

Kanayaka

“The light is on”

Understanding HIV and AIDS related Stigma in Urban and Rural Zambia



Tuli Antomwe - We Are Together

picture by Clement Mfuzi



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KARA COUNSELING

Positive and Fully Alive



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Understanding HIV and AIDS related Stigma in Urban and Rural Zambia

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Explanation of Title: *Kanayaka* is a Nyanja term meaning "the light is on". This term simultaneously touches on the see-through frailty of people living with HIV and AIDS, the fact that the infection and the infected person's sexual history can no longer be hidden from public view, and, impending death (since the warning light has come on and the flickering light can go out). Sometimes this term is translated as "it has started" or "he's got it", portraying how it has become progressively more synonymous with having HIV/AIDS. It was the most common nickname used in the urban sites. For example, an urban traditional healer said of someone suspected to have HIV and AIDS, "...[if the] signs are there...start backbiting that he is finished "*kanayaka kudala bayenda*" [the light is on, he is soon dying]".

The flickering candle also symbolises the fragile life of a TB patient or a person living with HIV and AIDS in the context of unemployment, poverty, poor sanitation and a high burden of infectious diseases, including a high incidence of TB and HIV.

By labelling this report with a widely recognised stigmatising term for people living with HIV and AIDS, the aim is to provoke curiosity, reflection and debate. *Kanayaka* is also the name given to a project funded by Community REACH, USAID and led by Kara, which aims to return to the research communities and carry out anti-stigma activities.

Definition of Stigma: HIV and AIDS related stigma is when someone has a spoilt identity just because they are either *suspected* or known to be HIV-positive. Erving Goffman [1963] coined the most widely used definition of stigma - "An attribute that is deeply discrediting" and that reduces the bearer "from a whole and usual person to a tainted, discounted one".

Definition of Discrimination: Any distinction or restriction based on exclusionary perceptions or attributes that restrict the rights of a person living with HIV and AIDS and their family, and, results in harmful actions (like violence) or sanctions (like isolation).

Personal Journeys: During the two years of conducting this research on stigma, we have made our own personal journeys in terms of understanding what exactly stigma is - and is not. We have explored and recognised our own stigmatising attitudes and actions and the times we have been stigmatised in our own lives. We have learnt how stigma hurts. For example, the realisation that gossiping about a work colleague whom you suspect might have HIV and AIDS is a damaging form of stigma and one that people who know or suspect they may be HIV-positive (in particular women or people of higher status) fear. It seems that only once you know what stigma looks like and reflect on- or indeed experience - how it hurts, can you be committed to actively reducing stigma. Stigma is **not** beyond our control; we need to start with ourselves and our daily lives.

We discovered during the research, that once we provided communities with a 'safe' space to talk about their perceptions and experiences of stigma and discrimination related to HIV and AIDS, they shared many personal and painful experiences with us. It was almost as if they needed to talk.

We are deeply in debt to the research communities for their openness, and hope that the research itself will prove to be a first step in recognising, in the words of Ross Kidd, that "*at the end of the day, stigma simply doesn't make sense*".

Throughout this report, we are using the term 'people living with HIV and AIDS', instead of PLHAs or PWLHAs. Our decision to do this follows the view expressed by a woman living with HIV, that she feels dehumanised when described as an acronym.



Executive Summary

Talking about Stigma in Zambia: We could not establish an equivalent to the English word "stigma" in Zambian languages, although an equivalent and widely used term for discrimination was *akapatalula* (meaning the isolation of an unwanted person). It was easier to talk about stigma using pictures and descriptions of stigmatising actions than to associate it with a single word. The evolving language around HIV and AIDS is influenced by popular songs, events and HIV education messages, and mostly harsh and negative with strong moral overtones, underwritten with ridicule. Once provided with a safe space to talk, people talked very openly about their perceptions and experiences of HIV-related stigma.

Targeted at people assumed to be HIV-positive: Most of the time, stigma is directed at people who are assumed to have HIV and AIDS, and who often do not know themselves what their status is. The community diagnosis of HIV is based not on medical tests but on observations made over time and on signs, symptoms and behaviour.

Limited capacity to cope, especially in the village: It is very difficult to manage to care for people living with HIV and AIDS who are sick and orphans in the context of absolute poverty and seasonal hunger. Poor households make painful decisions in difficult circumstances about the allocation of resources. These decisions include the reduction and/or withdrawal of food, treatment or space from people living with HIV and AIDS and orphans, and are experienced as stigmatising. Thus limited capacity in the context of poverty makes

both discriminatory actions and stigmatising experiences more common. In a sense then, a significant proportion of discriminatory actions are caused by the fact that HIV and AIDS is so very hard to manage in the context of poverty. Since spiralling poverty is accompanied by spiralling stigma, any services or interventions that check poverty, will reduce stigma by actively enhancing the capacity of households and communities to manage the special needs of people living with HIV and AIDS. This is evident in our material where there is overall less stigma in town due, in part, to easier access to health facilities, VCT, health education, NGO and institutional support in town than in the village - where some of these services are completely absent and where stigma is more pronounced.

Less stigma in urban site: There were types of stigma that were more pronounced in town - for example, name-calling and other forms of public defamation. And in the village, there was more emphasis on the tradition of caring for kin. But, it is evident that in urban area, stigma is less overall. In town, there are fewer cases of extreme discrimination, more openness (for example more discussion about disclosure), more awareness of the impact of stigma and discrimination, more awareness of the needs of people living with HIV and AIDS (for example, their need for nutritional food), fewer fears around casual transmission and more use of (and positive attitude to) condoms. This arises partly from: more in depth knowledge; a much greater range of sources of information; and special

services to turn to when households or individuals could no longer cope. HIV is simply much more manageable in town and people are aware that with access to better nutrition, treatment and money, people living with HIV and AIDS can extend their lives. There was a strong sense that urban households, even in poverty, were more in control and more able to cope with HIV and AIDS, and that rural households were more deprived and less able to cope.

Stigma and Risk: Stigma can be seen to be intimately linked to the reproduction of social inequalities and to the protection of self and in-group identity. The ideas of more dominant groups in society work against the interests of less empowered groups (women, youths and particularly sex-workers). This has been illustrated in that these groups are seen as more proactive in the spread of HIV and men portrayed as passive in that they lack control over their sexual desires. Dominant identity and power allow the distancing from personal risk, as risk is projected onto out-groups. This is especially evident in households and health care settings - *"like those nurses who are HIV-positive shout at patients to forget about the disease"* [church secretary, urban].

Stigma, the church and moral integrity: Health is seen as a reward for the morally good - and HIV as a punishment for the morally bad. All respondents associated immorality as the main factor influencing the spread of HIV. Some church preaching feeds this moral condemnation of people living with HIV and AIDS - and healing sessions for those living with HIV feed denial. HIV infection within the clergy is a hidden crisis and thorn, and clergy suspected to have HIV and AIDS are heavily stigmatised by their congregations and their fellow clergy. However, in practice, most people are morally condemning but forgiving too towards people living with HIV and AIDS and biblical discourse is used both to stigmatise and to dictate love and care.

Association between HIV and death: People living with HIV and AIDS are, especially in the rural site, regarded as close to death. The apparent inevitability of this fate leads to fear, depression, despondency and withdrawal of care and support.

Casual Transmission of HIV: Fears around casual, non-sexual transmission of HIV are a key cause of HIV-related stigma since these fears are used to justify physical and social isolation, public rejection and other forms of stigma. These fears are widespread, genuine and more acute in the rural site and amongst children, carers, health workers and more educated respondents. The fears arise from a number of factors, which include attributing HIV infection to transmission routes that remove the stigma of sexual transmission and leave identity morally intact. In a sense, these fears are partly an extension of the innocent-guilty continuum and blaming others for the spread of HIV. Inadequate knowledge is partly responsible for these fears. And the fears are perpetuated by the difficulties of caring for sick people living with HIV and AIDS in poor resource settings.

Knowledge and Stigma: Both bio-medical knowledge (for example about breastfeeding), distorted knowledge (for example that having sex with a virgin cures HIV) and knowledge gaps can fuel HIV-related stigma. Critical knowledge gaps were: the relationship between opportunistic infections and HIV; mother-to-child-transmission; and preventive therapies. Testimonies from people living with HIV and AIDS appeared a very memorable and powerful source of information.

Women and HIV-related Stigma: The metaphors around HIV and AIDS are riddled with accusations against women - for their sexual deviance, their temptation, their *"love of money"* and for spreading HIV. It seems that HIV is perceived as a disease of women, spread by women. Women, more vulnerable to name-calling and gossip, are also more vulnerable to deepening poverty exacerbated by brutal practices (such as property grabbing), widowhood and less income generating power. Women are more likely to be blamed for bringing HIV into the household and to be chased from the household, sent back to close relatives or abandoned when sick. The most extreme examples of neglect amongst people living with HIV and AIDS were women sex workers. Women are therefore more susceptible to, and impacted by, HIV-related stigma.

Experiences of stigma: Stigma takes many different forms; sometimes overt and public and sometimes more subtle and implied. Experiences of stigma are determined by different situations, settings and stages of disease. In some settings, like at the market or workplace, stigma can result in loss of livelihood; in others to social exclusion and isolation. Stigma is experienced at every stage of HIV and AIDS including sex, going for testing, getting sick and at burials. Many people do not disclose their HIV status for fear of stigma and some do not access health care because of previous experiences of mistreatment by health workers. Prevention measures like condom use are hampered by stigma, because of associations of HIV with promiscuity and immorality. Many people living with HIV internalise stigma, believing that they are worthless and are somehow to blame for their infection. This can have serious effects, in extreme circumstances, resulting in suicide or premature death. Families and particularly children, experience secondary stigma, because of their association with people with HIV and AIDS.

Opportunistic infections - in particular TB, chronic diarrhoea and certain skin rashes (especially herpes zoster) - are very strongly associated with HIV and AIDS. These diseases were all stigmatised before HIV, but since HIV, the stigma attached to them has deepened and extended. It is notable that the food and sex libels attached to these diseases both feed, and get fed by, fears of the casual, non-sexual transmission of HIV and the association of HIV with improper sex. Falling sick with one of these infections is a sign of HIV and AIDS and instigates gossip and name-calling. Failure to respond to treatment, or a progression or combination of infections, confirms a diagnosis by the community that this must be HIV and AIDS. Patients can be rejected and neglected on the basis of a diagnosis (particularly with TB) or if the infection is severe, prolonged and hard to manage. Episodes of diarrhoea appear to push carers to their limit. Ultimately, as with HIV, it is the patient that is to blame and the onus is on public good not private pain. Unsurprisingly, people falling sick with these infections may hide their illness or diagnosis to avoid stigma, and the connection with HIV *"weighs them down"* [priest, rural]. If TB patients know they are HIV-negative, this gives them the strength to

challenge and deflect stigma. If, on the other hand, they know they are HIV-positive, they often isolate themselves and are hurt and deeply affected by the stigma attached to opportunistic infections. As one urban clinical officer said, *"I think it is important to appreciate...the way the infected person feels about the condition"*.

Witchcraft pushes stigma away: The overlap between being bewitched and having HIV and AIDS helps deflect shame, blame and stigma and provides both families and patients with some encouragement and hope, and, with more sympathetic treatment than they often receive at the health centres or hospitals. In the rural site, witchcraft accusations often followed in the wake of HIV and AIDS. However, both traditional healers themselves and the community are growing more cynical about using witchcraft as *"a scapegoat"* and the rural healers in particular find it difficult to deal with HIV and AIDS because of the fact that it is incurable, the difficulties they face in diagnosis and because of poverty. In the absence of special interventions for people living with HIV and AIDS in the rural site, as deaths from HIV and AIDS continue unabated and traditional medicine proves ineffective at ultimately curing HIV, the danger is that traditional healers could become scapegoats. This is indicated by the anger directed at traditional healers in the research community meeting and from some of the respondents during the research itself. In addition, twenty years into the HIV pandemic in Zambia, witchcraft has now become a sign of HIV and AIDS and a witchcraft diagnosis can instigate HIV-related stigma.

Care and Support: Stigma does not exclude care; it is possible for them to co-exist. In both urban and rural sites, there was evidence of care and support for people living with HIV and AIDS. There was widespread knowledge about what constituted good care - nutrition, emotional support, spiritual care and external support from clinics, traditional healers, NGOs and other services. Over time, care becomes harder. The degree of care - and stigma - is influenced by the past relationships, reciprocal relationships, household status, poverty and gender. Close blood kin and especially women are the main carers.

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Introduction

As the impact of the HIV and AIDS epidemic deepens in Sub-Saharan Africa, and medical interventions to extend and improve the lives of people living with HIV and AIDS become more widely available, the need to understand and counter HIV and AIDS related stigma and discrimination has grown more urgent. It is widely acknowledged that stigma is one of the "greatest barriers" [Parker and Aggleton 2002] to HIV care and prevention. USAID recognized that there was a dearth of data to inform the design of interventions to reduce stigma and discriminatory practices and, in response, supported a three-country research study to be conducted by the International Center for Research (ICRW)¹, the CHANGE Project and local partners in Africa.

The ZAMBART Project² in partnership with Kara Counselling and Training Trust (KCTT) collaborated with ICRW to carry out the research in Zambia over a period of two years (November 2001 to November 2003). Companion studies were conducted in Tanzania³ and Ethiopia⁴. All the studies carried out community based research in

urban and rural sites, and, used qualitative methods to investigate stigma associated with HIV and AIDS - its causes, forms and consequences and the social, economic and cultural factors that underlie it. The multi-country findings have been written up in the form of a synthesis report (see Nyblade et al 2003⁵) and, the country findings, in the form of individual country reports (see Mbwambo et al 2003⁶, Banteyerga et al 2003⁷). This report should be read alongside the children's report, the synthesis report and other country reports.

The Zambian study has a special focus on:

- The stigma related to Tuberculosis and other opportunistic infections
- Intersections between poverty and stigma
- The fears of non-sexual transmission of HIV and stigma
- Experiences of stigma amongst affected children⁸
- Urban/rural differences in stigma
- Stigma as a coping strategy for risk

¹ Laura Nyblade was the Project Director for this multi-country research study.

² ZAMBART - The Zambia AIDS related Tuberculosis Research Project - is a fourteen-year collaborative project between the School of Medicine of the University of Zambia and the London School of Hygiene and Tropical Medicine.

³ The Tanzanian study was led by Jessie Mbwambo and Gad Kilonzo, Department of Psychiatry, Muhimbili College of Health Sciences (MUCHS), and Peter Kopoka, University of Dar-es-Salaam.

⁴ The Ethiopian study was led by Aklilu Kidanu and Hailom Banteyerga, Miz-Hasab Research Center.

⁵ Nyblade L, Pande R, Mathur S, MacQuarrie K, Kidd R, Banteyerga H, Kidanu A, Kilonzo G, Mbwambo J and Bond V, 2003, Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia, ICRW and the CHANGE Project. Available from: www.icrw.org

⁶ Mbwambo J, Kilonzo G, Peter Kopoka and Nyblade L, 2003, Understanding HIV-related Stigma in Tanzania, MUCHS.

⁷ Banteyerga H, Kidanu A, Nyblade L, Pande R and MacQuarrie K, 2003, Exploring HIV/AIDS Stigma and Related Discrimination in Ethiopia: Causes, Manifestations, Consequences and Coping Mechanisms, Miz-Hasab Research Center.

⁸ Although part of the same study, the children's research was led by Kara and written up separately - see Clay S, Bond V and Nyblade L, 2003, We can Tell Them AIDS Doesn't Come From Being Together, Children's Experiences of Stigma in Urban and Rural Zambia, ZAMBART.

As a direct result of the research, an anti-stigma training manual⁹ was developed with people from the three countries, led by Ross Kidd¹⁰ and Sue Clay. The training manual contains participatory exercises and games, informed by the key findings from the study, and aims to support communities to explore and challenge stigma.

The research was carried out in two adjacent Lusaka communities and one rural community in Choma District, Southern Province. We are acutely aware that because of the focus on stigma, much of the material presented here portrays the darker side of these communities. Our findings on stigma in these communities could extend to other urban and rural communities in Zambia - in other words, these are not communities that are extraordinary or stigmatise any more than others. They are also communities where care and support co-exists with stigma and discrimination and where, partly due to the research and due to the presence of Kara and other initiatives, there is a growing commitment to tackling and reducing stigma alongside other HIV and AIDS initiatives.



