

CENTRE FOR
SOCIAL SCIENCE RESEARCH

Aids and Society Research Unit

**Ties that Bind: HIV-Disclosure as
Consequence and Catalyst of Stigma
and Support in Households**

Elizabeth Mills
Brendan Maughan-Brown

CSSR Working Paper No. 266

December 2009

Elizabeth Mills is a DPhil candidate in the Knowledge, Technology and Society research team at the Institute of Development Studies, Sussex University.

Brendan Maughan-Brown, Ph.D. is a researcher at the AIDS and Society Research Unit (ASRU), University of Cape Town.

Ties that Bind: HIV-Disclosure as Consequence and Catalyst of Stigma and Support in Households

Abstract

Disclosure positions the HIV-positive individual at the juncture of stigma and support. This paper explores some of the factors that prompt HIV-positive individuals to disclose to members of their household through a close appraisal of disclosure as a consequence and catalyst of stigma and support for people living with HIV. The paper draws on both quantitative and qualitative research conducted between 2004 and 2008 in Cape Town, South Africa. The quantitative data come from two longitudinal surveys conducted in Khayelitsha, a township on the eastern periphery of Cape Town: a panel study conducted with a cohort of HIV-positive people on antiretroviral treatment and a second panel conducted with a control group comprising a matched sample of residents. The qualitative research includes participant observation and in-depth narrative interviews with thirty key informants and health care providers. The findings centre on two key aspects of disclosure within households: the process of disclosure, and the dynamics of disclosure, stigma and support. The quantitative findings indicate high levels of disclosure within households; we propose that this is a consequence of high levels of support and low levels of perceived stigma within families, notwithstanding higher levels of perceived stigma in the general population. The qualitative findings problematise some of the quantitative findings and indicate that disclosure was not only met with positive and supportive responses from household members, but that it has also catalysed stigmatising responses, particularly from parents within the household. These initial responses, however, shifted over time as individuals became more aware of the prevalence of HIV, and started to dissociate the virus from conceptions of promiscuity and death. The respondents in the qualitative study indicated a concern that disclosure would threaten supportive relationships among co-residential kin; in order to garner support and mitigate against stigma within their household, the respondents in the qualitative study first 'tested out' responses by disclosing to extended family on the periphery of their close social networks. This points to the nature of disclosure as an incremental process, rather than a once-off event. This paper argues that relationships within households are dynamic and change over time, and

therefore that the catalysts of disclosure also take new form within relationships in households, and in the broader community.

Introduction¹

“From a health policy perspective, an effective response [to HIV] across all levels centres on the creation of an enabling environment for disclosure of HIV status.” (Norman et al, 2005: iv).

Disclosure is closely connected to the management of HIV. It facilitates access to a range of public health, community and psycho-social resources to support people living with HIV (PLWH): disclosure has become an entry criterion for antiretroviral treatment programs that operate in resource-constrained settings; it facilitates adherence to complex treatment regimens; and access to state-funding, like disability grants, and social care, like home-based care, are dependent on disclosure. Disclosure does not only generate positive health outcomes for PLWH, however, it also catalyses stigma. Fear or experience of stigma disrupts the effective management of HIV as it undermines prevention, testing, access to treatment and adherence (Aggleton and Parker, 2003; Maughan-Brown, 2006a and 2006b; Mills et al., 2009; NSP, 2007).

Disclosure is not a generic ‘catch-all’ term to describe the act of informing another person of one’s HIV-status: it is a complex process that takes place in intimate spaces like bedrooms, kitchens and sitting rooms, within the context of relationships between parents, siblings and children, between partners and with friends. For some PLWH, disclosure may not take place in the context of interpersonal relationships, but may occur unwittingly in public spaces like clinics where people are identified by subtle indicators, like sitting in an area demarcated for people who wish to see HIV specialist doctors (Mills and Magazi, 2009). In this paper, we focus specifically on the dynamics and consequences of disclosure within the space of the household and in the context of relationships between family members.

In order to access psycho-social support, particularly as a precursor to initiating antiretroviral treatment, PLWH are encouraged to disclose to a member of their household. Disclosure may also catalyse discriminatory responses from

¹ The authors thank Colin Almeleh for his comments on earlier drafts of this paper. Colin Almeleh is currently completing his PhD at the University of Cape Town through the AIDS and Society Research Unit. He will expand on a number of issues discussed in this paper through his dissertation, drawing on the panel survey datasets.

household members. This paper explores how HIV-positive individuals make decisions around disclosure within households in order to access support and avoid stigma from other household members. We consider how disclosure decisions are informed by, and also shape, the structure of households and nature of relationships between household members in the context of South Africa's HIV epidemic. In particular, we explore two key aspects of disclosure within households. First, the paper draws on empirical research to highlight factors that inform HIV disclosure within households, and the ramifications of disclosure for PLWH. We argue that disclosure does not necessarily lead to positive outcomes, but that it positions HIV-positive individuals at the crossroad of potential stigma and support from household members, with broader ramifications on social interactions beyond the household. Second, the paper moves from looking at the consequences of disclosure to understanding the process of disclosure within households. We argue that disclosure does not occur as an 'event', but that it is a carefully managed series of social interactions.

We draw on the concept of 'stretched households' as it acknowledges the fluidity and porosity of household composition and denotes both those who 'eat from the same pot' and household members who are resident elsewhere for substantial periods of time, but who provide and draw on household-resources and are connected through extended social-networks (Jones, 1993; Ross, 1995; Spiegel and Mehlwana, 1997; Spiegel, Watson, & Wilkinson, 1996). Acknowledgement of household fluidity and porosity does not sufficiently account for the dynamics of household composition; in the context of South Africa's HIV epidemic, research points to strategic shifts in household dynamics in order to maximise scarce resources, like social assistance grants, and to manage AIDS morbidity and mortality (Neves, 2008; Ross, 2003; Seekings, 2008). We use the term 'household' to denote kinship-networks given that the households in which the research respondents resided were comprised almost entirely of family members. Like households, kinship networks are dynamic and as such, families cannot be conceptualised as homogenous or bounded units of social analysis. The White Paper for Social Welfare (1998) defines families as fluid, taking on multiple forms: "The social, religious and cultural diversity of families are acknowledged as well as the effects of social change on the nature and structure of families." (South African Law Commission 1998, Glossary).

Households and the relationships within them comprise the empirical and theoretical focus of this chapter for a number of reasons. First, chronic illness does not simply affect the HIV-infected individual; illness has a range of social, material and financial ramifications on the household members with whom HIV-positive people reside (Almeleh, 2006; Neves, 2008; Seekings, 2008). Second,

as described above, the successful management of HIV is reinforced through supportive relationships within the household particularly given the stringent adherence requirements placed on PLWH within antiretroviral treatment programs. Third, and conversely, experiences of stigma from household members may prompt reconfigurations of relationships within the household and shifts in household composition. These factors are explored in greater detail in the empirical section below.

Accordingly, this paper explores the interplay between stigma, support and disclosure in the households and families of a set of HIV-positive people living in Cape Town. The following section details the qualitative and quantitative research methods, followed by a description and analysis of the key research findings. Quantitative analysis of panel survey data, conducted among a group of HIV-positive people on highly active antiretroviral treatment (HAART) living in Khayelitsha, Cape Town, indicates high levels of disclosure to household members. We consider some of the factors that may account for high levels of disclosure, including the respondents' perception and experience of stigma and support from families following disclosure. Longitudinal data from this 'HAART survey' as well as from a second control survey indicate a dissonance between experiences and perceptions of stigma from co-resident household members and at the level of the community. This points to the analytical importance of differentiating between *perception* and *experience* of stigma and support, and the value of distinguishing between relationships that PLWH have with family and household members, and the relationships they may have with non-kin in the broader 'community'.

