might occur, is more akin to resilience and strategies of survival rather than resistance (Kanuha, 1999). As we have illustrated, individuals use a range of strategies, often switching between active resistance and passive avoidance.

Kahn (2004) argues that experiences of stigma and responses are shaped by locally specific factors. In South Africa, the fluid and unstable structure of poor families, often straddling urban and rural locations due to pre- and post-apartheid migration patterns, results in complex, and often weak, social networks. These circumstances are very similar to those described by participants in this study. In such social conditions disclosure is less likely to occur within a small stable group, and the associated vulnerability limits the resistance and resilience strategies available to people living with HIV/AIDS (PLWHA), as seen in the experience of Losta, Phosiwe and Thandiwe above.

Managing stigma in the context of coping with an incurable disease

The particular context under consideration here – stigma associated with disease, rather than race (Howarth, 2006) or childlessness (Riessman, 2000) – means that responses by the stigmatised are part of a broader set of strategies individuals use to cope with illness. To understand the processes at work in individuals' lives, resistance to stigma should not be considered in isolation. Coping with a life long illness often involves a search for meaning, attempts to regain mastery or control over the illness, and efforts to maintain self-esteem (Becker, 1997; Charmaz, 1991; Frank, 1995; Taylor, 1983). There is a need to 'create order' through generating a new identity that includes the illness (Kralik, Koch, Price & Howard, 2004). In a study of the narratives of 12 South African women, Soskolne (2003) describes how participants forge a positive self-identity in the face of HIV as a defence against underlying anxieties. The author shows how participants vacillated through conflicting notions of disempowerment and empowerment, purity and contagion, strength and weakness, death and continuity, in attempts to cope with anxiety and to resist stigma. Similarly, in an analysis of the experiences of 34 British HIV-positive participants, Squire (1999, p.109) shows how the 'self in the interview operates, not as a consistent reflexive project, but as an occasional, situated resistance'. The narratives interpreted here similarly show that maintaining a new identity is intertwined with resistance, resistance that is sometimes active and assertive, but at times takes more passive forms of resilience. The narratives also illustrate that multiple disadvantaged identities do not necessarily compound one another, but are derived from the social context, and negotiated in complex and varied ways. New

identities are generated (or denied) as a result of being valued or supported by others, within the immediate family and in the broader social arena.

People living with HIV have to negotiate relationships that have been fractured by a sense of betrayal and sexual jealousy associated with a potentially fatal, sexually transmitted illness. In such situations they resort to various modes of engagement: problem-focused responses that are active and confronting, associated with better self-reported health status, psychological resilience and self-esteem (Miller & Cohen 2001; Remien, Rabkin & Williams, 1992); passive responses including avoidance and withdrawal as way of self protection (Lazarus & Folkman, 1984); and maladaptive responses which include 'focusing on and venting emotions' (Carver, Scheier & Weintraub, 1989). The narratives recounted here have shown that modes of engagement may change over time, switching away from the initial inward perspective, inevitable after diagnosis, to an outward/problem-focused response. However, not only is this shift assisted by a degree of social support, but it is more likely to yield further social support. Phosiwe's or Paulinah's pro-active responses to isolation (Phosiwe) and a neighbour's stigmatising comments (Paulinah) led to further positive social support.

Implications for interventions

In efforts to reduce stigma strategies include counselling and support groups aimed at empowerment at the interpersonal level; patient centred approaches within organisations; and rights-based approaches at community and government levels (Ehiri, Anyanwu, Donath, Kanu & Jolly, 2005; Heijnders & Van Der Meij, 2006). A review of intervention studies (aimed primarily at increasing tolerance amongst general populations, increasing willingness of health staff to treat PLWHA, and improving ability of PLWHA to cope with stigma) concluded that the impact was small and short term (Brown, MacIntyre & Trujillo, 2002).

Often encompassing different components, social movements, supported by government action with a rights based approach to health, can build communal resistance to stigma, structurally changing the context in which both individuals and communities operate as they respond to HIV and AIDS (Heijnders & Van Der Meij, 2006). This has been the aim of the Treatment Action Campaign (TAC) in South Africa (with its focus on the right to treatment, and its 'living positively' campaign) (Robins, 2005), and of similar social movements in Brazil, Australia and the US (Achmat & Simcock, 2007; Altman, 1994; Epstein, 1996).