⁹ Kidd R and Clay S, 2003, Understanding and Challenging HIV-related Stigma: Toolkit for Action, Washington Change-AED. This training manual will be widely available by the end of 2003.

¹⁰ Ross Kidd was the regional consultant for the multi-country research study



Study Design and Methods

Ethical considerations:

The research adhered to basic research principles, namely the research should: do no harm; not proceed without the informed consent of participants; be appropriate to national and local needs; build local research capacity¹¹; and consistently ask of the research - knowledge for what?, knowledge of whom?, and knowledge for whom? [Akeroyd 1991].

Informed consent was written for all in-depth and individual interviews. Respondents were always asked to explain the purpose of the research back to the interviewer to make sure they understood. In addition, they were given a flyer, in the vernacular, explaining the study. Verbal informed consent was obtained for participatory activities and focus group discussions. The group research activities only took place once community consent has been obtained from the appropriate community leaders. Further, sensitivity to settings in which the interviews were conducted and participants' willingness or comfort to answer questions throughout were paramount. Likewise, respondents were clear of their right to withdraw or refuse to answer any questions.

Research on stigma runs the risk of perpetuating or actually being a source of stigma by singling out people living with HIV and AIDS, calling public attention to their status, forcing people to confront issues (e.g. around denial of HIV status) and putting people living with HIV and AIDS in a special

category [Bharat 2001, Brown et al 2001]. To minimise such harmful outcomes, people (including children) living with HIV and AIDS were recruited through existing programmes providing them with services (e.g. through Kara Counselling and Training Trust, Fountain of Hope and ZAMBART). Trusted counsellors were involved in recruitment and fully understood informed consent was obtained. Bharat [ibid] points out that the flip side of harmful effects is that research can sensitise others to the issue of stigma.

The researchers believe that research well done and documented that captures the dimensions and burden of stigma can provide impetus for funding and intervention [Weiss 2001]. Mechanisms for feeding back findings to the selected communities and nationally have been put in place and will take the form of disseminations in the research sites and a national dissemination, due to be held in November 2003. The three reports will be distributed through the disseminations. The research findings fed directly into the development of the anti-stigma toolkit, which involved some research assistants and participants from the research sites. In addition, the partnership with Kara Counselling allowed research findings to be incorporated into ongoing counselling training courses.

Ethical clearance was obtained from the University of Zambia's National Ethics Committee, November 2001.

Methods:

This qualitative research sought to maximize the validity and reliability of the findings through "methodological triangulation"; that is, by gathering data simultaneously by means of different techniques with different presumed sources of bias [Booth D, Milimo J et al 1995]. Thus, a range of qualitative methods was used (as outlined below). In lieu of the complexity, culturally embedded nature and sensitivity of stigma, some innovative methods were tried out.

Participatory Action Research:

This research approach encompasses a range of techniques that have been demonstrated to be effective and valid in studying health issues [Scrimshaw S C and Hurtado 1987, Shah et al 1999]. Specifically developed to collect anthropological data in a relatively short time in the field, this approach also aims to encourage people to undertake their own analysis and action and to have an explicit focus on local experiences, values, knowledge and expertise [Lindsey 1999, Cornwall & Jewkes 1995, Hall 1992]. In the Zambian study, the PAR methods were used in the first week of the research (during what we labelled "community trust building") and, within the in-depth interviews and focus group discussions. The PAR methods used included:

- a NGO stigma workshop in the urban sites where local NGOs gathered together to discuss stigma related to HIV/AIDS and TB; and a half-day community meeting in the rural site where local representations gathered to hear and ask questions about the research
- community maps where participants were asked to map their communities and then discuss where stigma emanates from
- free-listing and ranking of local terms for people living with HIV and AIDS and for TB patients over a series of two days at the beginning of the research with different groups and in different settings in the communities (e.g. school children, marketeers, church-goers)
- picture discussions using many of the pictures in this report. We also used silhouettes of different age groups and different groups to discuss who was most at risk of HIV

- ranking of settings and stigma at different stages of HIV infection
- matrixes of diseases, stigma at different stages of HIV infection and fears about the contagion of different types of bodily fluids
- timelines with elders about the history of TB and HIV and AIDS in the communities

Semi-Structured questionnaires with Key Informants:

The questionnaires¹² followed identified themes and had the same sequence and wording for all respondents. Probing questions were included in the interview schedule. Key-informants were identified through the NGO workshop/community meeting, the community trust building exercises, and through local research assistants. The aim was to interview a range of local leaders and/or informants with special knowledge about HIV and TB.

Focus-group discussions:

This is a discussion in which a small group of informants (6-12 people), guided by a facilitator, talk freely and spontaneously about themes. The discussion is tape-recorded if informants permit. It is important that informants are fairly homogenous - drawn from the same sex, age group and socio-economic background - to facilitate the discussion [Scrimshaw S and Hurtado E 1987]. FGDs are designed to "obtain perceptions on a defined area of interest in a permissive, non threatening environment" [Krueger 1988:18]. The participants for the FGDs included a representative range of community members. The FGD guide was split into three weekly sessions, to allow the issues to be discussed in depth and to allow rapport to be built with the respondents.

In total, 68 key-informant interviews and 53 FGDs were held. For an overview and breakdown of respondents see Appendix 1.

In both the key-informants and the FGDs, the following key-themes were addressed:

- general issues about health, HIV and TB in the community
- the association between TB and HIV, including groups most at risk, signs and symptoms, life

¹¹ Local research capacity was built through the recruitment and training of Zambian research assistants and extending all training on methods and data to Kara and ZAMBART staff.

¹² Questions were translated by the local research assistants into Nyanja in Lusaka and into Tonga in Choma District and back translated by professional translators.

expectancy, community responses and comparison between TB and HIV and other opportunistic infections, malaria, cancer and witchcraft

- knowledge about mother-to-child transmission
- words and language used to talk about men, women and families living with HIV and AIDS
- in what circumstances men and women would be blamed for bringing HIV into the family
- the effect of stigma on children
- treatment of people living with HIV and AIDS in different settings
- disclosure of HIV status for men and for women
- care and support for people living with HIV and AIDS, including differences if rich and poor
- burials for people living with HIV and AIDS
- knowledge and opinion of local organisations working with HIV and AIDS
- use of the English word "stigma"

Semi-structured indepth interviews with Household Respondents:

This research took advantage of two longitudinal research cohorts¹³ in the urban sites, to carry out a sequence of interviews with people who knew their HIV status and who had suffered from TB. The aims of the household study were to examine HIV and TB stigma in a household context and to examine experiences of stigma over time and to look at causes, manifestations and consequences of stigma, including individual and household coping strategies. Six rounds of in-depth interviews were carried out by a nurse counsellor (involved in the previous Ayles study) with 13 households¹⁴ over a period of 8 months. The interview themes included:

- Definitions and understanding of stigma
- Knowledge and beliefs about TB transmission
- Knowledge and beliefs about HIV transmission
- Association between TB and HIV
- HIV and 'Promiscuity'
- Experiences of testing and disclosure
- Community attitudes and reactions to people living with TB and/or HIV
- Children's' experiences of stigma

Sub-study on Children's Experiences of Stigma:

In the preliminary analysis of the urban data, we were distressed to see how stigmatised orphans and street kids were, and decided to do a sub-study on children's experiences of stigma in both the urban and rural sites. This research was led by Kara (Sue Clay, Gita Sheth and others) due to their experience with child counselling (see Clay et al 2003).

Research Assistants and Training:

In both sites, research assistants were recruited locally, through advertising in the community. They were chosen for their involvement in community activities, knowledge or interest in HIV and AIDS and understanding of research projects. The research assistants represented a cross section of the community in terms of age and life experience. The teams included peer educators, a home-based carer, a retired civil servant, a small businesswoman, a community elder and a graduate.

Training:

Ross Kidd, the regional training consultant, designed the training course in both urban and rural sites. In each site, research assistants participated in a two-week training course that was designed to build skills and knowledge in research techniques and deepen understanding of HIV and TB related stigma. Virginia Bond, Ross Kidd and members of Kara staff conducted the training.

The content of the course included:

- Overview of research methods: qualitative and quantitative
- Conceptual framework of HIV related stigma
- Ethical considerations - including confidentiality and personal safety
- Interview techniques
- Facilitation skills
- Community Mapping
- Using drama in the community
- Data collection
- Personal awareness and experiences of stigma
- What stigma looks like

- Keeping research diaries
- Focus group discussions
- Field work Practice

As a result of conducting the course, the lack of training materials on stigma became apparent. The development of the Anti-Stigma Toolkit was a response to this.

Fieldwork:

The urban community fieldwork stretched over four months - March to June 2002, with the exception of the household study that ran from December 2001 to July 2002. The rural community fieldwork started in September and finished in November 2002. The principal investigator, Virginia Bond, was present throughout fieldwork, debriefing research assistants regularly and conducting some interviews herself. Levy Chilikwela helped supervise the research assistants in both sites.

Almost all interviews were tape recorded (with the exception of four where respondents did not wish to be recorded) and transcribed during fieldwork from the vernacular into English. The transcriptions were then entered in Lusaka.¹⁵

Data Analysis:

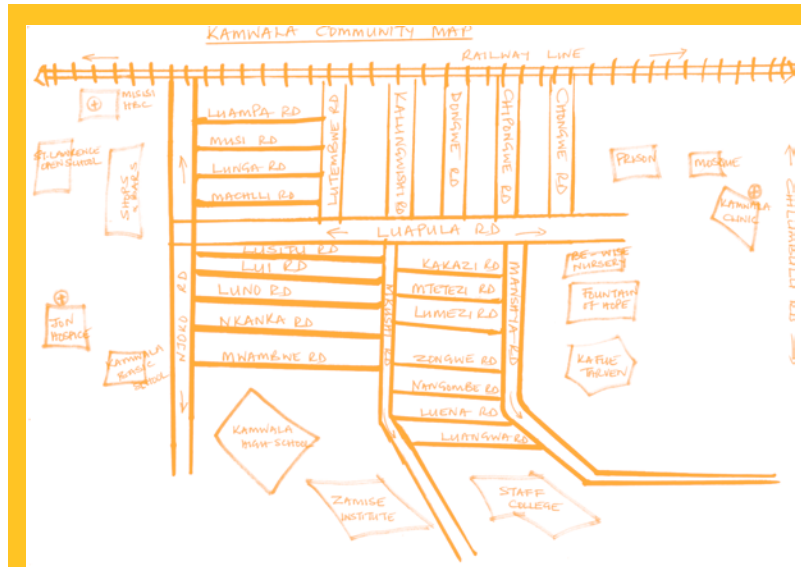
A coding frame was drawn up and developed by close examination of the full set of transcriptions. The coding frame reflected the same themes addressed in the interviews, with finer categories. The computer package NUD*IST N4/N6 [Richards 1998] was used to manage the data, and allowed the prevalence and substance of each theme to be ascertained, new coding to be easily added and for quick searches of the data. The core research team (P.I., Kara counterpart, two research assistants, one data entry clerk) were all trained in the use of NUDIST by ICRW.¹⁶ An MSc student¹⁷ from the LSHTM analysed part of the data for her dissertation.

Study Populations

The selection criteria for sites were: a community where Kara is present (to facilitate entry, counselling support and future interventions); community willingness to participate in the research; and one urban and one rural site.

The Urban Sites: Kamwala and Misisi¹⁸:

Kamwala and Misisi are two neighbouring high density compounds in the southern part of Lusaka. Both compounds were chosen because the household study extended into both and, although the communities share some core facilities, Misisi is a much more deprived and poorer community than Kamwala. As far as possible, we were careful to carry out research activities equally in both.



Kamwala has a population of 30,365 [CSO 2000]. It is a formal settlement, built in 1960s, and is divided from Misisi by a railway line. It has good quality housing, sanitation and piped water. Services in Kamwala include a health centre, a hospice, centre for street children, primary and secondary schools, a prison, a council market and commercial shops. Most people living there are middle class with a significant proportion of the population employed in the formal sector and many who retired civil servants.

¹³ From 1998-2001, Zambart had conducted a longitudinal study of households where sputum positive TB patients resided (see Ayles et al 2002). In addition, Kelly et al [1998] had been conducting a longitudinal study of HIV gastroenterology and morbidity. Both researchers gave permission for this study to approach their research participants, using their research assistants, for informed consent, and to access longitudinal data.

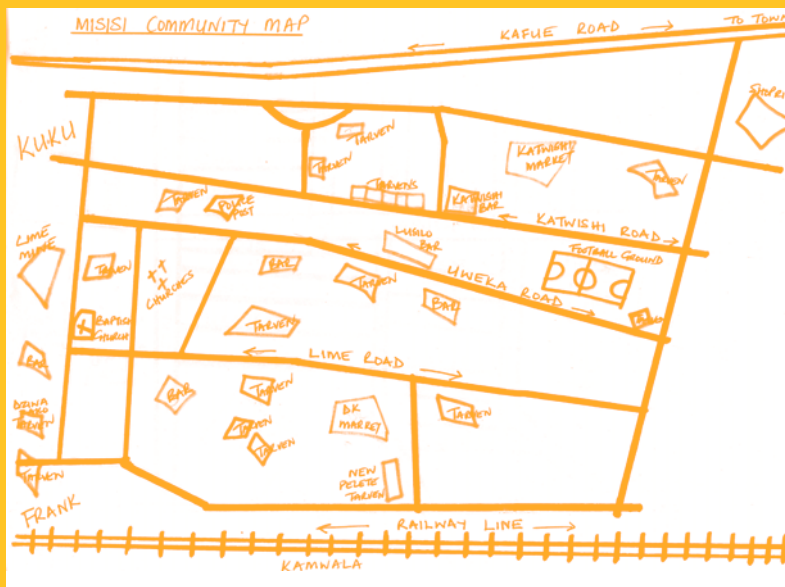
¹⁴ For Table of Households, see Appendix 2

¹⁵ To maintain confidentiality, all the completed transcripts were locked in a filing cabinet in the project office, and only the P.I. and the data entry clerk had access

¹⁶ The P.I. had additional training from a consultant in London.

¹⁷ Nadia Bettega - one of the authors of this report

¹⁸ See community maps on this page and page 18

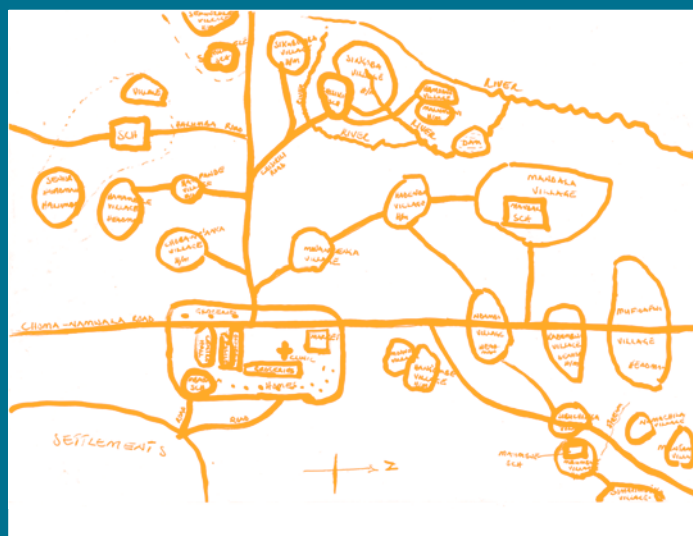


Misisi began as an illegal squatter settlement in 1964, which was only legalised in 1995. It has a population of roughly 20,000. The housing is poor quality and there is over crowding and little access to clean water, with high risks of water contamination. Misisi has high morbidity and mortality rates and virtually no services. For health facilities, Misisi residents use Kamwala Clinic and traditional healers. Most people earn a living in the informal sector. Misisi is renowned for having many bars and various clandestine activities.¹⁹ Community based organisations working in Misisi include the Catholic Home Based Care, a community school and Care International. A barber in Misisi described his community - "Very few children go to school and very few people go for work...People are failing to meet eating needs because they fail to find money".