Thereafter, we explore two linked dynamics of disclosure using qualitative data that contribute to a more nuanced understanding of the intersection between stigma, support and disclosure within households. First, the discrepancy between high levels of perceived stigma and low levels of experienced stigma among PLWH in the quantitative study correlates positively with high levels of support from family members. This indicates that disclosure may be both a consequence and a catalyst of support within the household. Second, the qualitative data reinforce the importance of understanding disclosure as a process rather than an event. Specifically, the qualitative data point to a selective and incremental process of disclosure that can be understood as a spiral: the respondents 'test out' their disclosure on individuals whom they trust, but whom are sufficiently removed from their immediate locus of personal and material safety. This spiral process can move in to the family, or out from the family to the broader community. The important aspect of this model is that it indicates a 'testing out' process through which PLWH develop a confidence in a response – either positive (support) or negative (stigma) – which influences whether or not, to

whom, and how they subsequently disclose their status. We argue that in addition to understanding the process of disclosure, it is also important to consider disclosure in relation to social processes of exclusion and inclusion and to recognise the dynamic nature of stigma and support as they change within relationships and over time.

Methodology

This chapter is based on qualitative and quantitative research conducted in Cape Town between 2003 and 2008. In 2004 the AIDS and Society Research Unit commenced a panel study with a baseline sample of 242 individuals on highly active antiretroviral therapy (HAART) and living in Khayelitsha (henceforth referred to as the HAART Study). This survey was administered again with the same individuals in 2006 (n = 224) and 2007 (n = 217). The HAART Study sample consists of two-thirds of all individuals who participated in the first pilot HAART programme in South Africa that was launched by Médecins Sans Frontières (MSF) in collaboration with the Western Cape Provincial government in May, 2001 in Cape Town's largest informal urban settlement – Khayelitsha. (For more details about the history, selection criteria and clinical outcomes of the programme see: Coetzee *et al.*, 2004a, 2004b; Médecins Sans Frontières *et al.*, 2003). As this study uses a sample from the MSF HAART pilot programme, it is important to note that – as is the case with most HAART programmes in developing countries – the vast majority of those who participated in the programme were women. There was thus an element of selection bias in the programme.²

The HAART Study cohort is thus particularly well situated for an assessment of patterns of disclosure within families and households, and experiences and perceptions of stigma amongst individuals who, on average, experienced a period of serious illness before they started HAART, had their health restored by treatment, and have now been living for a relatively long time on HAART.

For the purpose of comparison with the general population, a control panel survey was conducted with a sample of individuals living in Khayelitsha in 2004

² The overrepresentation of women may reflect the fact that health-seeking behaviour is socially constructed and constitutive of gender identity: gendered norms make it difficult for men to admit any health-related weakness and seek medical attention (Mills *et al.*, 2009; Nattrass, 2008). Further, at the time of the pilot, pregnancy appeared to be a primary determinant of a person participating in voluntary counselling and testing. This would have contributed to greater participation of women by virtue of more women knowing their HIV-status (Coetzee & Nattrass, 2004).

(n = 566), with the second and third waves conducted in 2005 (n = 535) and 2007 (n = 517) respectively. This study is referred to as the Khayelitsha Panel Study (KPS). Both surveys collected data on a range of issues including the impact of HAART on economic activity, perceived and experienced HIV-related stigma, health-seeking behaviour, sexual relationships and disclosure.

Qualitative research was conducted parallel to the panel surveys between 2004 and 2008. It comprised ethnographic participant observation and semi-structured narrative interviews. The ethnographic fieldwork took place in Nyanga, an older township than Khayelitsha, and less distant from the centre of the city. It was conducted with a home-based care organization that provided care for PLWH who were unwilling or unable to access public health care. In addition to participant observation, thirty narrative interviews were conducted in townships in the Cape Peninsula with PLWH, home-based carers, traditional healers and medical doctors in order to gather information on understandings of illness, health, medicine, health seeking behaviour and the interaction between health care providers and PLWH.

Quantitative Findings: Disclosure among Individuals on HAART

Survey data from the 2007 HAART Study indicate that the respondents lived in households that were comprised almost entirely of (close and extended) family members. The majority of the members were the respondent's biological parent (7%) or child/grandchild (41%), sibling (17%), spouse/partner (13%), or nephew/niece (10%). The average household size was 3.76 people. Participants in the 2007 HAART Study resided in households in which the majority (70%) of the other household members knew the participant's HIV status. The respondent had personally disclosed to 96% of these people, which suggests low levels of involuntary disclosure.³ The majority of the respondents initially disclosed (the first four times) to their spouse or partner, biological parent or biological sibling. Consistent with qualitative findings by Almeleh (2006), initial disclosures, on average, took place when individuals were extremely sick (just before they started HAART) and needed help and support. The respondents noted that, in most incidences, people reacted positively to initial disclosures and provided support. However, several respondents reported negative reactions to these disclosures. This was especially the case among spouses or partners, a significant minority of whom terminated their relationship with the respondent. In a few instances, people initially reacted negatively to the participants HIV-

³ Involuntary disclosure denotes disclosure via a third party.

status disclosure but subsequently provided support. This highlights the fluid nature of relationships and the evolution of responses over the course of the relationship.

Gender and age differentials between the respondents and household members influenced disclosure patterns in the survey. The majority of the respondents first disclosed to their mothers or sisters, indicating that gender plays a role in the sequencing of disclosure decisions among this cohort. Age differentials also shaped patterns of disclosure to family members. As described above, almost everyone had disclosed to their co-resident spouse or partner, and their biological parents. Most participants had also disclosed to their brothers and sisters, but only about half had disclosed to their children or nephews and nieces with whom they shared a home. There was a strong positive correlation between disclosure and the age of the children, grand children, nephew and nieces: approximately 93% of adults in the household knew the respondent's HIV-status and the majority of household members who did not know the participants HIV-status were younger than 10 years old. Men in the HAART cohort had disclosed to a slightly greater percentage of household members than women. Participants were more likely to disclose to women in the household than to men.

The survey findings therefore indicate that the households in which the HIV-positive respondents' lived comprised almost entirely of family members and that the respondents had disclosed to a large majority of the adult household members. The following discussion explores some of the factors that may account for high levels of disclosure within these households.

Factors that Shape Disclosure: Locating Stigma and Support in and beyond the Household

This discussion considers factors that may inform disclosure within households from the perspective of HIV-positive individuals from the HAART Study. Findings from the HAART Study iterate the importance of identifying specific social environments in which disclosure decisions take place: the respondents report different perceptions of stigma and support in their household compared to the general social environment beyond their household and family. In order to explore some of the underlying factors for the high rates of disclosure in the HAART Study, it is necessary to distinguish between experienced and perceived stigma in the general community and within the household. We contrast the

perspectives of PLWH (from the HAART Study) with perspectives of the general population (from the Khayelitsha Panel Study), and find that perceived and experienced stigma differ across the two sample groups, which may account for high rates of disclosure within households in the HAART Study.