Conceptualisation of stigma as a social process, framed by broader notions of power, makes clear the limitations of

interventions designed to provide more information about a particular illness to 'put right' incorrect beliefs, to increase tolerance by increasing empathy, or to reduce anxiety or fear on the part of the broader population, without confronting underlying social processes (Jewkes, 2006; Parker & Aggleton, 2003; Reidpath, Chan *et al.*, 2005; Varas-Diaz *et al.*, 2005;). These strategies need to be complemented by others built on an understanding of the factors that facilitate the agency of people to neutralise or resist stigma. Reidpath and colleagues (Reidpath, Chan *et al.*, 2005) argue that there is a fundamental need for societies to value individuals and groups, in order to provide a basis to determine group membership and allocation of social and material resources. As a result, interventions need to increase the social value of individuals, assisting the stigmatised to overcome the barriers to accessing resources, such that they are able to reciprocate, and so be of 'value' within a community.

Two examples provide evidence of this. Firstly, a project designed to assist farmers in West Africa affected by river blindness, enabled them to continue farming despite blindness, and so were no longer stigmatised and excluded from the community (Lewis, 2003). Secondly, an intervention to reduce internalised stigma amongst sex-workers in India developed the capacity of participants to deal with police raids, negotiate release after arrest, and to run an NGO to support other sex-workers. The result was an improved sense of entitlement due to their contribution to a section of society (Cornish, 2006). This present paper has also shown that identities or roles with social value are closely linked to resistance. Those participants able to find a meaningful social role (child care, counselling, supporting ones' family) were able to rebuild their self-esteem and were more likely to resist stigma, rather than using avoidance or passive strategies. Interventions that facilitate the development of meaningful social roles by the stigmatised are likely to increase their social 'value', enable social engagement between the stigmatised and stigmatising, as well as facilitating the resistance to stigma.

Conclusion

Stigmatisation needs to be conceptualised as a social process, understood in relation to broader notions of power, where the stigmatised have some degree of agency in the form of resistance. Multiple disadvantages and the identities that flow from them do not necessarily compound one another, however, but interact in complex ways, with individuals having varied access to social resources. Through different narratives of the experiences of living with HIV, this paper has shown agency (or ability to resist stigma) derives from a new role or identity with social value or meaning. Finding that new role requires financial (a source

of income, or financial support from friends and relatives), physical (such as accommodation), and social resources (such as emotional support and physical care while sick). If a person is dependent for any of these resources on family members with stigmatising attitudes, their ability to draw on these resources is constrained. Finding a new role also requires switching to an outward, problem-solving focus, itself requiring emotional support. Often a problem-solving focus and a new role can yield further support, leaving those with insufficient initial support trapped in social isolation.

Resistance to stigma is enabled both by the depth and breadth of social support available. In poor urban communities in South Africa, from which these participants come, both material and social resources are limited due to poverty, and exacerbated by unstable family relations, and broad, but weak social relations. Positive living is closely associated with better health outcomes (Douaihy & Singh, 2001), and mechanisms of support to people to resist stigma appears to be an important factor in this. Since the agency required to resist stigma is co-produced (requiring social support), it is the socially marginalised who have fewer opportunities to demonstrate their social value, who face the greatest risk of transmission, re-infection and failure to adhere to medication, and so require particular support from the health sector or community groups.

Acknowledgements

The research would not have been possible without the participants who shared their stories of the difficulties of living with HIV. We also wish to acknowledge Harry Nyathela, who conducted and translated the Sesotho interviews. The research was funded by the Canadian International Development Agency (CIDA).

References

- Achmat, Z. & Simcock, J. (2007). Combining prevention, treatment and care: lessons from South Africa. *AIDS*, 21 (Suppl 4), S11-20.
- Altman, D. (1994). *Power and community: Organisational and cultural responses to AIDS*. London: Taylor & Francis.
- Becker, G. (1997). *Disrupted lives: How people create meaning in a chaotic world*. San Francisco and Los Angeles: University of California Press.
- Campbell, C., Foulis, C.A., Maimane, S., & Sibiya, Z. (2005). "I have an evil child at my house": Stigma and HIV/AIDS management in a South African community. *American Journal of Public Health*, 95(5), 808-815.
- Carver, C.S., Scheier, M.F. & Weintraub, J.K. (1989). Assessing coping strategies: a theoretically based approach. *Journal of Personality and Social Psychology*, 56(2), 267-283.
- Castro, A. & Farmer, P. (2005). Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti. *American Journal of Public Health*, 95(1), 53-59.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, New Jersey: Rutgers University Press.
- Cornish, F. (2006). Challenging the stigma of sex work in India: Material context and symbolic change. *Journal of Community & Applied Social Psychology*, 16, 462-471.