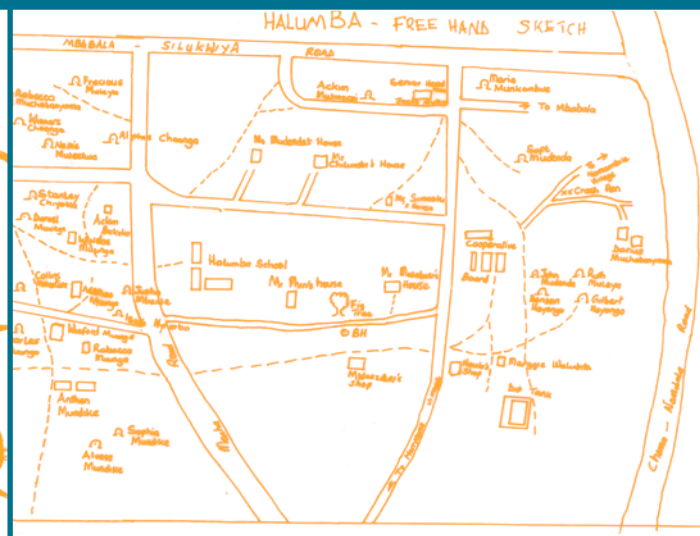
The Rural Site - Mbabala:

Mbabala constituency lies on the Namwala road to the north of Choma town in Southern Province. The area includes 36 villages, 1700 households, 21 settlements and a number of commercial farms. The population is 14,800 and the main ethnic group the Tonga. There is a small township, and several schools spread over a wide area. There is only one health centre that caters for the whole population. Research activities also extended to the north - namely Chilalantambo village (where the children's research was carried out) and Macha Mission Hospital. Mbabala, Chilalantambo and Macha all fall under

Chief Mapanza. Key-informant interviews and the children's research were also carried out in Choma town. Hunger was a big problem during rural fieldwork, because of drought and seasonal food scarcity. A rural blacksmith said of the hunger at the time, that people were eating wild fruits, looked thin and even stole to get food. "There is nowhere to get food", he said. In Mbabala township people have little access to safe water as the majority draw water from the stream, and the only borehole was at the Health Centre.



Mbabala



Halumba/Mbabala

¹⁹ See Kelly et al 1997, 2002 and Ndubani et al 1998, Ndubani 2002 for a detailed analysis of HIV, STDs, diarrhoea and reproductive health in Misisi compound.



Stage of HIV and AIDS epidemic in Zambia

Out of the three countries involved in this multi-country research, Zambia had the highest HIV prevalence. It was evident in the comparative data that this had an impact on stigma, with more stigmatising actions linked to the extreme fatigue of households and communities.²⁰ Prevalence rates in adults aged 15-49 years are estimated to be 21.5%, with variations between urban and rural areas. Around one in four households have experienced an HIV related death [UNAIDS 2002]. Young women aged 15-19 are five times more likely to be infected than young men in the same age group [CBOH 1999]. Lusaka and Southern Provinces (where the research was carried out) have the highest HIV prevalence - in Lusaka Province 22% of adults (aged 15-49 years) and in Southern Province 17.6% of adults are estimated to be infected with HIV [ZDHS 2002]. Eighteen percent of the child population in Southern Province²¹, and 17% in Lusaka Province, are estimated to be orphans [UNICEF 1999].

Recollections of deaths from HIV and AIDS stretch back to the early 1980s in both the urban and rural sites. Respondents recollect first who the person was, then their fears about being near them, the horror of the symptoms and the fact that HIV and AIDS is incurable. These memories point to many of the causes of HIV-related stigma - fear of contagion, fear of being physically frail (and even disfigured) and fear of death.

"I did see someone who was suspected to have HIV/AIDS - people were even fearing to get closer to this person, that was in 1986 when I knew there was AIDS. The person died and from there I knew AIDS had no cure....you get thinner and thinner until you die". [pregnant women, urban]

In our data it is apparent that people are very pre-occupied by the impact of the epidemic. In the stories that people shared with us, it is striking and distressing how many HIV and AIDS deaths families have had to deal with. Often the family left behind have many questions left unanswered and look for someone to blame for their loss.

"My young brother was married and divorced this woman, and this other man married my in-law and she got pregnant. After delivery this baby died, because of the man who was infected but the woman did not know that. After sometime that man also die. Another man again married that in law of mine. They had a baby, that baby later died and then the man died. So we were just looking what was happening? Where was the problem?" [men farmers, rural]

As a result of HIV, some families are very fragmented and vulnerable.

"We do not have parents - they all died. Even the parents to my parents all died. So even

²⁰ The children's research (see Clay et al 2003) and the section on poverty in this report explore this type of stigma in detail.

²¹ In the rural research site, at one primary school accessed by four villages, 72 of 350 pupils were orphans (21 double orphans) [2003].

these children I am keeping the mother also died. This one [her sister] is the only one who is alive but all her children died as well. But even this one is not well. She is sick with TB and and off just like that - admissions, injections. The one looking after us is our brother. He is a businessman". [woman TB patient, rural]

There was no denial in either site about the existence of the epidemic. Indeed, many respondents were open about HIV within their own families and amongst their friends. For example, an urban politician talking about friends who are HIV-positive says, *"these things are not new now. They started a long time ago and why should I claim that I will never be affected. I've been affected through family, friends, relatives...."*

Talking About Stigma²² in Zambian Communities

In many Southern African languages, there is no commonly understood word for stigma although there is often a word for discrimination [ICRW 2002b]. The first step in understanding stigma therefore is to find words to talk about it, and then to bridge any gaps between what terms officials and academics use and what terms the community use [Mbwambo et al 2002].

We tried to establish in the household study (which started before the wider community research) whether there was a single word for stigma in the vernacular by exploring the concepts of disgust, scar, spoil, tainted, disgrace, degrade and disrespect. We also discussed the leper parable, the stigmata of Christ and a story of a young man who was chased by his cousin's wife when he told her he had TB. But it was hard to establish an equivalent word for stigma in any Zambian language²³. Some of the

household respondents and community respondents had heard the English word before and related it to TB prohibitions, 'bad' behaviour, shame, fear and to the stigma of a flower. Overall, the majority of respondents were not familiar with the word stigma.

"Yes, we have heard about it, like those with TB. They say don't be very close to them because you are going to be infected". [elders, urban]

"Sometimes it is heard. Sometimes if a person tells you that you are stigma, then you don't feel ok. Then you can know that what you are doing is bad". [HIV-positive woman, urban household]

"Fear of what you don't know. Fearing shame". [HIV-negative man, urban household]

"I have heard about it - that is in science, Stigma of the flower, that part of the flower. That is the male part of the flower". [teacher, urban household]

The more educated respondents - NGO managers, health workers, politicians, priests - were more likely to know the word stigma but - like all of us - found it hard to define.²⁴ Stigmatising behaviour was often described both as using 'bad' language about, and bad treatment of, people suspected to have HIV and AIDS.

In order to talk about it within the research communities, we therefore decided to avoid using the word 'stigma', and instead used pictures²⁵ and the following phrase:

Sometimes TB patients or people who are HIV-positive are treated differently just because of

the disease they have. At times, this can lead them to being segregated, even by their own families or friends or in workplaces. This can make the TB patient or the person living with HIV feel isolated and depressed.

It was much easier to establish an equivalent term for discrimination, namely - *akapatalula*, meaning the isolation of an unwanted person. It is a Bemba term but is used quite widely amongst different language groups.

Language²⁶ and Stigma

"The metaphor implements the way particularly dreaded diseases are envisaged as an alien 'other', as enemies in modern war; and the move from the demonization of the illness to the attribution of fault to the patient is an inevitable one" [Sontag 1991].

In Zambian society, people often use innuendos, in the form of riddles, metaphors and euphemisms, to convey a point. This is evident in the rich, varied and harsh language that has evolved around HIV and AIDS. Metaphor is central to how HIV-related stigma is expressed, shaped and perpetuated as reflected in the different terms collected for people living with HIV and AIDS and TB patients during the research. Over the space of two days, during the community trust building, in the urban site 104 terms were collected, and in the rural site 62 terms were collected. The number of terms indicates, in part, the depth of discourse about and the prevalence of HIV and TB, with younger people recalling the greatest range of terms.²⁷ The higher number and greater range of terms in the urban site²⁸ reflects the diversity of ethnic groups and languages, the use of slang in town amongst the youth, the visibility of HIV and AIDS in a high-density environment and the more frequent use of public slander in the towns. In the village²⁹, where networks are smaller and retribution more common, public defamation of character is not so easy to get away with.

"They always say these words behind their backs, because if he listens, you can be charged for that. It is like an offence". [men farmers, rural]

"When he is passing, you find that people would just definitely call names like 'niyamene' [it is the one] and this person, if he is sensitive enough, will sense it". [pregnant women, urban]

Falling sick with diseases that people associate with HIV and AIDS usually instigates name-calling. Most of the TB patients in the household study recall people gossiping and calling them names. The home, the clinic, the market and the bar are settings that lend themselves more to calling people living with HIV and AIDS names to their face. Whereas in church, school and the neighbourhood, people tend to use such terms behind the backs of people suspected to have HIV and AIDS.

"They use all these names behind their backs. Sometimes they can shout or point at the person". [secondary school boys, rural]

"Others say it openly - that it is their own fault. But mainly people say these words behind backs, although they do fear that it might affect that person if they keep on saying things". [gatekeepers, urban]

The terms can be grouped into nine different generic categories - the three most common being terms to denote individual deviant behaviour, physical frailty analogies and metaphors, and, impending death euphemisms (see Table 1).

The terminology is dynamic, influenced by popular culture (for example, songs³⁰), events (for example, 'eclipse'³¹ or 'ICASA'³²) and by HIV education messages. Although some terms reflect how people have accepted the existence of HIV/AIDS, most of the categories are harsh and negative with strong

²² The word stigma is of Greek origin referring to bodily signs designed to expose something unusual and bad about the moral status of the signifier [Goffman 1963].

²³ It is possible that if we had asked about moral infractions that we might have had more success. Hugo Hineflaar, a social anthropologist, suggested that the Bemba word - *icilema* - might be equivalent to stigma. *icilema* means taboo, failure, social stigma, handicapped, not normal, that you have committed an act that is harmful to the community. For example, committing adultery whilst a wife is pregnant is *icilema* - an act that threatens the life blood of the community and breaches the moral code - and could cause the woman to have problems in labour. *icilema* can cause slimming. The Bemba associate HIV/AIDS and *icilema*, commenting about HIV, *"it is not something new"*. The Nyanja equivalent is *mdulo* (*kudula* to cut), a term used when people breach the behavioural code [Hineflaar, personal communication, 16/01/03].

²⁴ In Tanzania, Mbwambo et al [2002] found it easier for people to talk about HIV/AIDS related stigma using phrases of perceptions, actions and descriptions than to associate it with a single word.

²⁵ The pictures we most frequently used was a thin man sitting on his own on a bed, a woman seated surrounded by people standing with their backs to her (see Nyblade et al 2003) and two dejected children.

²⁶ For a more extensive analysis of the relationship between language and stigma, see the Tanzanian country report - Mbwambo et al 2003.

²⁷ Despite the research assistants trying to get people to distinguish between the names they used for TB patients and those that they used for people they suspected to have HIV/AIDS, respondents said that they used the same terms for both. It is possible that more probing could have revealed that some terms are exclusive to either TB patients or people suspected to have HIV/AIDS. Nevertheless, terms used for both are one indication of the strong association between TB and HIV/AIDS.

²⁸ In town, terms were most often in either Nyanja or Bemba. English, Tonga and Lenje were also used.

²⁹ In the rural site, the terms were predominantly Tonga, with a few Nyanja, English and Bemba terms.

^{30 31 32} see page 22 footnotes

Generic Category	Urban Name-calling	Rural Name-calling
Individual deviant behaviour	<i>anawila posa gwila</i> - laid your hands where you shouldn't	<i>sibwaa muhule</i> - very promiscuous
Frailty metaphors	<i>Kanayaka</i> - the light is on	<i>makuku kunyamuka</i> - hangwire/coat hanger
Impending death euphemisms	<i>kalaye noko</i> - say goodbye to your mother	<i>chuumbwe chenda</i> - moving coffin
Accepting existence of HIV/AIDS	<i>yamene yasu</i> - "It is ours"	<i>chakabolela ndiswe</i> - it came for us
History of the epidemic	Eclipse	<i>ijuni</i> - big bird
Public disclosure	<i>kanatongoka</i> - shelled like a groundnut	<i>chigeela</i> - tool that shaves
Other diseases	<i>Pwetetepwetete</i> - continuous diarrhoea	<i>kakwekwe</i> - coughing (TB)
Burden of people living with HIV and AIDS	<i>ka bvute amako</i> - go and trouble your mother	<i>bulwazi bwa ndiyanda nyama</i> - the disease that makes one only want to eat meat
Witchcraft	<i>kadoyo</i> - insect	<i>wakalumwa akanyama</i> - bitten by an animal

Table 1: Name-calling of People living with HIV and AIDS and TB patients

moral overtones and, occasionally, black humour. There were no terms in either site that were sympathetic. In the village, there is more use of rural imagery - for example, '*wakasumpwa*' meaning 'rotten like maize attacked by grain borers' - and allusions to witchcraft. In the town, the terms are harsher and stronger, with deviant terms heed one on top of the other.

"Women with HIV and AIDS are called different kinds of names because their behaviour is unpleasing which led them to contracting HIV/AIDS. She is a prostitute, a sex lover and a sex maniac". [young women, urban]

Some terms span more than one category, with more than one meaning, touching on different infractions and judgements. This is demonstrated by the most common term used in 14 different settings in the urban communities by men and women - *kanayaka*.³³ The second most common term in town is *kaliyondeyonde*, meaning "getting thinner and thinner". In the rural site, the most common terms touched on: a late 1980's HIV education campaign which used a picture of an eagle swooping down on some wasted people (*chiyuni* - big bird); witchcraft (*kanyama* - animal); retribution (*nkandauke* - cut into pieces); sexual transgressions (*dikimunwa* - second-

hand clothes or sex workeres); and death (*chuumbwe chenda* - moving grave). The categories point to some of the underlying causes for the stigma that both TB patients and people living with HIV/AIDS face, and to how often women are blamed for the spread of HIV.

Individual deviant behaviour:

This category includes terms where the onus is on the sexual and moral deviance of individuals. The implication is that individuals are infected through their own actions, because they have indulged in "bad behaviour" - having sex with those they should not have sex with, having sex with too many other partners, taking a risk and getting burnt or caught out, through behaving as they should not. Many more of these terms apply to women than to men.

Impending death euphemisms:

These terms underscore how HIV/AIDS (and sometimes, by association, TB) are equated with a death sentence (it is widely known that HIV/AIDS is incurable in these communities). Some of the terms also imply that the individual is at fault for contracting the disease - "*you have chosen to die*" - and demonstrate how people living with HIV and AIDS are taunted with death both by others and by themselves ("*beaten by their own thoughts*").

³⁰ For example, the term 'Julia' originates from a Bemba song about a girl called Julia who has different chronic symptoms - diarrhoea, TB - and denies that she has HIV/AIDS, making excuses that she breached food taboos - has "eaten trotters" [pigs feet]. When she falls sick, she demands "mangoes out of season" - the demands that a person living with HIV or AIDS put on a household is often encapsulated in their demands for special foods. Finally she gets dementia. The song ends by saying that this can happen to men as well. Another term 'Sandra' also originates from a very popular song by the Sakala Brothers about a girl called Sandra who "takes life fast", dressing in short skirts.

³¹ Another analogy for impending death since the light goes out when you have a total eclipse. In June 2001, there was a total eclipse of the sun in Zambia.

³² An international conference on HIV and AIDS held in Zambia in September 1999.

³³ See definition on inside cover.

Frailty analogies and metaphors

(Physical Appearance):

When people living with HIV and AIDS become symptomatic with certain diseases and begin to lose weight, they are exposed. The images of TB patients and people living with HIV and AIDS as wasted and worn out are captured by this category. Past sexual prowess is replaced by physical frailty - a person living with HIV and AIDS is a "*sick lion*".

Targeted at People Assumed to be HIV-positive

In Zambia, around 11% of people know their HIV status and access to VCT is limited, especially in the rural areas [ZHDS 2002].³⁴ Most of the time, therefore, stigma is directed at people who are assumed to have HIV and AIDS, and who often do not know themselves what their status is.³⁵ The following dialogue between young women in the rural site captures what we have coined as 'community diagnosis' of HIV; that is a diagnosis made over time and based on signs, symptoms and behaviour.