The HAART Study cohort reported that prior to 2004 extreme experiences of stigma were uncommon. Reporting on the consequences of disclosure to non-family members, 10% agreed that they had lost friends, 4% that many people avoided them and 6% that they had been treated with less respect. A larger proportion of respondents (36%), however, reported that people say unkind things behind their backs because they are HIV positive. This suggests that subtle manifestations of stigma are more pervasive in the lives of PLWH than overt forms of discrimination, like loss of friendship or avoidance. This is consistent with qualitative research from Cape Town indicating that gossip is the most common and hurtful form of stigmatising behaviour in the general population (Almeleh, 2006; Mills, 2006).

In contrast to stigma experienced beyond the family – which was not pervasive, but still reported by a significant minority – very little stigma was reported from within the family.⁴ Only 2% of participants agreed that family members and friends had treated them badly, and only 3% disagreed that when HIV made them very sick their close family members were willing to take care of them. This is consistent with the reported reactions from people to whom the participant initially disclosed their HIV-status. It is also consistent with qualitative work conducted in Soweto: Skhosana *et al.* (2006) found that individuals who had disclosed to members of their family were largely supported at the household level.

Measures of perceived stigma added to the emerging picture of general support from family members. Perceived stigma refers to the degree to which a person believes that HIV-positive individuals live in a stigmatising environment. This perception may result from personal experiences of stigma-related prejudice and discrimination, but is usually a product of social learning and exacerbated by reported incidents of stigmatising experiences (Scambler and Hopkins, 1986). There were low levels of perceived stigma within the family, which was generally believed to be supportive: the majority of individuals (62%) agreed, only 2% disagreed and the rest “neither agreed nor disagreed” with the statement “most people with HIV are supported by their families when they disclose their

⁴ It is noted that the term ‘family’ is used very loosely in these questions. It is therefore difficult to interpret which specific family members the respondents are referring to when answering the questions.

HIV status”. With respect to gender, a slightly greater percentage of men (67%) than women (61%) agreed with this statement.

Measures of perceived stigma among the general population of Khayelitsha indicated similarly high levels of support from family members: 80% of the KPS participants agreed that “most people with HIV are supported by their families when they disclose their HIV status”. Furthermore, the perception that families are supportive has increased over time: by 2007, a greater percentage of participants in both the HAART Study and KPS reported they believed that most people with HIV are supported by their family.

In contrast, stigma from ‘outside the family’ was perceived as pervasive. Although only a small percentage of the HAART Study participants reported experiencing stigma, the majority perceived most PLWH to live in a stigmatising environment.⁵ Most respondents agreed that people with HIV often get treated unfairly or badly by others (57%); and that people say unkind things about HIV positive people (67%); and almost a third agreed that most people prefer to avoid people with HIV as much as possible (30%).⁶ Perceived stigma in the Khayelitsha Panel Survey, with the general population, was more pronounced than in the HAART study.⁷ In 2007, 35% of the HAART Study participants reported that they currently try and keep their HIV-status hidden; as these participants had disclosed to almost all co-resident adult kin, it follows that they concealed their status from members of the general population. This highlights the importance of conceptualising different contexts in which disclosure occurs. As noted in other research, high levels of perceived stigma likely remains an obstacle for wider disclosure beyond the confines of the household (Skhosana *et al.*, 2006).

Returning to the household level data, not only had participants disclosed their HIV-status to almost all adults in the household, but only 3 respondents reported an unsupportive response from a household member. The high rates of disclosure to household members among the survey respondents may therefore

⁵ The discrepancy between individually experienced stigma and perceived stigma has emerged in findings from South India, where 97% of HIV-positive respondents reported perceived stigma, but only 26% reported actual experiences (Thomas *et al.*, 2005). Although the disjuncture was less pronounced in a study in the United States, it was also evident with 89% of the sample of young PLWH expressing perceived stigma but only 64% reporting individual experiences (Swendeman *et al.*, 2006).

⁶ For each of these questions, the majority of the other responses again fell on the ‘neither agree nor disagree’ option.

⁷ In 2004, the majority of KPS respondents agreed that people with HIV often get treated unfairly or badly by others (67%); that people say unkind things about HIV positive people (72%); and that most people prefer to avoid people with HIV as much as possible (64%).

be connected to the perception that families are more supportive and less stigmatising than the general community in which they live: there is a general recognition that stigma exists, but that it exists ‘out there’ in the lives of others. High levels of disclosure among PLWH in the HAART Study may be a consequence of the perception that families are largely supportive rather than stigmatising of PLWH following their disclosure. In this case, disclosure is connected to low levels of experienced stigma, and high levels of both experienced and perceived support among family members, who also constitute the households in which the respondents reside.

Although the pattern of higher levels of disclosure in households compared to other contexts is most likely generalisable across South Africa, the extremely low levels of stigma within the HAART Study households is probably not. Individuals in this study have been dealing with issues of disclosure for considerable lengths of time. Through MSF trial and the support groups (to which the majority belong) participants have had substantial support with these issues. In addition, residents of Khayelitsha – by virtue of living in the site of the first pilot HAART programme in South Africa – have had far more exposure to HIV-campaigns and HIV-related services than is the case for the average South African. The current composition of their household is therefore likely to be the culmination of a long process during which some individuals who initially reacted in a stigmatising way have become supportive and remain part of the household, while those who remain stigmatising no longer reside with the stigmatised HIV-positive individual (perhaps because the HIV-positive individual him- or herself moved out to a different, non-stigmatising household when faced with stigma). The apparently supportive environment in these households may therefore reflect a positive outcome of long-term HAART and accompanying services.

Qualitative Findings: The Process and Consequences of Disclosure in Households

This paper recognises the importance of contextualising research findings drawn from both quantitative and qualitative data, and points to areas of convergence and dissonance across the two sample groups. These distinctions may be a function of different research methodologies but they also point to empirical differences across the sample groups. For example, and as noted above, the respondents in the HAART Study were able to access psycho-social and biomedical support through the MSF trial, and this same level of support may not have been available to the general population who also lived in peri-urban

areas in Cape Town (in the KPS Survey and in the qualitative research). This paper does not aim to develop a direct comparison across the qualitative and quantitative data; instead, by exploring and contrasting the different sets of findings in the datasets, this paper aims to extend and deepen our understanding of the complex relationship between stigma, support and disclosure in households.

The qualitative research extends the quantitative findings on disclosure in households in two ways. First, the case studies presented below indicate that the HIV-positive respondents experienced a wider range of stigmatising responses from household members than reported by the HAART Study respondents. Fear and experience of overt and subtle stigma within and beyond the household prompted a set of pre-emptive actions to minimise further stigma following disclosure to other community and family members. Second, the nature of quantitative research is such that it can numerate events like disclosure to a household member, and can point to correlations between stigma, support and disclosure based on responses to a set of close-ended questions. The contours of the this ‘bigger picture’ are further defined through the qualitative research findings; they indicate the subtle processes of negotiation that were involved in the respondent’s decision to disclose, along with the range of consequence of disclosure on the respondents’ experience of support or stigma from household members. Although these findings cannot be generalised, they offer insight into the complex processes entailed in disclosure and they reiterate the importance of understanding disclosure as an incremental process that is inextricably connected to relationships within and beyond the household.

This paper suggests that in addition to conceptualising disclosure as incremental, it may also be useful to understand disclosure as a spiral in which the respondents ‘test out’ disclosure. This approach enables PLWH to manage the possible negative consequences of disclosure on their personal identity and they do not threaten the status quo of important social relationships. The process of testing out process recognises the instrumentality of disclosure in order to access particular resources, which range from emotional support, to material/financial sustenance and palliative care. The nature of disclosure as both incremental and instrumental can be mapped on to a continuum across a range of social relationships, and as such, we draw on the concept of ‘spiral disclosure’, to denote this process,.