- Dageid, W. & Duckert, F. (2008). Balancing between normality and social death: Black, rural, South African women coping with HIV/AIDS. *Qualitative Health Research*, 18(2), 182-195.
- Deacon, H. (2006). Towards a sustainable theory of health-related stigma: Lessons from the HIV/AIDS literature. *Journal of Community and Applied Social Psychology*, 16, 418-425.
- Douaihy, A. & Singh, N. (2001). Factors affecting quality of life in patients with HIV infection. *AIDS Reader*, 11(9), 450-4, 460-1, 475.
- Duffy, L. (2005). Suffering, shame, and silence: The stigma of HIV/AIDS. *Journal of Association of Nurses in AIDS Care*, 16(1), 13-20.
- Ehiri, J.E., Anyanwu, E.C., Donath, E., Kanu, I., & Jolly, P.E. (2005). AIDS-related stigma in sub-Saharan Africa: its contexts and potential intervention strategies. *AIDS Public Policy Journal* 20(1-2), 25-39.
- Epstein, S. (1996). *Impure science: AIDS, activism, and the politics of knowledge*. Berkeley and Los Angeles: University of California Press.
- Frank, A. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: Chicago University Press.
- Garcia, J.A. & Crocker, J. (2008). Reasons for disclosing depression matter: The consequences of having egosystem and ecosystem goals. *Social Science and Medicine*, 67(3), 453-462.
- Goffman, E. (1963). *Stigma. Notes on the management of spoiled identity*. London: Penguin Books.
- Heijnders, M. & Van Der Meij, S. (2006). The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychology, Health and Medicine*, 11(3), 353-363.
- Holzemer, W.L., Uys, L., & Makoae, et al. (2007). A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing*, 58(6), 541-551.
- Howarth, C. (2006). Race as stigma: Positioning the stigmatized as agents, not objects. *Journal of Community & Applied Social Psychology*, 16(6), 442-451.
- Jewkes, R. (2006). Beyond stigma: social responses to HIV in South Africa. *Lancet*, 368(9534), 430-431.
- Kahn, L. (2004). Experiences of HIV/AIDS diagnosis, disclosure and stigma in an urban informal settlement in the Cape Peninsula: A qualitative exploration. CSSR Working Paper. Cape Town, Centre for Social Science Research, University of Cape Town.
- Kalichman, S.C., Simbayi, L.C., Jooste, S., Toefy, Y., Cain, D., Cherry, C., & Kagee, A. (2005). Development of a brief scale to measure AIDS-related stigma in South Africa. *AIDS and Behavior*, 9(2), 135-143.
- Kanuha, V.K. (1999). The social process of "passing" to manage stigma: Acts of internalized oppression or acts of resistance? *Journal of Sociology and Social Welfare*, 26(4), 27-46.
- Kleinman, A. (1988). *Illness narratives: Suffering, healing, and the human condition*. New York: Basic Books, Inc.
- Kralik, D., Koch, T., Price, K., & Howard, N. (2004). Chronic illness self-management: taking action to create order. *Journal of Clinical Nursing*, 13(2), 259-267.
- Lazarus, R.S. & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Lewis, D. (2003). Conflict and disability, examples from Sierra Leone, disability in income poor setting. Australian International Health Institute Occasional Seminar. Melbourne: University of Melbourne.
- Lindsey, E., Hirschfeld, M., & Tlou, S. (2003). Home-based care in Botswana: experiences of older women and young girls. *Health Care Women International*, 24(6), 486-501.
- Link, B. & Phelan, J.C. (2001). Conceptualising stigma. *Annual Review of Sociology*, 27, 363-385.
- Makoae, L.N., Greeff, M., Phetlhu, R.D., et al. (2008). Coping with HIV-related stigma in five African countries. *Journal of Association of Nurses in AIDS Care*, 19(2), 137-146.
- Mason, C. (2006). Narrative research in health and illness. *Health, Risk & Society*, 8(2), 211-212.
- Mawar, N., Saha, S., Pandit, A., & Mahajan, U. (2005). The third phase of HIV pandemic: social consequences of HIV/AIDS stigma & discrimination & future needs. *Indian Journal of Medical Research*, 122(6), 471-484.