Respondent 1: "*Mostly here in Mbabala, people do not know if they have the virus. Because at this Mbabala clinic there are no tests carried out. People will only know by looking and seeing the symptoms and long illness. So you will find they are sure but only suspect they are HIV-positive*".

Respondent 2: "*They know by seeing some symptoms because they know and were taught how HIV/AIDS symptoms are*".

Respondent 3: "*It is not everybody who knows. There are some cases where by other people will know when himself he doesn't know anything about his status*". [young women, rural]

The irony of others knowing without you knowing is not lost on these young women, as captured by the

last response. Elders in the urban site comment how whether people have medical proof of a woman's HIV-status or not, does not make any difference. If they 'know' or suspect she has HIV, they will, "talk about them in different ways - like "*You are a prostitute! You have finished our husbands in this community and you have even infected them*". *Whatever is said to those who are HIV-positive - the treatment is the same to those suspected to have HIV and AIDS*". [elders, urban]

Intersections between Poverty and Stigma³⁶

"It is very difficult to look after someone living with HIV and AIDS if you don't have money". [young men, urban]

"When someone is sick and the family is poor, there are talks over what to eat, small things which need money. This brings problems in the family. Where will the family get the money?". [Man living with HIV and AIDS, rural]

The Importance of Context:

HIV and AIDS related stigma and discrimination need to be understood and addressed within the wider social context and recognised as part of that wider context [Bond 2002]. Context is "other-things-happening" [Wallman 1988] - the economic, political, structural, cultural and personal environment in which human activity takes place.

Part of the context in Zambia from the mid-1970's onwards, is a process of economic downturn, hardship and 'community unravelling', characterised by a rising incidence of violence and accusations of witchcraft, increasing alcohol consumption, out migration from poor rural areas, family breakdown and declining fertility [Sichone 2002, Clark et al 1995,

³⁴ The Zambia Sexual Behaviour Survey [2002] had a lower figure - it reported that 5% of rural and 7% of the urban population as having taken a HIV test.

³⁵ This resonates with formative research done amongst the Tonga in Southern Province on PMCT where the community made the distinction between being told that one has HIV and 'knowing' that one has HIV [Bond and Ndubani 2000].

³⁶ Several themes in the FGDs and K.I. interviews touched on poverty - opening questions about major problems, questions about care and support and a direct question - "Are people living with HIV/AIDS in the household seen as a burden by other household members? If so, why?" Probe: Burden of nursing, burden of cost, burden of not contributing to household income, burden of relatives who come to stay. Probe: Same for a man and a woman?

Scudder 1983]. Deepening poverty is especially evident in rural Zambia and there is a glaring disparity in the distribution of HIV and AIDS programmes, with many more in the urban areas (especially Lusaka) [Concern 2003].

This section aims to tease out the elements of rural and urban poverty that fuel discrimination towards people living with HIV and AIDS and result in painful stigmatising experiences. It also aims to examine the relationship between women's inequality, poverty and stigma, and orphanhood, poverty and stigma.

People living with HIV and AIDS are a burden in the context of poverty

In a "biting economy" [15 year old boy, urban], people living with HIV and AIDS are considered a "burden" because, respondents say, they are not able to contribute to household income when they are **sick** and they undermine the income generating and progress of the household. During periods of illness, they soak up money, energy and time. Both they, and relatives, who come to visit them, take up space. People living with HIV and AIDS are perceived as a burden for other reasons not related to poverty (for example, an emotional burden) but it was largely the economic burden that respondents in these communities focused on.

In order to meet the needs of people living with HIV and AIDS, households fall back on informal coping strategies (selling assets, borrowing, stealing) and can feel overwhelmed to breaking point.

"..the fact that he was but now is not contributing on food and money, that becomes a problem". [stonecrusher, woman, urban]

Carers are not able to work whilst people living with HIV and AIDS are extremely sick. When illness reaches a "climax", it is "very involving, programmes come to a standstill" [young men, rural], "your day to day duties are disrupted" [young women, rural], "progress and incomes are disturbed" [hospice worker, urban], "they shatter all your plans and activities" [secondary school children, urban].

In order to pay for treatment, food, surf (to wash linen) and water³⁷, respondents often reported spending money and selling assets and sometimes reported borrowing money or goods or even telling lies and stealing. "Your resources are milked", explained rural men farmers.

"A lot of money or wealth will be wasted during that nursing period and, as a result of the illness, you tend to borrow a lot and tell lies". [young men, rural]

Sometimes there is simply "no means" of getting money and/or food - these are households where there is often little, and sometimes nothing, to eat or where people are anyway eating "unrecommendable food".

"people in this area are living under poverty I can say, very few people can manage to look after these people [living with HIV and AIDS] if you look at the current situation. As at now, people are just feeding on unrecommendable food "ka pamela" per day, chiwawa and impwa³⁸. They think that if they start again looking after those people there are actually putting themselves in problems." [social worker, man, urban]

Complaints about demands for "special food" from people living with HIV and AIDS included "demands" for "chicken", "meat", "fruits out of season", and "tomatoes". Sometimes the treatment that is considered unaffordable is panadol.

"If I am poor, for example, I will not even afford to buy a panadol for K100 but the rich go very fast and buy medicine, even if there is no cure". [gatekeepers, rural]

It is an indication of how stretched some households are that they mention tomatoes and panadol as beyond their budget. As an urban transporter pointed out, the needs of people living with HIV and AIDS are often not budgeted for and "a week's supply becomes days only".

There is often a desperate concern that you cannot meet the special needs of the sick and that you are

unable, if poor, to "accept them fully" [young women, urban]. You can want to take them to the hospital, buy the medicine they are prescribed and buy them the food they ask for but you just don't have the money.

"If you are short of food, you can decide not to eat, but if you have a patient, you need to find food". [orphanage care assistant, urban]

Relatives from the village (especially men) who come to visit the sick are an added burden, requiring additional food, space, needs, transport expenses. Space in the house is very often limited. This is especially true if the visitors are men, said urban pregnant women, "the men will just come for luxury and other stuff. Men are a burden".

If it is your spouse that is dying or that dies, there is the burden of being the only breadwinner - "both breadwinner and a widow - the burden is very much there" [health workers, urban].

But, even in the context of absolute poverty, there are certain relationships which withstand the strain, in particular parent-child relationships since "you cannot throw away your own" [elders, rural]. Partly, then people whom you "belong" to (chiefly close blood relatives) are obliged to care for you, especially in the village.

The quality of the past relationship, reciprocal relationships, individual character and the household status of the sick person also influences care and stigma. It makes such a difference whether the person with HIV and AIDS is an old friend, family member, neighbour, stranger or someone you never much liked anyway [Bond 2002]. "It depends on how the patient used to relate to you before he or she got sick", explain urban TB patients, "If you were not good, you easily become a burden".

"There are some people even when they were okay they were so useless to the family and when such people are found in a situation, yes they are considered a burden". [headmaster, urban]

How you get treated depends partly on your household status - with previous breadwinners less likely to be stigmatised - and more junior or marginal members more likely to be stigmatised.

Spiralling poverty, needs and neglect:

Over time, when spiralling poverty is pitted against spiralling needs, "poverty flows in" [pastor, rural] and this can lead to spiralling neglect. It is an illness that "takes too long" [politician rural], involves "very special care" [bar owner, urban], and, "even when they are supposed to die it takes time" [community health workers, rural]. Underlying this fatigue is the knowledge that HIV is an incurable disease and that no matter what you do, the patient will eventually die. The fact that the illness takes a long time drags households down, and the more you continue to look after a patient, the more money you lose. An NGO manager comments that even if you thought you could manage to care, you gradually lose patience and can eventually give up. Even urban health workers lament, "it can be an added burden, it is too much and especially when they become more sick and when they carry on to get more and more sick, it can become difficult". Rural secondary school girls relay, "booking taxis taking the person to the clinic if the person is very sick. The hospital costs nowadays are very high and the food [costs]. When the person dies you find that all the money was spent on the sick person".

The language used by households in relation to caring for people living with HIV and AIDS included: "no, I cannot bear with this kind of problem" [NGO manager, rural], "tiresome" [bar owner, urban], "it is burdensome" [traditional healer, rural].

Over time, as fatigue sets in and poverty worsens, households are likely to develop negative attitudes to people living with HIV and AIDS who are then are more likely to experience different forms of stigma³⁹. They are accused of wasting time and money, and, basic needs like treatment, clean clothes, linen, food and emotional support are not always met or even cut out. Some people are sent elsewhere, often back to the village. Households say they are "not prepared to handle" [health worker, urban] the people living with HIV and AIDS.

³⁷ In both urban sites and Mbabala township, people had to pay for water, and water was in short supply.

³⁸ "ka Pamela" - a small bag of maize meal (usually half a kilogram), *chiwawa* - pumpkin leaves and *impwa* - small wild yellow eggplants.

³⁹ See Experiences of Stigma in this report and Nyblade et al 2003 for more detail of the different forms of stigma.

"If someone has been looking after a HIV-positive person for a long time, he will think 'I am just wasting my time. Why should I care for this person? He is just spending my money for nothing - after all he will die.....after a long time the care will drastically change'".
[young men, urban]

"...the poor even segregate the patient because there is nothing they can do to help".
[secondary school pupils, rural]

Respondents reported that sometimes you actually want the patient to die, or, are advised to let the patient die.

"...other relatives who are spending on that person would you advise you to do it roughly so that he dies then they spend on the funeral".
[traditional healers, urban]

"They [the carers] will start preparing for the funeral and raising money for the coffin, instead of buying food and some stuff".
[young men, urban]

Powerlessness of poor people living with HIV and AIDS:

The powerlessness, marginality and vulnerability of poor people living with HIV and AIDS who are sick was widely acknowledged, and attributed to the fact that they have nothing to offer and are therefore "overlooked" [young men, urban]. Similar to street kids, children out of school and sex workers, they are almost invisible and unaccounted for.

"...you who is dog poor, they [community] just pass by you, not looking at you".
[TB patients, men, rural]

"...[people living with HIV and AIDS] are unwanted and unprotected....if there is no-one to help them, the poor die".
[young women, urban].

"Because of the hunger situation, it is a problem. You find that when one is poor, there are a few to nurse him". [gatekeepers, rural].

The situation of the poor was a sharp contrast to the rich. As urban secondary school children candidly observed, *"The poor live one year, the rich ten"*. There is a strong sense that having HIV and AIDS is very different for people with money - that their money buys them more space to hide, live longer, helps cushion the impact and allows them to more easily find support and love. In the urban area, primary school children mentioned how the rich could exchange their "contaminated blood" for clean blood and a number of other respondents mentioned how the rich could go outside the country for treatment. A few respondents mentioned the rich being able to buy anti-retrovirals.

"Since they introduced these ARVs, the rich man can easily manage to get them while the poor can't because they cost a lot of money".
[secondary school girls, rural]

A business woman in town commented that the differential treatment of the rich and poor "starts from hospital up to homes". There was evidence that the rich received preferential treatment in clinics, and the ulterior motive of looking after rich was often mentioned - "people are after his wealth" [primary school boys, rural]. Indeed, the rich were reputed to have no problem in finding bedside carers, "but if it's a poor person, this one has just a pair of *Tropicals* [flip flops], what can he leave behind? So they abandon him" [secondary school boys, rural]. So for people living with HIV and AIDS, as a rural headman so vividly described, "the disease becomes deeper and deeper".

"With the rich, you find even if he has soiled linen, many people will be willing to wash them, while for the poor, they will just leave everything, being there is no soap, a lack of water nowadays and the person will be sleeping on dirty linen and the disease will be even worse". [pregnant women, urban]

Poor people are more likely to accept humiliation - "poor keep quiet and accept any treatment" [secondary school pupils, rural]. One example of accepting humiliation is a TB patient, whose elder brother chased him out of the house when he revealed his TB diagnosis, and who waited outside until his elder brother came out and "gave me what

I wanted [cash] - I didn't bother getting annoyed"
[urban household].

People living with HIV and AIDS who are poor have less space to hide from stigma when they are sick, they are sick more often, and they "die faster" or "when they are not supposed to" [headman, rural] and occasionally alone. Their funerals are more likely to be shorter, cheaper and involve "less crying" [man living with HIV and AIDS, rural].

Poverty, Orphans and HIV and AIDS Related Stigma:

Both this material and other literature points out and demonstrates how stigma deepens existing inequalities and exclusions [Parker and Aggleton 2003, Bharat 1999, Gilmore and Somerville 1994, Goffman 1963]. As the children's research demonstrates (see Clay et al 2003), orphans often experience differential treatment in the household. One of the main causes of this is being an orphan in a poor society. To take in additional children when "the economy is very bad and mostly families are failing....is really heavy" [women TB patients, rural]. Their "needs are always a second priority" [development officer, rural], and poor guardians are forced, or decide, to withdraw education, adequate food and clothing from orphans. Orphans are regarded to be "wasting money" [secondary school girls, rural]. You can "have the heart of looking after the children [orphans] but how?", exclaims an urban nursery school teacher.

"Small ones who can't do things on their own are especially a burden".
[woman, urban household]

"In our Zambian society, it is our custom to look after people, if my brother has died, it is my duty to look after his children, but because of these economic changes, we are not able to look after the children, because of the economy...". [Head teacher, urban]

Even your own children can be considered a burden in the context of poverty. An ex-TB patient in the household study explains how when he was sick, "my son was a burden because I was not working", and rural women TB patients explain how "Parents

don't have enough to give to their own children". Clay et al [2003] show how treating orphans as a burden can spark off a cycle of vulnerability and increased risk-taking, especially for girls.

"Yes, they are seen as a burden because it's not possible for one to spend a lot of money on medicine, transport, food, instead of using it on one's own children for school".
[peer educator, urban]

Women, Poverty and HIV and AIDS related Stigma:

Respondents considered women more vulnerable to deepening poverty and stigma. Women have less income generating power so if their husband is sick, the "financial problem in the house will be very big, they finish all the money and will end up selling furniture" [secondary school girls, rural], and the wife "will take all the responsibilities" [traditional healers, rural]. Urban TB patients think that women are also more dependent than men on relatives for money, and the relatives "easily get fed up, complain and later stop [giving help]". A member of a drama group in Misisi pointed out that when husbands are sick, women are sometimes forced into sex work in order to raise money for their husband's medicine.

"Women in this community depend on their men or their husbands. It becomes a big problem if a man gets sick because he won't be able to bring money or food at home".
[teacher, urban]

The burden of caring for the sick falls largely on women and this takes time away from caring for children and earning their own money since their "duty becomes only taking care of that sick person" [community health workers, rural].

If their husband dies first, women and children will often suffer. A widow in the household study said that she worried after her husband died and his business closed that she wouldn't "have the means to look after the children". In the event, she moved out of the house they lived in and owned, and rented it to give her an income. The custom of property

⁴⁰ Property grabbing is a customary practice of a husband's family taking goods from his widow. It was made illegal in Zambia in 1989 in the Interstate Succession Act (No 57).

grabbing⁴⁰ can leave women and children in abject poverty.

"usually what I have seen when the man dies, the woman is mistreated, the relatives of the man would want to grab everything from the woman even forgetting the children. They will sometimes even call her names or she will be blamed that she is the causer. But when it is the woman who has died, the family from the woman will not bother the man..."
[gatekeepers, urban]

The combination of being a woman breadwinner and a widow⁴¹ is brutal and it is both harder for widows to raise enough money to get by and to remarry. Women - especially aunts and stepmothers - are often cited as abusing orphans reflecting the immense stress they are under [Clay et al 2003]. Urban traditional healers commented that women "shout" at their husband and children "because of HIV".

If poor women themselves fall sick, they are more vulnerable to "being chased" back to their parents, deserted or neglected by husbands, especially if they fall sick first or if they learn of their HIV-positive status first. A rural traditional healer commented that a HIV-positive woman, "will be isolated like a hoe without a person to use it" [traditional healer, rural]. A household comes to a standstill when a woman is sick because "not all that a woman does can be done by a man, so it will be at a standstill" [community health workers, rural].

Within poor communities, there is understanding, even coercion, around sex work until women or girls are thought to have HIV and AIDS, at which stage they are chastised, rejected and blamed - or the mother is blamed for her daughter's transgressions and assumed status. At that stage, the focus is not on the poverty but **how** she got infected and **she** is blamed for having transgressed. School children were aware of sex as a survival strategy, and how women are blamed if they fall sick. Looking at a picture of a woman seated surrounded by people with their backs to her, urban primary school children commented, "she was naughty so everyone

is reminding others what she used to do for money and no-one is willing to help her out". Secondary school boys in the same urban site related how "Nowadays, the biggest problem is poverty. You find in a family no-one works or goes to work, so she [the mother] will decide to go and have a temporal affair so she can raise some money".