The quantitative findings indicate that the respondents felt a greater level of support from their families than from their friends and acquaintances. This perception maps on to the quantitative findings around stigma, with the HAART Study respondents reporting higher levels of experienced stigma within the

broader community compared to reports of overt and subtle forms of stigma within their family. Mzimazi, a 41 year old HIV-positive volunteer for the Treatment Action Campaign (TAC), offers a different perspective on the factors that informed the process of his disclosure. Because he derived significant support from the family members with whom he lived, Mzimazi was also most concerned about disclosing his HIV-status within his household as it may jeopardise these supportive relationships. He describes a disclosure process in which he ‘spiralled in’ to eventually disclose to the family with whom he lived: his mother, sister and niece. Mzimazi required psychosocial support from extended family in order to reassure him that these peripheral, but supportive, relationships would not be jeopardised as a result of his disclosure. Further, as he ‘spiralled in’ through a series of disclosures to one family member, and then another, he established supportive kinship network around a particular aspect of his identity – his HIV-positive status – that, he hoped, would enable him to risk the potentially negative consequences of disclosure to his close family in his household. The following quote indicates the iterative disclosure process of ‘spiralling in’ from peripheral kinship networks to the intimate space of his household and family:

“I was thinking about whether or not I should talk about my status. Then I phoned my cousin and told her about my problem and she said ... I must come to her place so that we can sit and talk about this. She suggested that I also go to her sister and speak to her, so I went there and we had a chat. I was scared to tell her about my status but I eventually told her. She supported me and gave me advice... So she advised to disclose my status to my family, but I did not want to tell them before I met my cousin [again]. So I went to my cousin over the weekend, she explained to me and supported me.” (Interview with Mzimazi, 2006)

This perspective corresponds with the quantitative research because it highlights the value of support derived from family members. However, Mzimazi’s disclosure to the family members of his household diverges from the quantitative findings. The quantitative findings note higher levels of support within the household and family compared to the general community, which correspond with the perception that stigma exists ‘out there’ in the community, but not at the level of the family.⁸ Mzimazi met with greater support from his

⁸ As noted above, the differences across the two sets of data may be a result of the different sample groups; we acknowledge that we are drawing on two different sets of data, and aim to highlight some nuances across the findings, rather than to compare them directly. The survey respondents had been on HAART for an average of 4.5 years by 2007 and may have moved through a spiral process of disclosure during this time. We do not have data preceding this

extended kin compared to the family members with whom he shared a home; this indicates the value of understanding the dynamics of family network in which the HIV-positive individual is located within and beyond the context of the household. After ‘testing out’ disclosure responses from his extended family, Mzimazi decided to disclose to the family members with whom he lived:

“My mother said to me, ‘Mzi, I can see that you have not been yourself since you came back from hospital and you did not tell us what is bothering you.’ I said, ‘Heh! Ma let me tell you the truth... I have HIV. Eyi my mother was shocked! I would say that’s where the stigma started at home... Especially my sister and her daughter because after I told them they started treating me differently and badly: I had to use separate utensils from those they were using. I could not do anything at home. So I felt very bad about the way they treated me. And my mother likes her granddaughter very much, so my mother sided with them.” (Interview with Mzimazi, 2006).

Although he had received supportive responses from his extended family, Mzimazi’s fear that he would jeopardise the support he derived from his intimate family relationships was accurate. He describes the overt nature of the stigma he experienced – separation of eating utensils - as painful. Stigma is layered, and also extends to a sense of betrayal, particularly when a supportive relationship changes shape following disclosure to a relationship characterised by mistrust. This sense of betrayal can operate across both individuals in the relationship dyad, but given that our research centres on the perspective of the HIV-positive respondent, our findings point to the experience of betrayal from their perspective. For example, in addition to the overt discrimination Mzimazi experienced in his household, he also expressed a deep sense of betrayal from his mother as she ‘sided’ with his sister and niece against him. These experiences suggest the layers of stigma that operate to reinforce secrecy, and the consequences of disclosure for relationships within and beyond the household. Mzimazi’s disclosure prompted support from his extended family, but it catalysed a set of deeply hurtful responses from the family with whom he lived. His experience of stigma within the household confirmed Mzimazi’s fear that disclosure would threaten rather than reinforce the supportive relationships he held with his close family in their shared home.

Mzimazi’s experience of stigma, and his sense of betrayal following his mother’s decision to side with her daughter and granddaughter, compelled him to move out of the house he was living in:

sample’s commencement on HAART, and therefore cannot deduce further information regarding the history of the quantitative respondent’s disclosure process.

“I was not happy at home and I decided to move out. I am living on my own for two years now. I rent a shack for R50 a month. Things are better now because I joined a support here in Mbekweni, so I gained more information about HIV from people who came from TAC, ARC, so they often come and run workshops.”

As a consequence of the process of ‘spiral disclosure’, Mzimazi was able to draw on a wide network of support that, importantly, extended beyond his household and his immediate family members to the broader activist community and his extended family, including his cousin and her sister. Both the support from his extended family and community networks, and the experience of stigma within his initial household, prompted Mzimazi to leave his home and live on his own. In this respect, the experience of stigma from household members resulted in a change in the household composition; in addition to the quantitative shift in household composition, the nature of the relationships between Mzimazi and both his close and extended kin also changed shape following his disclosure.

Households are not only about the technical dimensions of composition and space: they are also about the relationships that are built between people within and beyond these spaces. Mzimazi entered in to a new set of supportive networks with non-kin and extended family: these relationships were significantly shaped around the testing out process of spiral disclosure which catalysed support networks based on his HIV-positive status. The negative outcomes – particularly stigma and deep betrayal – also had positive ramifications for Mzimazi as he was encouraged to actively draw on alternative sources of support in his community, through the TAC for example. As Mzimazi developed a sense of confidence in the positive ramifications of the disclosure process (like accessing support networks) he was able to support other HIV-people initiate their process of disclosure to their families and household members.

Disclosure is inherently instrumental; as discussed above, disclosure facilitates access to a range of public health resources, like antiretrovirals, that are important for the effective management of HIV. Earlier studies indicate that PLWH disclose because they need, or anticipate needing, significant help and palliative care (Almeleh, 2006). The research on which this paper is based took place almost four years after the commencement of the HAART roll-out and for all the qualitative respondents their disclosure was pre-symptomatic of AIDS illness and not impelled by a fear of serious disease or imminent death. As HIV is transformed from an acute series of ailments to a chronic manageable condition, the perceptions and associated behaviours around disclosure, stigma

and support, also undergo a transformation. As such, the instrumental nature of disclosure changes shape.

We suggest that instrumentality through disclosure persists, but that the nature of this instrumentality extends to subtle forms of exchange. Mzimazi's 'spiralling in' process of disclosure enabled him to access support from his extended family, and later, from community networks like the TAC. Like Mzimazi, Dolly chose not to disclose to co-resident kin when she learnt of her HIV-positive status. Dolly is a 43 year-old HIV-positive woman and lives with her two children, her parents and sister. Dolly's disclosure to her sexual partner and non-kin with whom she does not live was motivated by a form of instrumentality: in exchange for being open about her status, she hoped that these individuals would agree to have an HIV test. Her disclosure was intended to serve a purpose, and as such, it was instrumental. The nature of her relationship with her sexual partner, however, may have prompted her disclosure for a range of other reasons (including the prevention of HIV-re-infection through unsafe sex), but these further motivations are not evident in the narrative interview.