- Meyer, I.H., Schwartz, S., & Frost, D.M. (2008). Social patterning of stress and coping: does disadvantaged social statuses confer more stress and fewer coping resources? *Social Science & Medicine*, 67(3), 368-379.
- Miller, G.E. & Cohen, S. (2001). Psychological interventions and the immune system: A meta-analytic review and critique. *Health Psychology*, 20, 47-63.
- Mills, E.A. (2006). From the physical self to the social body: Expressions and effects of HIV-related stigma in South Africa. *Journal of Community & Applied Social Psychology*, 16, 498-503.
- Mohatt, G.V., Plaetke, R., Klejka, J., et al. (2007). The Center for Alaska Native Health Research study: A community-based participatory research study of obesity and chronic disease-related protective and risk factors. *International Journal of Circumpolar Health*, 66(1), 8-18.
- Nyblade, L.C. (2006). Measuring HIV stigma: existing knowledge and gaps. *Psychology Health and Medicine*, 11(3), 335-345.
- Olenja, J.M. (1999). Assessing community attitude towards home-based care for people with AIDS (PWAs) in Kenya. *Journal of Community Health*, 24(3), 187-199.
- Parker, R. & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science and Medicine*, 57(1), 13-24.
- Poindexter, C.C. (2005). The lion at the gate: An HIV-affected caregiver resists stigma. *Health & Social Work*, 30(1), 64-74.
- Pool, R., Nyanzi, S., & Whitworth, J.A. (2001). Attitudes to voluntary counselling and testing for HIV among pregnant women in rural south-west Uganda. *AIDS Care*, 13(5), 605-615.
- Reidpath, D.D., Brinjath, D., & Chan, K.Y. (2005). An Asia-Pacific six-country study on HIV-related discrimination: An introduction. *AIDS Care*, 17 (Supplement 2), S117-127.
- Reidpath, D.D., Chan, K.Y., Gifford, S.M., & Allotey, P. (2005). 'He hath the French pox': stigma, social value, and social exclusion. *Sociology of Health & Illness*, 27(4), 468-489.
- Remien, R.H., Rabkin, J.G., & Williams, J.B.W. (1992). Coping strategies and health beliefs of AIDS longterm survivors. *Psychology and Health*, 6, 335-345.
- Riessman, C. (1993). *Narrative analysis*. London: Sage Publications.
- Riessman, C. K. (2000). Stigma and everyday resistance practices - Childless women in South India. *Gender & Society*, 14(1), 111-135.
- Robins, S. (2005). Rights passages from 'near death' to 'new life': AIDS activism and treatment testimonies in South Africa. IDS Working Paper. Brighton, Institute of Development Studies.
- Rohleder, P. & Gibson, K. (2006). 'We are not fresh': HIV-positive women talk of their experience of living with their 'spoiled identity'. *South African Journal of Psychology*, 36(1), 25-44.
- Simbayi, L.C., Kalichman, S., Strelbel, A., Cloete, A., Henda, N., & Mqeketo, A. (2007). Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. *Social Science & Medicine*, 64(9), 1823-1831.
- Skinner, D. & Mfecane, S. (2004). Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Sahara J*, 1(3), 157-164.
- Soskolne, T. (2003). Moving beyond the margins: A narrative analysis of the life stories of women living with HIV/AIDS in Khayelitsha. CSSR Working Paper. Cape Town, Centre for Social Science Research, UCT.
- Squire, C. (1999). "Neighbors who might become friends": Selves, genres, and citizenship in narratives of HIV. *Sociological Quarterly*, 40(1), 109-137.
- Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*, 38, 1161-1173.
- Varas-Diaz, N., Serrano-Garcia, I., Toro-Alfonso, J. (2005). AIDS-related stigma and social interaction: Puerto Ricans living with HIV/AIDS. *Qualitative Health Research*, 15(2), 169-187.
- Whittaker, A.M. (1992). Living with HIV - Resistance by positive people. *Medical Anthropology Quarterly*, 6(4), 385-390.