"For women, people like pin-pointing their mothers that they are the ones who used to send them so that she brings money, especially in Misisi". [TB patients, urban]

Women in general are more likely to be deserted by their husband, or sent back to their family, when they are sick. If they have no close family to return to, they are deeply vulnerable to neglect.⁴²

"If you don't have a mother, no children you will have problems. Relatives don't usually help. I say so because I witnessed this myself. A woman was sick her husband runs away from, she had no children only her relatives were there. If you don't have relatives, some are buried very dirt, masked with faeces".
[traditional healers, urban]

In poor communities, sex workers are extremely vulnerable to not being cared for when they are sick. The only case in respondents in town recalled of a woman who died uncared for was of a sex worker.

Text Box 1: Extreme neglect - the lonely death of a sex worker

"A woman, a patroniser at the Cockpit [bar], she just died. She was sick for a long time and the relatives just abandoned her, they organised a small girl relative, who was sleeping with her the time she died. She didn't even know her aunt passed away. She just said "oh this is the way the aunt sleeps, she is sleeping". The rats also started chewing the body parts, now after that odour the body started decomposing, the neighbours started saying the neighbour her, I don't see her, smell, flies".
[politician, urban]

"No support or visit from neighbours because they regard us as outcasts or "not human beings" because of our business... If I then get sick, they wouldn't even give me water if I needed it... They always wish us to die...It's not our wish to be called sex workers but it's due to poverty". [sex worker, urban]

Poverty, Blame⁴³ and Stigma:

Within explanations of poverty, underlying judgements often creep in to justify the stigmatising actions. The implication is that poor people living with HIV and AIDS - more especially poor women and children - are blamed for their predicament.

"Orphans are neglected or isolated so to say or they can become the laughing stock of the streets. It is people that say your parents died of HIV/AIDS, no wonder you are now orphans. They are seen as a burden due to our economic status, which makes it impossible to take extra responsibilities of looking after others including your own. They are said to be upcoming street kids whose parents are soon dying of HIV and AIDS". [young men, urban]

"Household members some of them they say it is a burden and some of them are the people killing their own children very fast. They leave them to die slowly, painfully because they insult them and say bad names - "You alone went making money" and allsorts of words, which makes the patient have depression. They stop buying medicine..."we can't manage"... "If you want this type of food", they say you have to eat what we have because we have no money. We never costed but you costed all these, all the problems you have brought into this house." Others are shunned very much". [nutritionist, urban]

Often it seems as though people are also aware of what they are doing - almost as though they are justifying why death has selected one person and not another. And there is recognition that the bad words, the complaining adversely affect the patient.

⁴³ See Experiences of Stigma for a more detailed discussion of blame.

⁴⁴ As mentioned in the description of the study sites, the rural fieldwork was conducted during a period of food scarcity, which exacerbated household stress.

⁴⁵ People may want to die or be buried in the village, close to their ancestors.

Urban health workers, discussing how a family with no income and no other support cannot care for people with HIV and AIDS, comment, "you start complaining deep down in your heart, so even the patient won't get well because you are complaining".

Rural poverty⁴⁴ and Stigma:

Some urban families will not have rural ties - but for those that do (especially the more recent migrants), there is a trend of people suspected to have HIV and AIDS, and orphans, being sent back to the village. A rural traditional healer commented, "...the village is now the dumping ground", and young rural men said that people in town were "throwing" the problem to the village. The motives for doing this include: spiritual connections⁴⁵; close family ties in the village; and the tradition of care in the village - what rural gatekeepers called being cared for in "your own circles". But other motives are more discriminatory - wanting to grab property in the town; wanting to get rid of the problem; not having enough money to cope; and that funerals are cheaper in the village - people often die at home and can be buried just in a blanket or a homemade coffin.

The irony of this trend is that - in the face of limited food and services and support - people living with HIV and AIDS will die quicker in the village. There are stories of children resisting attempts to send a surviving parent to the village, and, comments about how people who are sick in town and return to the village, will not have the friends in the village to support them (recognising it is especially hard to forge friendships when sick). Returning sick and in need of help to the village is not as life should be - people in the village look to urban kin to support them. And it is clear that those relatives who had supported rural kin whilst in town are much more likely to be cared for than those who did not and were "eating their money alone" [transporter, rural]. Village kin also worry that they are not able to give their town relatives the lifestyle and food that they are used to.

⁴¹ Stephen Lewis calls the combination of hunger and HIV the "the most ferocious assault on women ever" [Stephen Lewis, UNICEF, 2003].

⁴² See the Stigma and Opportunistic Infections section for another story of a woman TB patient being abandoned - this time by close relatives. She was a woman who did not have any children.

"In the village, we look forward to these people who are in town to help us, but if they come sick, it's an added load, it's a burden". [pastor, rural]

Seasonal food scarcity and farming activities make it hard to care adequately when people living with HIV and AIDS are sick during the farming season⁴⁶ - farming activities cannot be postponed easily, and rural respondents complained bitterly about not being able to farm properly due to the care demanded by people living with HIV and AIDS.⁴⁷ Economic options are much more limited in the village and it is harder to both generate and borrow cash in crisis.

"This patient at home has disturbed them. They don't finish the work at the fields properly. The patient also complains to them saying that they take a long time to give him food. They will also say that, "At the field that is where your food comes from". They will blame the patient all the time". [women farmers, rural]

Urban Poverty and Stigma:

People in the village realise that it is better to be in town if you are HIV-positive and sick. They pinpointed institutional care in hospices, HIV and AIDS activities (clubs, NGOs, Home Based Care (HBC) organisations) and more HIV and AIDS information as the advantages of being in town, and said that people living with HIV and AIDS would live longer in town. Indeed, in the context of the extreme urban poverty of Misisi, if people are unable to cope with people living with HIV and AIDS, they can and do turn to the hospice, HBC, churches, orphanages, Umoyo training centre for girls and the Fountain of Hope. There are simply more places to turn to when people can no longer cope at home. For example, urban respondents often mentioned taking patients to the hospice when they could not cope.

"..like financially, they would rather not keep them at home and will take them to the hospice if they are very sick". [gatekeepers, urban]

⁴⁶ The farming season starts in October, with clearing the fields, and runs through until May when the fields are harvested. Vegetable gardens and gathering and selling wild fruits are often dry season farming activities, but not so labour intensive.

⁴⁷ Cliggett [1997] and Moore and Vaughan [1994] write about how old people and young children are often neglected during the farming months, and left without adequate food and water in the house whilst people work in the fields.

"If..you cannot afford to look after an HIV patient nowadays, we have home based care centres where they give support. These people will give assistance". [elders, urban]

There is also more cash in circulation and it is easier to borrow money or raise cash. However, looking after people living with HIV and AIDS does deepen poverty in town, as well as in the village. It can stop people going to work or force them to take leave. Households may even employ someone to care for the sick person, or, if people are involved in the informal economy (stone crushing, trading), it can result in reduced business. It can be an excuse for relatives to come from the village and these relatives, unless women carers, are regarded as an added burden.

Root Causes of HIV and AIDS related Stigma in Zambia

It is often easier to recognise the forms and consequences of HIV-related stigma than it is to identify the causes. In training and toolkit workshops, understanding what caused stigma was critical to formulating research questions and to anti-stigma action. The root causes of HIV related stigma in Zambia are: firstly, the process of assigning the spread of HIV to more dis-empowered groups and distancing one's own group and identity from the risk of HIV. Secondly, the association of HIV with improper sex and the accompanying moral discourse and judgements. (The role of the church in the latter is explored in depth.) Thirdly, stigma is caused by the association of HIV with death. The fear of non-sexual transmission of HIV and AIDS is the fourth cause. The complicated relationship between knowledge and stigma is a fifth cause, and not recognising stigmatising actions and language a sixth. And the disruptive nature of HIV and the lack of a HIV and AIDS policy are the final causes identified in this research.

Usually, combinations of causes are what actually cause stigmatising actions. People fit pieces of

Text Box 2: Causes of HIV and TB related Stigma

Case Study of Peter⁴⁸, a 22-year-old cobbler, who is HIV-positive and has suffered (and been cured of) TB. When he found out he had TB and was HIV-positive, he told his sister and his wife. His wife deserted him, taking all the household assets with her, and his sister took him and his young son in. Although she was instrumental in helping him get diagnosed, treated and cured of TB, whilst he stayed in her house, his sister verbally abused and teased him (used "words of hate") and made he and his young son eat separately from her family. She also gave them less food. The other household members isolated him, the neighbours used to talk about how he was sick and people in the community called him "kanayaka". When he got better, he left her house and rented his own, resuming his business. Peter comments how people were surprised how he had got better, and that he has become "a good teacher because of the experience". He has resumed a sexual relationship with his wife and hopes to reunite with her. Peter is very sociable, and drinks and smokes marijuana, and says he copes with stigma by being friendly to everyone - which makes it harder to stigmatise him. However, his sister's husband confided in the counsellor that he saw Peter as a "problem", and he condemns him for his drinking and his sickness. "If he tries to stay here again, I will chase him and his sister out of my house!", Peter's brother-in-law proclaims.

people's lives together - their past history, their past relationship with that person, symptoms, deaths in the household, their identity - and it is the combination of these that dictate the degree of stigma. Bad relationships, low or high status, marginal groups, household and clinic settings are linked to more pronounced stigma. The case-study in Text Box 2 reveals how a young man experiences a range of stigmatising experiences sparked off by his HIV and TB diagnosis. The stigma he experiences is related to: his HIV status; his TB diagnosis; his social transgressions (drinking and smoking marijuana); his sexual transgressions (multiple partners, history of sexually transmitted infections); his dependency whilst sick; and his junior status.

The way in which the local meaning of the epidemic is linked to certain groups is illustrated in chart 1. The chart depicts groups most frequently mentioned as spreading HIV and arranged in a hierarchical order with the groups ranked as most responsible situated at a higher position in the diagram. A guilty - innocent continuum illustrates how certain groups are considered guiltier than others. Those considered the most guilty are situated at the far left and those the most innocent situated at the far right.

The "us" and "them" boundary: One of the main causes of stigma is how dominant representations⁴⁹ throw up a boundary between "us" and "them". "Us"⁵⁰ is us the morally up-right, 'normal' and uninfected. "Them" is the 'other' immoral, deviant and infected. HIV is linked to "them" - groups with which respondents do not identify, and thereby the in-group identity and self-identity is protected. The boundaries between "us" and "them" drive, perpetuate and cause stigma. Breaking down these boundaries is key to anti-stigma education.⁵¹



Groups associated with the spread of HIV and AIDS⁵²

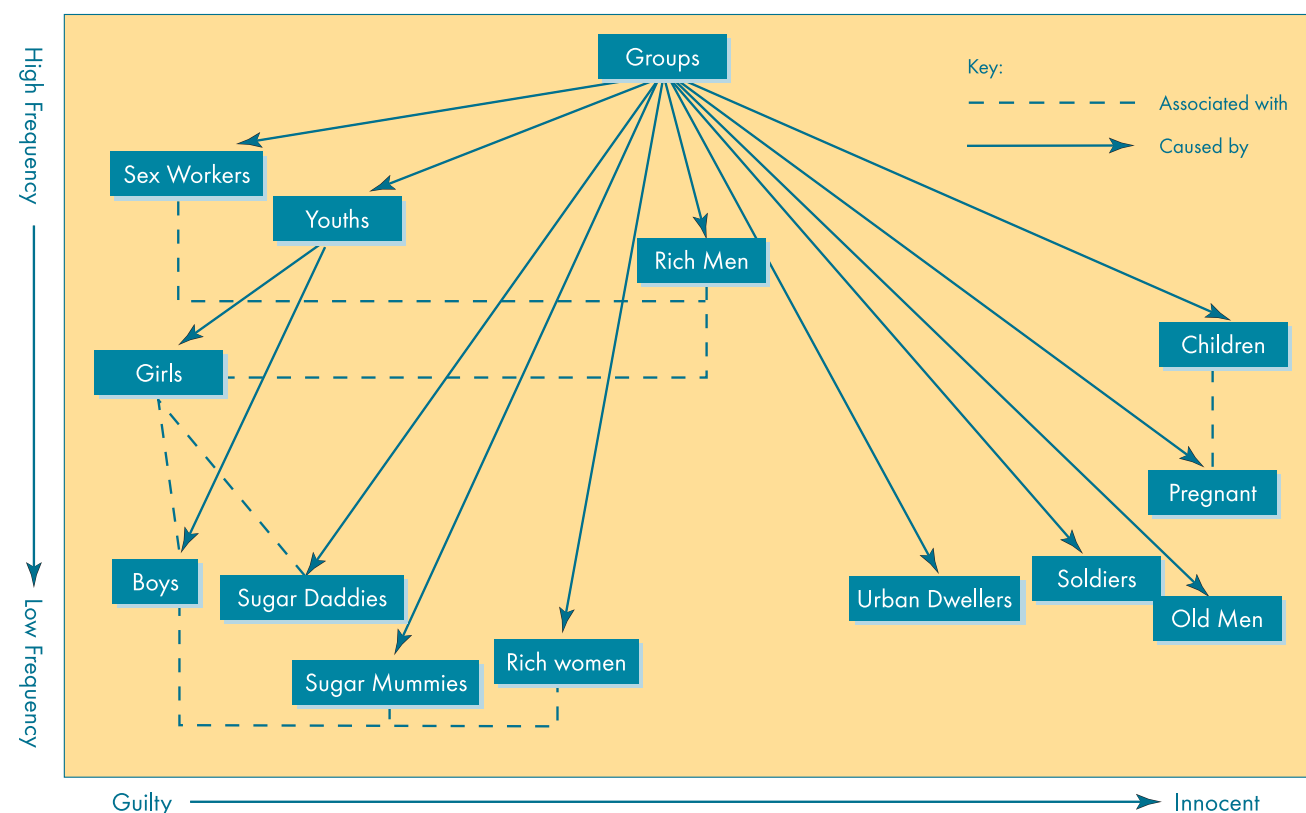
⁴⁸ This name is a pseudonym.

⁴⁹ Similar to hegemony, dominant social representations are the norms, values or shared ideas that dominate and control a society [Moscovici 1961]. These representations will often hold dis-empowered groups as responsible for HIV and AIDS. These groups may well end up internalising these representations [Joffe 1996].

⁵⁰ "Us" is sometimes labelled as the 'in-group' [Joffe 1999]. And 'out-group' refers to a group with which respondents clearly do not identify.

⁵¹ See Kidd and Clay 2003, 'Naming the problem' module in the anti-stigma toolkit.

Chart 1: Groups associated with the spread of HIV/AIDS



• **Sex workers:** The vast majority of the respondents view sex workers as playing the leading role in the spread of AIDS - "They say the nation is really in trouble due to sex workers" [teacher, urban]. The extent to which sex workers are negatively valued is particularly evident in how they are dehumanised, referred to as mere "sperm chambers" [social worker, urban]. Once debased, sex workers become a repository for blame, and are deemed guilty of selling sex due to lack of money or, (considered even worse), their "love of money".⁵³

• **Youths:**⁵⁴ After sex workers, youth are the group most commonly implicated in the spread of HIV/AIDS. A dominant theme here concerns the sexual relations that adolescents have with older men ("sugar daddies") or women ("sugar mummies") in exchange for money or gifts or school fees. "Those who are likely to be infected are school going girls and boys because girls like sugar daddies that may be supporting them ... This also applies with boys who also like sugar mummies for support" [religious leader, urban]. Young people are

also reputed to ignore knowledge or advice. "The information people are getting is straightforward... The older ones just advise us... The problem is the youths, who are stubborn... We have the message but we are not doing what the message is saying" [peer educator, urban].

• **Adolescent girls** are more likely to be implicated in the spread of HIV/AIDS compared to their male counterparts and it is vital to note that both sex workers and young girls represent less empowered members of the society.