Unlike Mzimazi, Dolly was not concerned that her close family would reject her following her disclosure, but that they would associate HIV with death, and feel sorrow in anticipation of her death. After living with HIV for two years, Dolly felt able to challenge her family's perception that HIV caused immediate death by proving to them that she had been healthy, and HIV-positive, for a lengthy amount of time:

"The people that I did not tell immediately are my family, I thought about how they would react on receiving the news. I was not thinking that they might treat me badly but I was thinking that they would be very worried and think that I would die. So I told them after two years. They don't have a problem." (Interview with Dolly, 2006).

Dolly was met with unequivocal support following disclosure to members of her household and family. This support took a number of different forms, from encouraging her to visit the clinic when she became ill, to looking after her children, washing her clothes and purchasing medicine and arranging for Dolly to see a private doctor:

"After I had told my family I felt like I had shaken something off my back and realised that my family and I are carrying this together. Do you understand? If I am not feeling well, my family does not like to see me lying in bed. They get worried and they advise and encourage me to go to the clinic the next day... My sister has medical aid. When I am not feeling well she asks me what medication she can buy or ask

if I wanted to see a doctor. When I am sick my family looks after my children and they do my laundry.” (Interview with Dolly, 2006).

The timing of disclosure to household members emerged as an important finding in Almeleh’s (2004) research with HIV-positive people living in Khayelitsha. Disclosure timing was linked to the respondents’ concern that they would become seriously ill and require a range of different levels of support - physical, financial, emotional – from members of their household (ibid). The findings from the qualitative component of this particular study indicate that disclosure continues to be carefully timed, but that this timing is not motivated by a fear of imminent illness; in this study, disclosure to household members took place when the HIV-positive respondents were pre-symptomatic. In fact, it was important for Dolly to maintain her health for a substantial period of time as a form of ‘proof’ for her family that she would not become sick and die prematurely. The instrumentality of disclosure persists across this study and connects with a range of other studies in the region, as discussed below. Dolly disclosed to non-household members, like her sexual partner, in order to motivate them to test for HIV. Her subsequent disclosure to her family was not for the purpose of instrumentally accessing a greater degree of support, but her family was able to provide tailored care and support to her when they understood the particular pressures of living with HIV as a chronic illness.

Dolly has become an icon in her community: a symbol of ‘living positively’ and managing HIV through disclosure to her family. Her disclosure catalysed support, and this dynamic within Dolly’s household is perhaps one case that informs the perception among the survey respondents that families are generally supportive of PLWH:

“Many people in my area know about my status so much that parents wish their children could be like me and open up. Some parents are maybe living with a child who is HIV positive and the child doesn’t want to disclose to the family. It [HIV] is a subject that’s never talked about between a child and a parent. So some parents wish their children could open up and share their status with their parents. There are other people who come to my house and ask for my advice because I am open about my status... Like a parent with a child who has HIV comes to me and ask, when this happen what must I do.”

This quote points out that a discontent also exists around non-disclosure, or more specifically, around the wish to gain clarity and offer support to family members, like children, who may be HIV-positive, but unwilling to disclose. A subtle sense of shame, and internalised rather than perceived or experienced stigma, may discourage individuals from disclosing their status. Further research

is required to explore interconnections, and dissonance, between perceived stigma ‘out there’ and shame; each may operate independently, while both deter disclosure. Or stigma may fuel individual shame, and vice versa, which reinforce secrecy and undermine disclosure. This quote also indicates challenges entailed in inter-generational disclosure, and the desire of parents to seek clarity and openness with their children, but also the difficulties that preclude parents from precipitating disclosure with their children. Below, we discuss Bongani’s experience of disclosing to his parents, and his story complements Dolly’s quote above, as it sheds lights on some of the difficulties children may have when choosing to disclose to their parents.

The ‘elephant-in-the-living-room’ scenario, where HIV is privately known but publically hidden, may reflect deeper social conventions in inter-generational relationships around a reluctance to discuss sex, and its moral successors: sin and shame. It is interesting to note the parent’s desire to support their children while not insisting on disclosure; this dynamic offers scope for further research into the factors that maintain the silence that is built around HIV. The dynamics of inter-generational disclosure of HIV and discussions around sex play a role in shaping the nature of relationships within households, particularly those households in which parents and children are co-residents.

The difficulties entailed in disclosure of HIV across generations, and particularly within the household, emerged in the interview with Bongani, a 44 year old HIV-positive man, who lives with his parents in Khayelitsha. Unlike the inter-generational dynamics that Dolly refers to in the quote above, Bongani states that he did not equivocate on whether or not to disclose his status to his parents and extended family members. His disclosure was met with support from his mother and other family, but his father was initially angry that Bongani had ‘brought the disease in to his house’:

“After I was diagnosed I was not accepted by my father. You know it’s hard for an elderly Xhosa man to understand these things. He used to treat me negatively and said I brought diseases to his house. You will remember that before HIV was interpreted wrongly and associated with promiscuity”. (Interview with Bongani, 2006).

The correlation between HIV and promiscuously informed his father’s initial response to his son’s disclosure and the excerpt also connects to a perception of HIV as a pollutant that soils the home. By linking HIV with promiscuity, Bongani’s father refers to them as both inextricably connected and equally disreputable. In South Africa, HIV is predominantly transmitted through unsafe sex, and therefore disclosure of one’s HIV-positive status is also a disclosure that one is sexually active. If families do not discuss sex or HIV, but link the two

together, and assume that HIV is a consequence of promiscuity, then the stigmas attached to HIV are also linked to the stigmas attached to sex as shameful.

In a household where parents live with children, and where there are unstated but implicit expectations around appropriate and inappropriate sexual behaviours, a child's disclosure of their HIV-positive status to their parents may elicit a range of stigmatising response from parents. A child's HIV-positive status may be perceived as a precursor to premature death, as Dolly's narrative indicates above, which disrupts the generational process in which parents die before children; the association of HIV with sex may prompt a moral crisis in which the parents associate HIV with an absence of sexual morality, and blame their child for contracting the virus; and, as in Bongani's case, the association of HIV with promiscuity prohibits a supportive response from the parents, and fuels a stigmatising attitude that links HIV – and HIV-positive people – with dissidence. Later in the interview with Bongani, he was asked about his current relationship with his father:

Interviewer: And your father? How is he now?

Bongani: He is much better now. He can see that this [HIV] is spreading around the world. (Interview with Bongani, 2006).

Like the virus which is constantly morphing, the way in which HIV is biomedical managed, socially perceived and personally experienced, is also changing. These findings point to a series of shifts across this body of research and other studies conducted at different points along the trajectory of HIV research. For example, Bongani's initial experience of stigma, and later of acceptance, from his father highlights how relationships evolve and are affected by broader shifts, like an awareness of the general prevalence of HIV and the corresponding but slow stripping away of moralistic assumptions that link HIV to sex, promiscuity and shame. Earlier in this section we described how Mzimazi was concerned that disclosure would disrupt the supportive relationship that he had with the close family with whom he shared a home – his mother, sister and niece. His mother had sided with his sister and niece in their discriminatory treatment of him in their home, prompting Mzimazi to leave the household. Like Bongani, Mzimazi noted later in the interview that his relationship with his mother has improved "because the stigma is not as bad as it was before because there are many people who are HIV positive now."