• **Rich men** are the next most likely group to be implicated in the spread of HIV and AIDS. Wealth enables them to have good diets and access better treatment, which reduces the appearance of symptoms, rendering them healthy and attractive. Their affluent lifestyle increases the risk of infection in that it attracts women (particularly sex workers and young girls) and they can afford to drink. Although they are guilty because they show off their money, rich men are also described as the innocent "victims" of sex workers and young girls because they (like all men) lack control, need sex and are

under the influence of alcohol. "The man in a suit looks strong [healthy] and moves too much because he has money which is an attraction to sex workers therefore he is likely to be infected" [traditional healer, urban].

• **Urban dwellers:** Decadent urban dwellers are sometimes blamed for bringing HIV and AIDS to rural communities. "Those from town, they bring it to us. [They] come to do business and lure our girls... or a certain man, maybe he goes to town to sell and sleeps with someone there" [NGO worker, rural].

• **Soldiers:** Soldiers embody the notion of masculinity and their 'immoral' behaviour is somewhat excused in that extra-marital affairs are seen as the result of being stationed away from their families for long periods of time, leaving their male sexual drives unsatisfied. This in turn renders them unable to resist the temptations posed by seeing other women.

• **Old men** are seen as innocent, or less guilty, as their chances of being infected by sexual contact are slim. This is due to the fact that their sexual drive diminishes with age, they are "out of business" [retiree, rural]. However, the possibility of contracting HIV still exists through contact with contaminated instruments, nursing infected family members or the temptations of women.

• **Pregnant women and children** are seen to play a role in the spread of the epidemic but are represented as relatively innocent in that they often contract HIV through circumstances over which they have little control, for example through being infected within a health setting through a dirty razor blade or needle or, in the case of children, from their mother. However, there is still a possibility of guilt. Pregnant women may have had extramarital affairs or multiple partners, and children may have inherited the "bad" behaviour of their parents (see Clay et al 2003).

Because HIV and AIDS is ascribed to groups with which most respondents do not identify, this leaves intact a strong group and self-identity and results in a diminished sense of vulnerability towards risks.

Not all groups are afforded identity protection, some are considered guilty and "deserve" to be punished or stigmatised, whereas others are innocent victims. Our research demonstrates that those in the former group - for example sex workers and youths - do recognise and internalise the representations of the group they belong to.

Stigma as a Coping Strategy for Risk:

As a direct consequence of the associations described above, most respondents are left with an unrealistic sense of invulnerability to being at risk from HIV. Stigma therefore serves to distance people from risk and danger. Danger is threats that are both tangible and symbolic⁵⁵. Our motivation to avoid danger is often followed by an "often exaggerated perception of characteristics that promote threat, and accompanied by a social sharing of these perceptions with others" [Stangor and Crandall 2000]. This process perpetuates stigma, creating an unrealistic sense of invulnerability. In-group and self-identity might be protected through the projection of blame onto out-groups, but it creates an environment in which testing and disclosure are indications of guilt and a society where out-groups are increasingly stigmatised. This argument is illustrated in Chart 2 (page 34), with the dotted lines representing the links with stigma, and the hard lines the process of stigma and the impact on HIV transmission.

Stigma in the form of blame is seen as a way of 'taming' disease, and, ultimately death. Blaming the infected for bringing ill health and death upon themselves results in a perpetuation of 'the other' or 'out group' and a protection of 'the self' and 'in group'. It provides reassurance that 'I am not like them, I do not do things that they do, therefore I am not at risk'. HIV and AIDS and the resulting stigma feeds into and out of this sense of invulnerability. Representations are set up to maintain identity protection and the reasoning follows a pattern "They are at risk because they are immoral and bring ill health upon themselves, they deserve to be punished. I am not like them, therefore I am not at risk". It is a flight from disease and death.

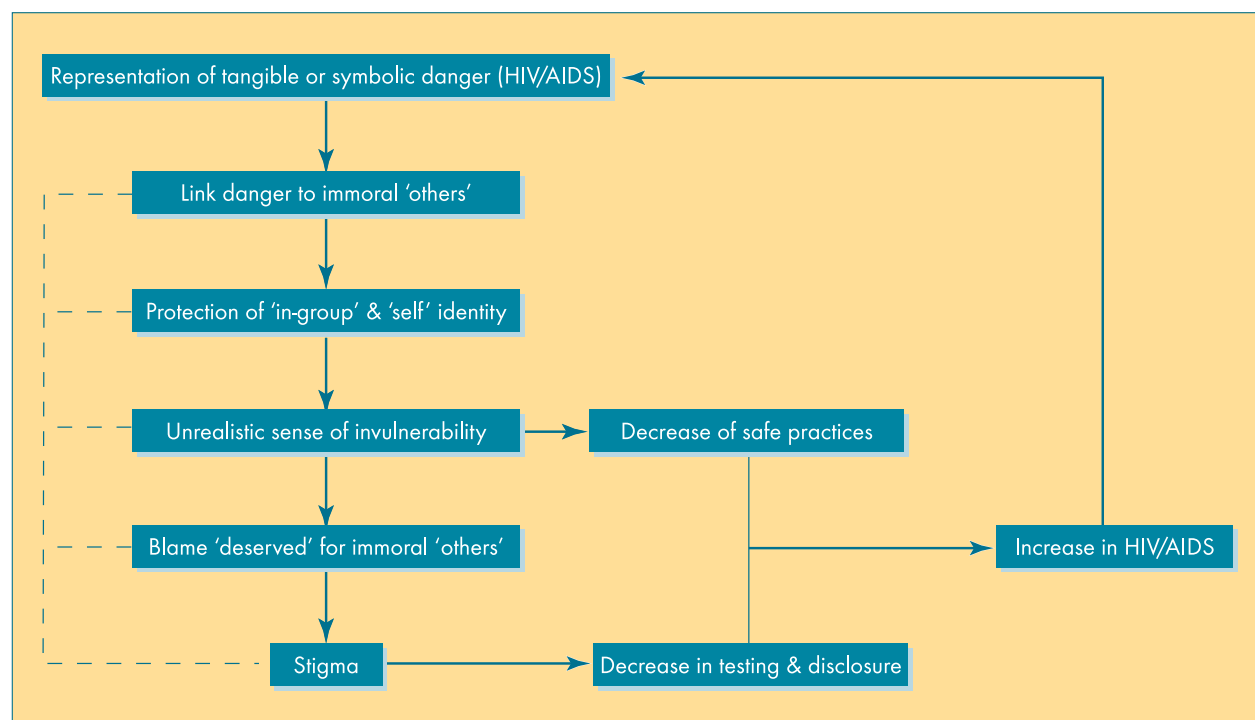
⁵² See Chart 1. Membership of these groups can extend to more than one group, particularly for women where there is a strong overlap between sex workers, women and adolescent girls in the way in which people talk about the three groups.

⁵³ This was a theme mentioned by over a third of key respondents.

⁵⁴ Youths refer to adolescents and children to much younger children

⁵⁵ Tangible threats are threats to actual health and symbolic threats are threats to the values of society (see Douglas 1994).

Chart 2: The relationship between stigma and risk in perpetuating HIV/AIDS



Association of HIV with Improper sex and Moral Discourse and Judgements:

Hand in hand with the sexual transmission of HIV, are assumptions about group membership (explored above) and moral integrity. Because HIV and AIDS is predominantly sexually transmitted, in Zambia, when people are suspected to have HIV and AIDS, the question uppermost in people's minds is "Where did you get it?".⁵⁶ This is a question often posed to people living with HIV and AIDS who make public testimonies. Most people are assumed to have got HIV through sex, and - with the exception of "innocent" married women infected by their errant husbands - are assumed to have been infected through 'disorderly' sex [Mogenson 1995, 1997] and are shamed and blamed for their 'immoral' behaviour.

"People think that AIDS comes through immorality, a person's misbehaviour. If you behave, you cannot get it".
[traditional healer, rural]

"You won't get infected if you shun wrong doings". [pastor, rural]

All respondents associated immorality as the main factor influencing the spread of HIV and AIDS. This is perhaps made most explicit where HIV/AIDS is seen as direct punishment from God for immoral behaviour, which predominantly involves having sexual relations before or outside marriage.

"Those patients are promiscuous... careless with themselves. God is punishing them for disobedience.... because the diseases are not traditional in nature and those affected are examples of what God can do to those who disobey His commandments...".
[religious leader, urban]

Those who are 'punished' for 'immoral' behaviour bring ill health upon themselves and are held outside the culture symbolically. Punishment in the form of stigma is seen as a way of ensuring that the moral codes and values of that society are upheld. Health is subsequently seen as a reward for the morally good. Having set up representations which link misfortunes to certain immoral groups or behaviours builds an unrealistic image of the self as someone who is innocent, not guilty of sin/immorality. In Zambia, the exploding influence of the church - and in particular evangelical churches - on this discourse is blatant.

⁵⁶ In the anti-stigma toolkit, there is an exercise designed by people living with HIV and AIDS called "Where did you get it?". Participants stand in a circle and pass around an object, singing. When the singing stops, the person with the object stands in the centre of the circle and everyone points a finger at them and asks in one voice "Where did you get it?". When we did this exercise with teachers in a rural area, most of them said they had got it through non-sexual means, demonstrating how central the process of distancing and self-protection is. The point of the game is to make people realise that it is a painful and humiliating question.

As HIV continues to be a discourse concerning morality by lay and experts alike, it simultaneously brings about the consolidation of values that are important to the society and distinguish the morally good from the morally bad. Order is maintained through the protection of self and in-group from the out-group. It is ironic that in the process of maintaining order - for example the inequality of men and women - that disorder is created, since HIV and HIV-related stigma will not be checked until women are more empowered.

This discourse also feeds into HIV prevention messages, with a strong focus on abstinence and a good deal of mistrust about condoms, especially amongst elders and the church. The purposeful stigmatising of condoms by the church has leads to misconceptions and fuelling of myths surrounding the safety of condoms, undermining the use of condoms. This ultimately fuels the epidemic.

"In one country they have come across 2078 customers of condoms already infected with HIV/AIDS, because if you examine condoms you may find there's oil inside it. Who knows the purpose of that oil? That is why you heard people in Makeni were caught sleeping with dogs using condoms.....People might feel by using a condom they are well protected from the virus infection it is not proper prevention, it's better to abstain rather than wearing a condom". [traditional healers, urban]

"The church and other people are still negative about the use of condoms". [politician, urban]

It is important to note, however, that moral condemnation can occur hand in hand with care and support. There are some hard-liners⁵⁷ who would refuse to help people living with HIV and AIDS and who fall back on biblical language to justify their stance.

"They consider the sick to be more sinners than Satan. The church is against transmission modules through sex. They call it fornication".
[social worker, urban]

⁵⁷ For this analysis, we are indebted to the ideas of Emmanuel Ntilima and for Ross Kidd to documenting them in his report from the Choma research assistant training workshop.

⁵⁸ The Zion Church is a religious sect that places strong emphasis on the role that spirits can play in possessing a person.

But mostly people fall into the category of being morally condemning but forgiving - they think that people living with HIV and AIDS were not 'living right' and are paying for their sins, but they feel they should not give up on or abandon them.

"It reminds me of the societies of the children of Israel. There was this problem of leprosy. Anyone who was struck by this disease of leprosy was neglected by everyone and people finally accepted it as a punishment from God because the person had not lived right...there is a lot of neglect [with HIV] and we hope that in the future people will be accepted".
[pastor, rural]

Increasingly in Zambia, there is the emphasis that HIV can bring you back to God, and indeed, that people can be healed of HIV through prayer. In the rural site, we heard innumerable stories about this, with most the healing sessions taking place within the Zion⁵⁸ church.

"People are prayed for when they are sick, so that they lead life as a Christian is supposed to...We pray for them, tell them to change their way of life, maybe that person has moved with a lot of girls. We tell him to go back to his wife if he is married. If it is done, he will get better. AIDS is completely cured if this is followed". [pastor, rural]

Similar to witchcraft, this healing can push stigma away and give people hope - but it is very bound up with denial and in itself can be stigmatising. At the sessions themselves, the act of going up front to renounce your sins is confirmation to others in the congregation of your guilt. And if the healing does not prevent the person from falling sick again, and even dying, then that is taken as indication that since they were healed and cured, they have yet again indulged in 'immoral' behaviour, and they are doubly condemned.

Text Box 3: "They prayed for him but the virus was still there". [pastor, rural]

After ten years of knowingly living with HIV, a pastor attended one healing session outside his own church and his own area, and travelled some distance to test himself again for HIV, convinced that he would now be HIV-negative. When he discovered he was still HIV-positive, he was devastated. His fellow pastor who recounted the tale, commented, "They prayed for him but the virus was still there".

This poignant tale (see Text Box 3) reveals how, at this stage of the epidemic in Zambia, there are many pastors, priests and nuns who have HIV and AIDS but the church, and in particular the Catholic church for whom celibacy is still a pre-requisite for nuns and priests, remains quiet.

"Most people thought that maybe those in the church could not be affected but now there a number of cases.....I think the church is losing its saltiness I could say because you have to live as an example whereby you find pastors being infected with this HIV. I think it brings a disgrace to the church, even to God because he tells us to be good examples".
[pastor, rural]

The reference to the "saltiness" is from Mathew, Chapter 5/11, where Mathew talks to the apostles telling them, "you are the salt of the earth....But if the salt becomes tasteless....It is good for nothing". HIV is making the boundary between pure and impure collapse within the church, and, as Goffman [1963] points out for stigmatisers who discover they belong to the group they have been stigmatising, the clergy face the added "disapproval of self", as their own moralising and the community's harsh judgements fly back into their face. In the eyes of the community, clergy who are suspected to have HIV and AIDS, lose their right to be in the pulpit and indeed even touch the bible.

"If lets say the pastor has HIV/AIDS the respect there goes away. Even the Bible he is holding, people will say it's also contaminated. Whatever he says, people won't listen - "Who are you teaching? Where did you get it?"".
[traditional healers, urban]

Text Box 4: Caring for a fellow priest living with HIV and AIDS

One priest talked about his experience of caring for an older priest living with HIV and AIDS. The care of the older priest was left largely in the hands of the young seminarian, with some support from the sisters. The Bishop couldn't handle the situation, other priests shunned the priest living with HIV and AIDS, who isolated himself from others. "Why are you bothering to care for me when it is obvious what disease I have?", the older priest would ask the younger carer. Eventually he was taken to a mission in the bush where he died. "That experience made a man out of me", the young priest stated.

It was evident that these moralising attitudes forces clergy living with HIV and AIDS to withdraw from society and to be hidden by the church. (See Text Box 4)

In both sites, the difficulty of talking about sex, in church and to children, was raised. A rural policeman explained, "It is like a taboo talking about HIV and AIDS in the rural", and, one urban headmaster wryly commented, "It is easier to talk about HIV outside a home than to your own children" [headmaster, urban]. A number of respondents commented that the church did not often speak about HIV from the pulpit - one rural parish priest said "I have never preached about HIV in a sermon".

Although moral discourse can be used to justify and propagate stigma towards people living with HIV and AIDS, it can also be used to suspend judgement and to dictate love and care. People in Zambia feel very comfortable to debate the meaning of the bible. (See Text Box 5)

Association with HIV and Death:

Mogenson [1995, 1997] writes that HIV and AIDS is about "disorderly sex" and "disorderly death". Disorderly death strikes young adults (who appear dead although living) and signifies death over which you have an absolute lack of control. The association between death and HIV further translates into people living with HIV and AIDS being regarded as unproductive and close to death. Impending death is one of the main images of HIV captured in current metaphors and even early public health campaigns.

Text Box 5: "Will people who have HIV and AIDS enter the Kingdom of Heaven?"

During a focus group discussion, urban traditional healers held a very heated and circular discussion about sin and HIV/AIDS sparked off by the question about innocent victims. The debate moved from pastors regarded as contaminated by their HIV infection, to the question - "will people who have HIV/AIDS enter the kingdom of heaven?". Initially, the view was that they would not but then some participants raised the issues of being infected "by accident" (for example, in a barber shop), through your husband's behaviour, from parents (if a child). Indeed, however one got infected with HIV, thinking that you not able to go to heaven is very demoralising, and surely if one does not look after those with HIV/AIDS, then YOU will not enter the Kingdom of God, "after all Jesus came to heal the sick, we should love one another as he loves us". Without any intervention at all, the opening argument to isolate the pastor living with HIV and AIDS was turned on its head and the conclusion was that the pastor should be cared for.

Once you know you have HIV, respondents reiterate that there is no going back - "once you have it then it is death" [TBA, rural]. It is a "killer" disease, animated into a "serial killer", reflecting the dominant myth about the purposeful spread of HIV from people living with HIV and AIDS. And, some respondents say that HIV as an incurable disease is an indication of the end of time.

"HIV/AIDS is like a mark which will not be rubbed off even if the doctors at the hospital try all their efforts, you just have to go - HIV is HIV and it's death". [men farmers, rural]

In the rural site, there is little mention of people with HIV and AIDS being able to live a long time and of positive living. In the urban sites, there is a wider realisation that with good nutrition and access to medical treatment and money, people with HIV and AIDS can extend their lives.

Fear of non-sexual transmission of HIV and AIDS:

Fears around casual, non-sexual transmission of HIV are a key cause of HIV-related stigma since these fears are used to justify physical and social isolation, public rejection and other forms of stigma. These fears are widespread and more acute in the rural site and amongst children, carers, health workers and more educated respondents.

Table 2 (pages 38-9) looks in detail at the fears that key-informants had around HIV being transmitted through contact with the bodily fluids, clothes, bedding, room, utensils, food, instruments and the body of (or belonging to) a person living with HIV and AIDS. It is evident that many respondents believed that HIV could be transmitted through brief contact only and that an exchange of fluids was not necessary. The bodily fluids of a person living with

HIV and AIDS - particularly blood - are recognised as having the virus in them, but even objects or substances, which could come into contact with these fluids, are then believed to be infectious. In the late stages of illness, people living with HIV and AIDS are regarded as more contagious.

Sontag writes, "Infectious diseases to which sexual fault is attached always inspires fears of easy contagion and bizarre fantasies of transmission by nonvenereal means in public places", and, "a person judged to be wrong is regarded as, at least potentially, a source of pollution" [1991]. Her analysis resounds with a rural policeman, who explained why a marketeer living with HIV and AIDS would be isolated on the premise, "Because AIDS is like a person who is dirty. He is dirt. He will contaminate them". Sometimes, people imply that infecting others is a vindictive act.

"Like those nurses who are HIV positive, shout at patients to forget about the disease or get their blood and inject the patient who has TB because of the brief that when you have TB then its HIV. By so doing the nurse is happy that a lot of them will die with her. So I advise patients to be very careful with such nurses and make sure they buy their own injection instruments". [church secretary, urban]

As the risk of acquiring HIV is ascribed to deviant behaviour and to deviant groups or partners, then this process of external attribution - contracting HIV by mistake or by accident without any intentional involvement - creates the possibility of absolving people if they get HIV. If a health worker can claim that she or he were infected through their work, and not their sexual behaviour, and that they are therefore innocent, this allows them to retain their moral character. Of course, in reality, other people

Table 2. Breakdown of perceptions of risk of non-sexual transmission

Mode of Transmission	Rationale of Risk	Reported Transmission Route with HIV and AIDS to others	Groups at Considered Most at Risk	Resulting Prevention Measures	Frequency (No of KI who mentioned)	Resulting Stigma for People living with HIV and AIDS
Blood "...they know the virus lives in the blood. Immediately they see blood, they think of the virus. ...this is the type of contact they fear most" [NGO manager, rural]	Blood is where the virus lives.	<ul style="list-style-type: none"> Contact with blood through: cleaning up, blood soiled linen, during labour, from cut/open wound, needles, razor blades, barber scissors/blades, contaminated food (blood in food). Exchange of blood Blood Transfusion 	<ul style="list-style-type: none"> Carers Health workers & TBAs Household members, including children School Children 	<ul style="list-style-type: none"> Wear gloves Sterilise equipment Wash blades/scissors Delegate cleaning to elders, or relatives Avoid contact Stop cleaning up 	Over two thirds of key-informants: 44/68 (27/34 rural; 17/34 urban). More fears about blood contact in rural site	<ul style="list-style-type: none"> Physical isolation Rejection in household, clinic & community Refusal to buy food Neglect Withdrawal of care & treatment
Sharing Utensils "If we share a home with one who has AIDS, then that person gets a cup and uses it, when I come and want to use the same cup then I will get soap first and wash it before use. Sharing utensils is not so advisable" [transporter, rural]	The risk of bodily fluids - saliva, vomit, germs (including TB), blood (from sores in mouth) - being on the object - "something will remain there" [blacksmith, rural]. The idea that PLWHA are "dirty" and that their utensils will be likewise.	<ul style="list-style-type: none"> Sharing cups, plates and other utensils 	<ul style="list-style-type: none"> Household members Work colleagues Bar/ Restaurant clientele 	<ul style="list-style-type: none"> Give PLWHA their own utensils Bury utensils with them when they die (this is customary anyway) Wash with soap all shared utensils Avoid eating with PLWHA 	Over two thirds of key-informants: 43/68 (24/34 rural; 19/34 urban) Second most feared route of transmission, more fears in rural site	<ul style="list-style-type: none"> Isolation at mealtimes Being given own utensils Exclusion from communal events where people are eating Given food on paper [peer educator, urban] Churches introducing individual cups for communion wine [NGO manager, rural]
Mother-to-Child-Transmission (MTCT) "Pregnant woman might infect the baby depending on the means [how] she got pregnant. She looks young so it might be contracted through experiments [sex outside marriage]". [CHW, rural]	If mother is HIV-positive, then child will be HIV-positive (born with it, infected through labour, infected through breast-feeding, infected through clinic negligence), though it depends on how she got pregnant - deviant sex more likely to involve HIV transmission.	<ul style="list-style-type: none"> Through sex (main focus on transmission through deviant sex) In-utero During labour During delivery During breastfeeding 	<ul style="list-style-type: none"> Unborn baby Breastfed baby Midwives Nurses TBAs Doctors Sexual partner/s 	<ul style="list-style-type: none"> Wear gloves during delivery Avoid breastfeeding Avoid deviant sex 	Just under half of all key-informants: 31/64 (12/34 rural; 19/34 urban) Less known about MTCT in rural site	<ul style="list-style-type: none"> Assumed to have transmitted sexually - "the mother did not behave properly" Clinic blamed (old needles) HEALTH STAFF WHO ARE INVOLVED IN DELIVERY AVOIDED?
Sharing clothes/linen "they just know if one ...exchanges clothes with a HIV person, you can contract the disease" [peer educator, rural] "perspiration can spread the virus" [pastor, rural]	The risk of having contact with bodily fluids, perspiration and germs on soiled linen ("bedding") and clothes or used (and unwashed) beddings and clothes. Contact with beddings, pants and trouser pants especially risky. If PLWHA has sores, the risk is higher.	<ul style="list-style-type: none"> Close contact with used and unwashed bedding and/or clothes e.g. borrowing clothes, sharing bedding Washing clothes & beddings 	<ul style="list-style-type: none"> Spouses or siblings who share bedding Carers who wash clothes & bedding Relatives & friends who borrow or use clothes 	<ul style="list-style-type: none"> Disinfect Burn, throw away or place in coffin after death Wash wearing gloves Boil in hot water 	Just under half of key-informants: 43/64 (24/34 rural; 19/34 urban) Slightly more fears around this in rural site	<ul style="list-style-type: none"> Physical isolation Banned from normal exchange of clothes Sleep on your own
Excreta/Urine and Vomit "...the major problem which a lot of people fear...that mess-up [diarrhoea, vomit] might infect them" [politician, urban] "when he's vomiting, I don't have to be there but I have to be outside" [dramatist, urban]	The presence of the virus in excreta, urine and vomit - though recognised as "low" and less than in blood. Possibility of blood in these fluids - especially vomit from cuts in the mouth. Revulsion ("nausea") of handling these bodily fluids.	<ul style="list-style-type: none"> Close contact through touching or washing soiled clothes & linen Close contact during episodes of diarrhoea & vomiting as carer Sharing a bathroom Sharing a toilet 	<ul style="list-style-type: none"> Carers Health workers Household members Neighbours (shared toilet) 	<ul style="list-style-type: none"> Wear gloves when handling or washing Plastic nappies (throw away) Pots to vomit in Disinfect Carers of own sex Elders as carers 	Just over one third of key-informants thought excreta/urine risky: 24/64 (19/34 rural; 5/34 urban), and slightly less thought vomit risky: 21/64 (16/34 rural; 5/34 urban) Many more anxieties in rural site	<ul style="list-style-type: none"> Not cleaned up Rejection from neighbours Physical isolation (different bathroom, different toilet)
Instruments - razor blades, injection needles, sewing needles, barber tools "infected razor blades and injections we are given at the clinic, you can't know whether they are new or not". [teacher, urban]	If the instruments are either used by or on people living with HIV and AIDS, there is a risk that the instruments might have blood on them, which could then transmit HIV.	<ul style="list-style-type: none"> Razor blades used in homes, barber shops, by traditional healers for tattoos, healthcare settings (cutting umbilical cord), schools (to sharpen pencils) or vindictively in health care settings. Sewing needles used in the home Scissors used in homes, barber shops, healthcare settings 	<ul style="list-style-type: none"> Carers Household members Children (in home or school) Men attending barber-shops Those who have tattoos Sick people or pregnant women attending health care settings Health workers & TBAs 	<ul style="list-style-type: none"> Don't share Throw away once used Bring own instruments Wash instruments Sterilise instruments from children Keep instruments away "some nurses 'throw' an injection to make sure that there is no contact between you and me as if you are playing darts because they are scared and make you feel that I am contaminated" [nurse, urban]. 	Just under one third of key-informants: 22/64 (7/34 rural; 15/34 urban) Many more fears in urban	<ul style="list-style-type: none"> Children in school isolated Use of gloves on PLWHA PLWHA neglected within health facilities Health workers blamed/avoided "Warning others" regarding possibility of transmissi: in barber salons if prior customer is assumed to be HIV-positive.
Sharing a room "sleeping on the same bed - that through breathing you can contract the disease" [Traditional healer, rural]	The risk of bodily fluids on bedding and bed, and being close to "breathing" and "coughing" ("TB germs") of PLWHA.	<ul style="list-style-type: none"> Close contact within the room - the closer the contact, the higher the risk - sharing bedding or the same bed particularly risky. 	<ul style="list-style-type: none"> Carer ("often has no choice" [TBA, rural]) Spouse Household members 	<ul style="list-style-type: none"> Patient in their own room Don't share bed - only room Polish floor Open windows 	Just under one third of key-informants: 20/64 (16/34 rural; 4/34 urban) Many more fears in rural site	<ul style="list-style-type: none"> Sleep alone Social isolation
Washing a patient "...people fear because during washing you can contract the disease" [business lady, rural]	The risk of contact with sores or cuts during washing, or of bodily fluids remaining in the bath tub.	<ul style="list-style-type: none"> Washing person with sores Washing dead body Sharing bath tubs 	<ul style="list-style-type: none"> Carer Health workers 	<ul style="list-style-type: none"> Wear gloves Avoid washing - delegate to elders or relatives 	Just under one third of key-informants: 19/64 (16/34 rural; 3/34 urban). Many more fears in rural site	<ul style="list-style-type: none"> Not washed, or washed less frequently Gloves used when washing?
Food Contact "They do not buy food from them because they feel whatever they touch is contaminated" [mechanic, rural]	The risk of food being "contaminated" with either saliva or blood (myth that women food sellers mix blood into food for good luck), and "maybe when I eat with him, I will swallow a virus and contract the HIV/AIDS" [blacksmith, rural].	<ul style="list-style-type: none"> Sharing food Buying food in the market prepared by someone living with HIV and AIDS 	<ul style="list-style-type: none"> Household members Clients of food vendor Friends, fellow vendors or relatives that share food 	<ul style="list-style-type: none"> Children instructed "don't eat anything from that house" [politician, urban] Avoid buying food from vendor Move stand away from vendor Stop vendor selling cooked food 	Just under one quarter of key-informants: 15/64 (8/34 rural; 7/34 urban). Fewer fears around this route of transmission in both sites	<ul style="list-style-type: none"> Stopped from selling food - altogether or not allowed to sell cooked food Public rejection

will still speculate about how the health worker got infected and make judgements about sexual behaviour, but the distance between deviant sex and HIV infection has been widened to protect the health worker's identity.

Not all respondents held fears around non-sexual transmission of HIV - but especially in the rural site - a significant number of key-informants did hold fears about casual transmission. These fears are genuine, complex and cannot be dismissed. They arise from, and are fed by:

- **Knowledge gaps** - incomplete, out-of-date, contradictory and shallow knowledge about HIV and AIDS and opportunistic infections. Knowledge emanates from a number of different sources which have different agendas - for example, the church, school, parents, elders, peer groups, Anti-AIDS clubs. People have to sort through and make sense of the different messages, and, have unequal access to information. Knowledge is also often imparted in a didactic manner, not allowing room to discuss more fully people's perceptions and fears. Although some of the non-sexual risks of HIV transmission have been adequately addressed in prevention campaigns - for example the risk of dirty needles and razor blades - , others have not been tackled - for example, the risk of HIV infection through contact with excreta and urine. In addition, new knowledge about HIV is continually emerging. This is not given consistently to communities but they pick up on these emerging findings. Sometimes the new knowledge contradicts earlier information, for example, for a long time, communities were told that HIV was not transmitted through breastfeeding. This message changed radically in the late 1990s where it emerged that breastfeeding was a significant transmission route for HIV.⁵⁹

- **Identity protection** - ascribing the risk of HIV not to personal sexual behaviour but to the careless, vindictive and immoral behaviours and infections of other groups, and to the possibility of infecting oneself unintentionally through casual contact with these groups, or their belongings. In the process, one's own moral identity is retained intact. Indeed, in our material, it seems the further one places one's identity from the "out groups" (for

example sex workers), the more likely people are to focus on casual transmission. This was evident in the more educated respondents who often had more fears around casual transmission. This indicates that knowledge can be overshadowed by moral discourse and maintaining identity.

- **Inadequate protection for carers in health settings and the home.** Working as a midwife, for example, in a country of high HIV prevalence, and in health settings where working conditions are frequently inadequate and resources limited, the focus on the risk of casual transmission of HIV is understandable. Delivering a baby without gloves for midwives, TBAs or other women who assist in labour is risky and must cause anxieties [see Bond et al 2002]. Likewise, the fears of casual transmission amongst poor carers of sick people living with HIV and AIDS is also understandable when water and washing powder is in limited supply and access to gloves and disinfectants non-existent. Difficulties in day to day management of sick people living with HIV and AIDS feed fears about casual transmission.

- **The casual transmission of opportunistic infections**, such as TB. If infections closely associated with HIV can be transmitted through non-sexual contact, this enhances the possibility of HIV being transmitted through the same routes.⁶⁰

- **Cultural perceptions that certain bodily fluids are disgusting** and/or polluting and dirty. Elders are less susceptible to this pollution and therefore make appropriate carers.

- **Making sense of high HIV prevalence.** If HIV were transmitted through mosquitoes, for example, this would help explain why so many people in Zambia are HIV-positive. It would especially explain HIV infection amongst groups who are thought to be not sexually active - like younger children or old people.

- The latent and variable **natural epidemiology of HIV.** HIV is a disease that is hard to understand - often undetectable, seemingly selective and running an unpredictable course.

The complexity and the unknown dimensions of HIV leave open the possibility of non-sexual transmission routes.

- Beliefs in the **casual transmission of diseases**, which are **caused through sexual infractions**. For example, the transmission of *kafungo* - caused by casual contact with a woman polluted by miscarriage or abortion.⁶¹

- **Witchcraft.** Bewitched people are afflicted unintentionally - sometimes even as they sleep - and sometimes through casual contact (for example, stepping on medicine or charms). There is now a strong evolving overlie between witchcraft and HIV, and transmission routes for witchcraft (for example using an insect to inflict witchcraft) can become possible transmission routes for HIV.⁶²

Knowledge:

In the preceding discussion on casual transmission, the relationship between knowledge and stigma was partially explored. As indicated by the anomaly around educated people having more fears about casual transmission, knowledge has a peculiar relationship with stigma.

Certain types of knowledge can fuel stigma. For example, the knowledge that breast-feeding is a significant transmission route for HIV from mother to child means that not breastfeeding can be a sign that a woman has HIV and she can be stigmatised on this basis [Bond & Ndubani 2000, Nyblade and Field 2000]. Media images can also contribute to stigma - the eagle swooping down on wasted people, an image used in the early 1990s, is an scary image recalled by many rural respondents and how they visualised HIV.