HIV has become more visible - not simply inscribed as an indomitable disease on people's weakened bodies but as a disease that can be dominated by medicine, and other forms of support, to restore wellbeing and ensure long lives. The shape of stigma is shifting as the disease changes shape.

Stigma may be shifting, but it is still pernicious. The quantitative findings indicate high levels of perceived stigma within communities, compared to lower levels of perceived stigma within families. We suggest that this relationship may account for the high levels of disclosure among the survey respondents to members of their household. The qualitative findings discussed above point to the process and also the consequence of disclosure kin within households, and to kin and non-kin beyond the household. Subtle processes of disclosure, like ‘testing out’ potential responses and establishing the ‘proof’ of health, catalysed a range of different responses. Conversely, however, deep-seated fears of stigma and rejection from household members and from members of the community also emerged in the qualitative narratives.

Perceived stigma, linked to these instances where disclosure is not met with support but with condemnation, played a role in Mangwanya’s decision not to disclose her status to the other member of her household – her husband. Mangwanya is 51 years old, and she and her husband have been married for over twenty years, and have seven children. When talking about returning home after receiving the results of her HIV-test, she says:

“I was told that I have this thing: AIDS. I had ringworms all over my face, at one stage I used a calamine to cover my face, and did not want people to see the marks on my face... I did not want to go outside. If I wanted to go outside I would first peep and see if there were no neighbours or other people around who will see me.

...

I kept my status to myself for fear of being ridiculed in the community; I thought they will always refer to me as a person with AIDS.... I am hearing people saying we must be open and talk about our status, for me I will never let people about my status because that causes anxiety... Because I am going to tell someone or my neighbour about my pain, then my neighbour will empathize with me and as soon as I turn back she will gossip about me.” (Interview with Mangwanya, 2006).

The marks of illness were visible on Mangwanya’s body, prompting her to mask them with Calamine lotion and stay in doors away from the glare of public scrutiny and malicious gossip. With few material and emotional resources, Mangwanya was not prepared to risk losing her social standing within her community, nor was she prepared to disclose to her husband. Her home, therefore, was a place of safety from potential gossip in her community, but it did not house a relationship that she trusted enough to risk disclosing her status to her husband. Her fear of disclosure extended to her refusal to use condoms when having sex with her husband as she was concerned that he would label her

as HIV-positive, and blame her for bringing HIV in to their home. Introducing condoms in a long-term relationship, where condoms had not previously been used, is perceived as tantamount to disclosure. This indicates that disclosure is not necessarily a verbal process, but that it can also take place in subtle – but obvious – ways through the association of a condom as a barrier to transmission of HIV. This is an under-researched area, particularly in light of sexual concurrency and the sexual and reproductive health of partners who are also in long-term relationships. Using a similar discourse of ‘bringing HIV in to the home’ as Bongani’s father had used when hearing that his son was HIV-positive, Mangwanya described how she was concerned that her husband would blame her for bringing the illness in to their home – in to their relationship. For this reason, she chose not to disclose to her husband, and continued to have unprotected sex with him, risking HIV-transmission (if her husband was HIV-negative), re-infection (if they were both HIV-positive) and later potentially undermining the efficacy of ARVs.

The quantitative and qualitative findings intersect and diverge at a number of key points. We summarise these key points here, and discuss them in relation to broader literature in the next section. Rates of disclosure to adult household members are high across the quantitative and qualitative research. We find that disclosure is shaped by gender in the quantitative research, whereas the qualitative research does not point conclusively to the role of gender in disclosure decisions; a large proportion of the survey respondents first disclosed to a female member of the household. Age also shaped the nature of disclosure for the survey respondents; the majority of the respondents had disclosed to most of the members of the household, and those who they had not disclosed to were predominantly children. Stigma and support prompted and were also catalysts of disclosure to co-residential kin. Reported perceptions and experiences of stigma were significantly lower among family members compared to perceived and experienced stigma in the community. A perception of lower stigma and greater support in families compared to the broader community may account for the high rates of disclosure to household members in the survey findings. The qualitative findings indicate that perceived and experienced stigma and support operated slightly differently for the respondents. Although they report similar perceptions to those in the survey, some of the respondents were concerned that they may jeopardise supportive relationship among family members within their household; in order to counter-act this concern, they disclosed to family members who were on the periphery of their social support networks, and built up a sense of confidence in a positive response which encouraged them to disclose to their family. Mzimazi’s disclosure to his family in his household was met with stigma, and prompted him to move out of his home. This case study indicates that value of

understanding the layers of support and stigma across kin and non-kin networks as they are connected to, but extend beyond the household.

The correlation between disclosure, timing and instrumentality was not evident in the survey findings, but emerged more strongly in the qualitative research. We find that timing and instrumentality play a role in PLWH's decision to disclose to household members, but that the nature of these dynamics is shifting as HIV becomes a chronic and manageable illness. Across the qualitative and quantitative research we found high levels of disclosure to households correlated with positive experiences of support following disclosure. Instances where disclosure catalysed stigma from household members emerged in the qualitative interviews, and did affect one respondent's decision to move out of his home. However, their initial experiences of stigma from their parents shifted over time, and this indicates the value of understanding the nature of relationships within households and families, and not simply adopting a blanket conceptual approach to the static nature of stigma, or of households the families that live in them.

A Balancing Act: Disclosure as catalyst and consequence of stigma and support

HIV-disclosure and household dynamics could be quantified by a mechanical appraisal of numbers: who, how many, age, sex, income, expenditure. In addition to these concrete numbers, the physical nature of the home – the walls, furniture, pipes and drains – is infinitely variable. We need to look more closely at the less tangible aspects of home: the relationships between people who live, eat, fight, love, hate and sleep together. In order to avoid obtuse abstraction of human experiences, this discussion aims to connect the empirical material with a broader set of theory and studies from the region that enhance our understanding of disclosure dynamics in the context of the relationships between people sharing a home.

The main deterrent to disclosure in households, based on the qualitative research, was fear of stigma. The findings highlight that stigma is both layered and dynamic. The case of Mzimazi, for example, indicates the layers of rejection and betrayal that he experienced from his family after he had disclosed his status to them. Stigma is not static: it shifts over time as more and more people become aware of the prevalence of HIV and the transformative capacity of ARVs to restore ill individuals to health; it has also shifted in the relationships between the respondents of this study and other members of their household. This concurs with Deacon's (2006) assertion that stigma is a dynamic and often

resisted process rather than a label, or a brand, that is attached to an individual based on their deviation from the accepted norm. As illustrated by the findings, stigma is not all-encompassing, it does not affect every sphere of PLWH's lives, and individuals who initially respond to HIV status disclosure in a stigmatising manner may become supportive over time.

Further, this paper distinguishes between experienced and perceived stigma; this distinction is important given the role of perceived and experienced stigma on PLWH's decisions to disclose their HIV-status to other members of their household. Experienced stigma is discrimination that occurs due to an individual's HIV status, while perceived stigma refers to the degree to which a person believes the public stigmatises PLWH (Maughan-Brown, 2006a and 2006b; Swendeman *et al.*, 2006; Thomas *et al.*, 2005). High levels of perceived stigma 'out there' in the community were reported in the data from both surveys, and also in the qualitative data. This perception did not, however, apply to families and household members; instead, they were perceived to be supportive of PLWH. Overt experiences of stigma were rare across the quantitative and qualitative data sets, but fear of stigma, particularly gossip, was reported more frequently in both data sets. Gossip is a particularly pernicious deterrent to disclosure as individuals base their concern about disclosure on conjecture, or their experiences of gossip about other PLWH. In the qualitative research, one respondent refused to disclose to her husband, with whom she shared a home, and any one in her community because she was concerned that they would reject her. This case connects to Ashforth's description of 'circuits of gossip' in which an environment of gossip facilitates malicious suspicion and discussion, and reinforces a climate of secrecy (2005). He compares circuits of gossip to pathways of suspicion surrounding witchcraft. Like HIV, witchcraft is perceived as highly threatening and dangerous, and people who are perceived as 'polluted' (or polluting) through witchcraft and HIV, are subject to similar stigmas, particularly in the form of gossip:

“Witchcraft, then, has a necessary connection to gossip by virtue of the dynamics of intimacy and secrecy... The circuits of gossip within social networks are the same as those of witchcraft suspicions, with parallel intensity and prevalence, because they both engage the same personal connections and emotions.” (Ashforth, 2005: 67)

Mangwanya's fear of stigma was based on her experience of gossip; she had heard members of her community speaking about other member of their community. This 'environment of gossip', and her fear of being blamed for 'polluting' the home and relationship she shared with her husband, deterred her from disclosing her status. She was also concerned that the marks on her body would make her status visible, highlighting the subtle ways that disclosure may

unwittingly take place through symbols of disease, and not only through words acknowledging illness. In order to shield herself from the eyes and words of people in her community, Mangwanya covered these marks with Calamine lotion and stayed indoors.

Moving from considering factors, like stigma, that discourage PLWH from disclosing to household members, and are also catalysed by disclosure, we look at some of the factors that may account for the high levels of household-level disclosure in this study. As stated in the introduction, disclosure is a precursor for accessing a range of resources like home-based care, food parcels, antiretroviral treatment and social grants, particularly the disability grant. A study conducted across 18 households in South Africa found that:

“HIV positive people in the community with higher rates of disclosure had greater access to formal institutional support through local NGOs and government social services and greater opportunities to take a positive leadership role as HIV positive individuals in the community.” (Norman et al, 2005: iii)

This study noted, however, that disclosure was not a one-time event, but a carefully managed process that ‘tested’ out whether full disclosure would expose one to stigma or support. Just as it is important to unpack the nature of relationships within households, it is also important to problematise disclosure as a once-off event, or a verbal interaction between two people.

The qualitative findings indicate the careful negotiations entailed in disclosure, the way in which potential responses were tested out, and the changing nature of relationships following disclosure. Dolly describes how she waited for two years before disclosing to her family because she wanted them to have ‘proof’ that she could live a healthy productive life. Mzimazi and Bongani both initially experienced stigmatising responses from their parents. In Mzimazi’s case, this response prompted him to move out of his home and set up supportive networks through community organisations and extended family members; this reinforces Norman *et al.*’s (2005) assertion above, given that disclosure had prompted stigma from his close family, but had also enabled him to access greater levels of institutional support from organisations like TAC. Both Bongani and Mzimazi reported a shift in their relationship with their father and mother respectively as their parents came to understand that HIV affected many people and was not necessarily a sign of promiscuity or general deviance.

There are two main approaches to theorising disclosure among PLWH (Almeleh, 2006). The disease progression theory suggests that an HIV-positive person will disclose their status when their body starts to reflect signs of illness

linked to the progression of HIV to AIDS (Babcock, 1998; Kalichman, 2003). Implicit in this theory is the assumption that HIV-positive individuals choose to keep their status a secret until they are compelled to disclose because they are unable to ‘disguise’ their illness any longer (Almeleh, 2006; Serovich, 2001). The competing consequence approach challenges this assumption, and suggests that there is not a clear relationship between disease progression and disclosure (*ibid*). As discussed above, the introduction of ARVs further disrupts this linear relationship; when chronic illness is successfully managed with medicine, disease progression from HIV to AIDS cannot easily be mapped (or seen) on the physical body. The competing consequence theory allows for greater agency on the part of the HIV-positive individual, and suggests that a potential range of consequences are weighed up and evaluated by PLWH prior to disclosure. Both of these theories are limited as they do not account for contextual factors, or altruistic motivations, that may also influence disclosure decisions (Almeleh, 2006 and 2004).

The findings discussed in this paper suggest that disclosure decisions entail a careful balancing act in which perceptions and experiences of stigma are balanced against a range of positive outcomes following disclosure. To this end, the findings reflect the competing consequence theory given that the respondents evaluate and manage the consequences of disclosure in order to maximise support and minimise potential stigma within their household. This chapter therefore concurs with Almeleh’s findings that “disclosure is both a response to, and in turn shapes, the social world of people living with HIV/AIDS.” (2006: 9). We considered the timing and instrumentality of disclosure in the findings above, and suggest that both apply to the disclosure decisions among the respondents in the qualitative study. Almeleh (2006) found that disclosure was prompted by an instrumental desire to secure support from household members when the HIV-positive individual became ill. The timing of disclosure among the respondents in Almeleh’s (2006) study, therefore, frequently coincided with illness episodes. In our study the respondents were either on ARVs, or they were pre-symptomatic. The qualitative narratives indicate that the respondent’s decision to disclose was not prompted by illness, or fear of illness. Rather, it was informed by a range of other concerns. The factors that catalysed disclosure connect with Almeleh’s study in that they also indicate forms of instrumentality. Instrumentality is not the antonym of altruism; disclosure may serve a purpose, even if it does not directly benefit PLWH. Dolly, for example, disclosed to her sexual partner and other non-kin with the intention of encouraging them to get tested for HIV. The consequence of her subsequent disclosure to her family members with whom she lived was a greater degree of support; her sister bought her medicine through her medical aid, and her mother assisted with domestic work when Dolly was acutely ill.

The Communication Privacy Management (CPM) theory is a conceptual framework for analysing disclosure among PLWH, and is based on Green *et al.*'s (2003) argument that fear of stigma compels PLWH to set up defensive 'boundaries' that separates their private information from public view (Green, 2003 cited in Almeleh, 2006). Decisions to disclose are based on a complex set of rules relating to privacy management (*ibid*), and this in turn is connected to identity management (Goffman, 1963); disclosure takes place when the HIV-positive individual has assessed how disclosure to a particular person may 'spoil' their identity and open them up to HIV-related stigma, or whether the individual to whom they disclose can be trusted to respond supportively. According to CMP theory, a trusted individual enters the 'privacy boundary' when private information has been disclosed to them (Almeleh, 2006; Green *et al.* 2003). The findings suggest that these boundaries are not only shaped by fear of stigma, but also by its corollary – support. Through the process of 'testing' disclosure to trusted individuals on the periphery of their close social and kinship networks, they were able to develop a network of support that enabled them, finally, to disclose to the people who could directly influence the respondents' locus of emotional and material wellbeing within the household.

Conclusion

This paper demonstrates that in addition to generating a range of outcomes for people living with HIV, disclosure within households is not a uniform 'event' but a complex process that informs, and is informed by, the nature of the relationship between members of the household. High levels of disclosure within households exist across both sets of data, and we suggest that this correlates with high levels of support and low levels of perceived stigma in the family, contrasted with high levels of perceived stigma in the general community. In addition to exploring disclosure as a catalyst and consequence of support and stigma, the paper presents a process model for understanding disclosure as a spiral that can move in or out between extended family and non-kin to co-resident family.

The qualitative findings indicate some of the direct consequences of stigma on household composition, but overall household composition remained consistent following disclosure. The nature of the relationships within the household, however, changed shape. Dolly, for example, received greater support to assist her in managing her illness. Mzimazi's relationship with his mother improved over time as she became aware of other people who were living with HIV. Similarly, Bongani's relationship with his father shifted as his father realised that HIV was not necessarily a consequence of sexual promiscuity. Dolly's

concern that her family would associate HIV with AIDS deterred her from initially disclosing to her household, but once her family were aware of her status, they too came to realise that it is possible to live a long life with HIV. These findings indicate the dynamics of disclosure within households in the context of a changing landscape of HIV in South Africa: HIV is no longer an acute precursor of death, but rather a chronic disease that is successfully managed, in part, through supportive interpersonal relationships within and beyond the household.

References

- Aggleton, P., Parker, R. & Maluwa, M. (2003). *Stigma, discrimination and HIV/AIDS in Latin America and the Caribbean*. Inter-American Development Bank. Available at http://www.iadb.org/sds/doc/SOC130Stigma_and_AIDS.pdf
- Almeleh, C. (2004). The Longlife AIDS-advocacy Intervention: An Exploration into Public Disclosure. *Centre for Social Science Working Paper 96*, Cape Town: University of Cape Town.
- Almeleh, C. (2006). Why do people disclose their HIV status? Qualitative evidence from a group of activist women in Khayelitsha. *Social Dynamics*, 32(2), 136-169.
- Ashforth, A. (2005). *Witchcraft, Violence and Democracy in South Africa*. Chicago: University of Chicago Press.
- Coetzee, C. & Nattrass, N. (2004). Living on AIDS treatment: a socio-economic profile of Africans receiving antiretroviral therapy in Khayelitsha, Cape Town. *Centre for Social Science Working Paper 71*, Cape Town: University of Cape Town.
- Coetzee, D., Boulle, A., Hildebrand, K., Asselman, V., Van Cutsem, G. & Goemaere, E. (2004a). Promoting adherence to antiretroviral therapy: the experience from a primary care setting in Khayelitsha, South Africa. *AIDS*, 18(3), 27-31.
- Coetzee, D., Hildebrand, K., Boulle, A., Maartens, G., Louis, F., Labatala, V., Reuter, H., Ntwana, N. & Goemaere, E. (2004b). Outcomes after two years of providing treatment in Khayelitsha, South Africa. *AIDS*, 18(6), 887-895.
- Deacon, H. (2006). Towards a Sustainable Theory of Health-Related Stigma: Lessons from the HIV/AIDS Literature. *Journal of Community & Applied Social Psychology*, 16, 418 – 425.
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoilt Identity*. London: Penguin Books.
- Jones, S. (1993). *Assaulting Childhood. Children's Experiences of Migrancy and Hostel Life in South Africa*. Witwatersrand University Press: Johannesburg.

Kalichman, S., DiMarco, M., Austin, J., Luke, W. & DiFonzo, K. (2003). Stress, Social Support, and HIV-Status Disclosure to Family and Friends Among HIV-Positive Men and Women. *Journal of Behavioral Medicine*, 26(4), 315-332. .

Maughan-Brown, B. (2006a). Quantifying Stigma in the Adult Population of Cape Town. *Centre for Social Science Working Paper 165*, Cape Town: University of Cape Town.

Maughan-Brown, B. (2006b). Attitudes towards people with HIV/AIDS: Stigma and its determinants amongst young adults in Cape Town, South Africa. *South African Review of Sociology*. 37(2), 165-88.

Médecins Sans Frontières, The Department of Public Health at the University of Cape Town, and the Provincial Administration of the Western Cape. (2003). *Antiretroviral Therapy in Primary Health Care: The Experience of the Khayelitsha Programme in South Africa*. Geneva: World Health Organisation.

Mills, E. (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.

Mills, E. and Magazi, B. (2009). From Rhetoric to Reality: An Empirical Appraisal of South Africa's 2007 – 2011 National Strategic Plan. *Centre for Social Science Working Paper 258*, Cape Town: University of Cape Town.

Mills, E., de Paoli, M. and Grønningsæter, A. (2009). Love in the Time of AIDS: The Relational Gender Dynamics of Prevention, Testing and Treatment. *Centre for Social Science Working Paper 252*, Cape Town: University of Cape Town.

Nattrass, N. (2008). Gender and Access to Antiretroviral Treatment in South Africa. *Feminist Economics*, 14(4), 19 - 36.

Neves, D. (2008). The consequences of AIDS related illness and death on households in the Eastern Cape. *Centre for Social Science Working Paper 232*, Cape Town: University of Cape Town.

Norman, A., Chopra, M. & Kadiyala, S. (2005). *HIV Disclosure in South Africa: Enabling the Gateway to Effective Response*. Regional Network on HIV/AIDS, Rural Livelihoods and Food Security. Retrieved February 2008 from: <http://www.ifpri.org/renewal/pdf/RENEWALSADisclosure.pdf>

Parker, R. & Aggleton, P. (2003). HIV and AIDS-related Stigma and Discrimination: A Conceptual Framework and Implications for Action. *Social Science & Medicine* 57, 13–24.

Ross, F. (1995). *Houses without Doors: Diffusing domesticity in Die Bos*. HSRC: Pretoria.

Ross, F. (2003). Dependents and Dependence: A Case Study of Housing and Heuristics in an Informal Settlement in the Western Cape. *Social Dynamics* 29(2), 132-52.

Scambler, G. & Hopkins, A. (1986). Being Epileptic: Coming to Terms with Stigma. *Sociology of Health & Illness*, 8(1), 26-43.

Seekings, J. (2008). Beyond 'Fluidity': Kinship and households and social projects. *Centre for Social Science Working Paper 237*, Cape Town: University of Cape Town.

Serovich, J. (2001). A Test of Two HIV Disclosure Theories. *AIDS Educ Prev*. 2001 August . 13(4), 355–364.

Skhosana, N., Struthers, H., Gray, G. & McIntyre, J. (2006). HIV disclosure and other factors that impact on adherence to antiretroviral therapy: the case of Soweto, South Africa. *African Journal of AIDS Research*, 5(1), 17-26.

Spiegel, A. Watson, V. & Wilkinson, P. (1996). Domestic diversity and fluidity among some African households in Greater Cape Town. *Social Dynamics* 22 (1), 7-30.

Spiegel, A. & Mehlwana. (1997). *Family as social network: Kinship and sporadic migrancy in the Western Cape's Khayelitsha*. HSRC: Pretoria.

Spiegel, A. Watson, V. & Wilkinson, P. (1996). Speaking Truth to Power? Some Problems using Ethnographic Methods to Influence the Formulation of Housing Policy in South Africa. In Cheater, A. (ed) *The Anthropology of Power: Empowerment and Disempowerment in Changing Structures*. ASA monographs No. 36, 175-190. London and New York: Routledge.

Swendeman, D., Rotheram-Borus, M., Comulada, S., Weiss, R. & Ramos, E. (2006). Predictors of HIV-Related Stigma Among Young People Living with HIV. *Health Psychology*, 25(4), 501-509.

Thomas, B., Rehman, F., Suryanarayanan, D., Josephine, K., Dilip, M., Dorairaj, V. & Swaminathan, S. (2005). How Stigmatizing is Stigma in the Life of People Living with HIV: A Study of HIV Positive Individuals from Chennai, South India. *AIDS Care*, 17(7), 795-801.