"They used same words for a man and he is also blamed saying, "He is a bird with long nails - stay away from him! He is going to scratch you!" [gatekeepers, rural]

Urban respondents also mentioned the "scary" HIV posters and how, *"in the end, they just make people scared"* [health worker, urban].

⁶¹ See Blaming Women for a more detailed discussion of *kafungo*.

⁶² Indeed, Probst [1996], conducting fieldwork in Malawi, writes how HIV educator's use of the term "*kadoyo*" to describe the HIV virus, reinforced the association between witchcraft and HIV, since *kadoyo* is a term meaning insect, but an insect sent by witches to inflict harm on others. See section on witchcraft in this report.

⁶³ We asked a person living with HIV and AIDS to talk at the community meeting we held at the beginning of our research in Mbabala. You could have heard a pin drop when Joseph told his story, and some of the women looked scared. Mainly the men asked him questions about how he had got infected (i.e. who infected him) and whether he was now sexually active. For weeks afterwards, people were talking about his testimony. One headman told me that he realised the advantages of knowing your HIV status from Joseph's story - *"he wouldn't be alive today if he hadn't had the courage and it meant he could get help from higher people"* [Bond fieldnotes 2003].

On the other hand, knowledge gaps can fuel stigma. Inadequate knowledge about the chances of children born to and/or living with parents living with HIV and AIDS being HIV-positive, and, about the relationship between opportunistic infections and HIV cause stigma towards children and people with opportunistic infections (see Clay et al 2003, and section in this report on opportunistic infections).

Another dimension of knowledge and stigma is what an urban health worker called *"distorted knowledge"* - myths *"like sleeping with a virgin girl for cure"* that can cause stigma.

In Zambia, there was a huge disparity between the amount of HIV and AIDS information available in the urban and rural sites. Government, health facilities, schools, research groups, the media (especially television), friends, peer educators, IEC materials, seminars for traditional healers and a number of churches and NGOs were cited as sources of information in the urban site. In the village, sources of information were much more limited - there are fewer NGOs, far less IEC materials (and hardly any in Tonga), less government effort in the health facilities and schools, fewer research groups and no special services in Mbabala for people living with HIV and AIDS. The scattered population and bad roads contribute to the paucity of information.

"This time it [HIV/AIDS] is prevalent even in the villages... because of ignorance, they don't know much, they do not have access to news papers, TVs to see how a person can suffer from AIDS... Many times they don't know that there is AIDS". [policeman, rural]

Testimonies made by people living with HIV and AIDS on TV were mentioned as sources of information in both sites. In the rural site, many people had never seen a person stand up and talk publicly about their HIV status.⁶³ Even in the urban site, there was no one living in either community who had gone public about their status but there were

⁵⁹ See the Tanzanian country report, Mbwambo et al 2003, which explores the fears of casual transmission amongst health professionals, based on a sub-study of the latter.

⁶⁰ See discussion of this in Stigma of Opportunistic Infections later in this report

people living with HIV and AIDS doing outreach in the area. This type of education appeared very memorable, although in the urban site sometimes people were suspicious about the motives behind going public, suspecting that it was a money making strategy.

"People now started saying it's the way of making money, then that guy has got a child why is that child not dying. But he is sick actually; he is even taking drugs up to now. People wonder why he is not dying and the child is also not dying". [taxi driver, urban]

In town there was more in-depth knowledge about HIV transmission, prevention (including preventive therapies), psychosocial needs, and, how to care for people living with HIV and AIDS.

Competing discourses in both sites sometimes proved confusing and contradictory. For example, the Zion church and some traditional healers claim HIV can be cured. This is in direct opposition to standard AIDS education messages. News of ARVs had filtered down to both sites, but there was little understanding of what they entailed and whether they were a treatment or a cure.

Lack of Reflexivity:

It is evident that people do not always recognise their stigmatising language and actions. One of the tried and tested anti-stigma toolkit exercises asks participants to list "things people say about" different categories of people - TB patients, people living with HIV and AIDS, orphans, street kids, teenage girls. In the de-briefing of the exercise, often participants are appalled by the harsh language, the condemnation and the negative imagery.

"Others do it [isolating people living with HIV and AIDS] out of ignorance to protect themselves but they often do not know they are hurting". [health worker, urban]

However, some people are aware that stigma - and in particular stigmatising language - hurts. Awareness of this was higher in the urban site.

"They are called all sorts of names. It is not sometimes the disease that kill these patients, it is the bad words and the remarks from people". [gatekeepers, urban]

Disruptiveness:

HIV is disruptive in a range of settings - and in particular in households and in health settings. It is disruptive to resources and to household dynamics and a range of other relationships. This disruptiveness can cause anger and stigma, with women and children often at the receiving end.

"I was not wanted because I was not their blood daughter. I used to cry a lot...." [girl, urban]

Lack of HIV/AIDS policy:

A number of respondents saw the lack of a special HIV and AIDS policy and/or law as a cause of stigma. Most of their suggestions for laws were punitive, for example, the people with HIV and AIDS should disclose their status or be penalised for infecting others. Even though the framework of human rights often seems quite removed from these communities, there was evidence from the urban sites that laws could make a difference. Five urban respondents mentioned the existence and the enforcement of the interstate law, which protects widows from property grabbing.

"Nowadays people give the personal items to wife/husband and children. People fear to grab belongings because of the law and victim support units within the community. I remember two of my relatives died of HIV/AIDS from Garden and Chaisa compounds, their belongings we gave them to the family left behind". [traditional healer, urban]

Experiences of Stigma

Stigma is experienced by people living with HIV and AIDS as well as by those associated with them, like children, other family members and caregivers. In this section of the report we discuss:

- Common forms of stigma experienced by people living with or suspected of having HIV and AIDS;
- The trajectory of stigma, as it takes different forms according to the progression of the virus and the well-being or illness of the person living with HIV and AIDS;
- Experience, causes, and consequences of stigma in different community settings;

- Self-stigmatising experiences of people living with HIV and AIDS;
- Secondary stigma experienced by those affected by HIV and AIDS.

Common Forms of Stigma

Exclusion: One of the most common experiences of stigma reported in the study was that of the social and physical exclusion of people living with HIV and AIDS.⁶⁴ If illness is prolonged, people living with HIV and AIDS often get progressively more excluded. This usually goes hand in hand with mounting fear of contagion and neglect.

"I remember before my father died [from HIV and AIDS], he was admitted in University Teaching Hospital. So when they took him to the bathroom for bathing, my uncle ran away and left him alone in the bathroom". [church secretary, urban]

When people living with HIV and AIDS are sick⁶⁵, they may be segregated to a small separate room where only a few people go, usually to give him or her food. Sleeping and eating separately are unusual experiences for most Zambians and are a powerful manifestation of rejection. In town, sending the person who is sick with AIDS to the hospice is sometimes interpreted as a form of exclusion.

"The family members will bring the patient at Jon Hospice and then leave the patient to die. So really revealing the HIV/AIDS status to some individuals has caused a lot of problems". [hospice worker, urban]

People suspected of having HIV, can be shunned, isolated and boycotted in more public places like the market place and the bar. These actions are justified on the basis of the risk of infection.

"In the market people won't be buying from the person thinking what she's selling (products) they can contract the disease" [men farmers, rural]

"They are isolated they don't drink together, saying that he can infect you. Using the same tin when drinking you can contract the disease so they are isolated". [man living with HIV and AIDS, rural]

One health provider from the urban site told how some people even refuse to greet people living with HIV.

"Others will even avoid shaking hands with the person. We cannot contract the HIV/AIDS through shaking hands - this is the stigma we are talking about; it is not good". [woman health worker, urban]

Others may avoid sitting next to someone who is perceived to be sick, for example in the minibus or in church. Fear of association - being seen with a someone who is living with HIV - contributes to the exclusion.

Blame:

Blame is one of the harshest forms of stigma. When someone finds out they are living with HIV or begins to get sick, they often encounter blame. This is especially so within the family. People are blamed for contracting HIV and for bringing disease into the family, which in turn brings shame. Often the links that people make between HIV and promiscuity are raised, with the person's past sexual behaviour being brought into question.

"... they will only say bad things to the person who is sick, maybe because she never used to respect herself. Others do blame both sides from the man and the woman, like "the way he/she has started, the whole family is going to finish"". [male farmers, rural]

"They are also blamed by looking at the past relationships that the person had whose friends died from some unknown illness. "It is his fault", we used to tell him" [pregnant women, rural]

⁶⁴ See self-isolation later in this section.

⁶⁵ It also depends what they are sick with - certain types of infection dictate segregation, whilst others don't. See following section on opportunistic infections and stigma.

People living with HIV and AIDS are also blamed for vindictively spreading HIV to others. This was a widespread form of blame in both sites.

"I think HIV/AIDS will never end because these elderly men are going for schoolgirls just to infect them, not to satisfy their sexual desires".
[sex worker, urban]

"He knows "I have AIDS - why should I die alone?" Then he starts spreading".
[NGO worker, rural]

When a person gets sick and caring for them is progressively seen as a burden on the family, the blame increases, provoked by different types of sickness⁶⁶ and the increasing needs of the sick person.

"They will refuse and say let him be alone that is what he wanted. Sometimes AIDS patients have a lot diarrhoea we don't want to touch him. AIDS patient want to eat meat all the time so, the family members complain that he will finish our chicken. They blame him because he got it deliberately".
[young men, rural]

The degree of blame is partly determined by any resentment about a person's past behaviour and by existing family relationships. For example, if someone was viewed as selfish - not sharing their money or food when they were well or not visiting the family in the village - HIV may be viewed as a just reward, a punishment for past sins.

"Village, there is no good reception because the person will be told that we used to tell you that you should be bringing things for us in the village. You were just eating alone [yet] now that you are sick you want to be taken care of"
[driver, rural]

"HIV is the reward of the careless".
[HIV-positive man, urban household]

Another form of blame, already discussed in the preceding section, is blaming others - groups with whom one does not identify or belong to. For example rich people, sex workers, people from town and other ethnic groups.⁶⁷ This type of blame Goffman [1963] called "tribal stigma".

Another dimension of blame is who blames who. In-laws, husbands and wives, and, parents and children, are likely to sling blame at each other. Marginal and deviant groups are blamed by the dominant 'in-groups'. And women are blamed more than men.

Blaming Women:

Although men are often seen as responsible for infecting their wives with HIV⁶⁸ and women are cited as taking care of themselves more than men, women are ultimately blamed for the spread of HIV and AIDS. Women are more susceptible to, and impacted by, the shaming and blaming that accompanies HIV and, subsequently, more scared of being stigmatised.

"The word disgrace is used more on women.... People say women are the ones who bring sickness most of the time. They are the ones who start [the illness]".
[HIV-positive woman, urban household]

"...women [living with HIV and AIDS] are in most cases treated badly".
[gatekeepers, urban]

Since blame is often embedded in gossip, women are especially sensitive to gossip since "on women, people talk too much" [women TB patients, rural].

"Like for me, the widow, they say the husband died recently - she is also going to die. Have you seen the way she is looking?"
[woman health worker, urban]

However, it was evident that in town, in comparison to the rural site, there was more awareness of women's rights and lack of power and more emphasis on men bringing HIV into the house.

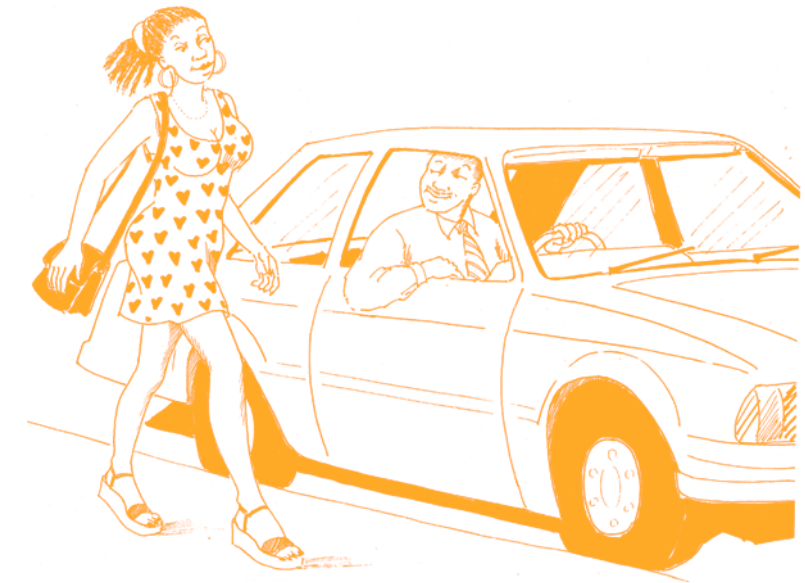
"The Gender Filter": [James 2003]: In an analysis of masculinity and HIV-related stigma in Uganda, James [ibid] demonstrates convincingly how masculinity interacts with stigmatising views to negate stigma for men and deflect stigma onto women - what he refers to as "the gender filter". For example, if it is acceptable for men to be polygamous, then men are not to blame for HIV but women are. Hegemonic⁶⁹ masculinity means that men's views largely shape and construct stigma. An elder in one urban site explains that men blame women for bringing the disease because, "he is the one who has power over the woman".

"Women are regarded to be under men, so you find women are despised [for having HIV and AIDS], while men are not. The women get most of the blame - more than the man".
[secondary school girls, rural]

Innocent Victim: Some women with HIV are considered "innocent". These women are married women whose husbands are judged to have infected them, and traditional birth attendants, midwives⁷⁰, health workers and carers who are thought to be infected through assisting delivery or nursing. In these cases, HIV is regarded as someone else's "sin" and they can "die peacefully, an innocent victim" [traditional healers, urban].

"There is no way we can blame the woman because the woman is innocent in that she is always at home and when she complains of the man coming home very late, the man shouts at the woman. Like - "I give you everything! What else do you want?". Then the woman just keeps quiet without even saying a word. The man infected the innocent woman....". [elders, urban]

Guilty until proven innocent: In accordance with Zambian law, people are guilty until proved otherwise. With HIV, this appears to have been extended to people living with HIV, and in particular women living with HIV and AIDS. Women living with HIV and AIDS (or more often suspected to be living with HIV and AIDS) are regarded as everything they should not be - sick and slim when



they should be healthy, being cared for when they should be caring for others, sexually deviant when they should be sexually righteous. To be HIV-positive is not to be a proper woman.

"A woman should care for her family but instead she makes them suffer".
[women TB patients, rural]

Relatives of men living with HIV and AIDS were reported to accuse the wives of "bringing the disease". The wife's family might also accuse the husband in the same way but the accusatory language is harsher and the implications of accusation more severe for women. Women are more frequently cited as "the causer" of HIV infection.

"The parents of the husband [living with HIV and AIDS] would say that we will not bury our son. When he dies, you will eat him, since you are the one who brought the disease".
[gatekeepers, rural]

"A HIV-positive woman will be abandoned if it is known that she is the one who brought the disease". [traditional healers, rural]

"Mostly the way we see things in the village, if a woman is sick, a lot of bad treatment will be there because they always say she brought it and forget their past behaviour. More blame is given to a woman than a man".
[women TB patients, rural]

⁶⁶ As implied in the quote that follows, chronic diarrhoea is hard to manage and will provoke more extreme blame and neglect. See the following section for more detailed analysis.

⁶⁷ The Tonga sometimes blamed the Ila for spreading HIV. The Ila are the neighbouring ethnic group and for historical reasons, have been associated with sexual transgressions.

⁶⁸ Men are blamed for acquiring HIV through drinking, their need for sex, their lack of control and their money.

⁶⁹ Hegemony is a term sometimes used to indicate values and norms of the dominant /ruling class.

⁷⁰ Sometimes though, midwives and traditional birth attendants are blamed for being "careless" and not protecting themselves during delivery.

For women who test first - as is the case in many of the PMTCT programmes - it is hard to tell their husbands their results. One HIV-positive woman in the household study said she did not at first share her test results with her husband, "because I thought he would say that you have tested first, you are the one who has brought the illness....I thought that maybe my husband could divorce me".⁷¹

"You reap what you sow": Thus the majority of women are considered "guilty" if they have HIV and AIDS. It seems that often HIV is retribution for poor character, poor social behaviour (for example, not sharing money), sexual transgression and for being a woman. As discussed in the section on root causes, the more marginal, junior and deviant the woman, the guiltier, with sex workers at the far end of the guilty spectrum - regarded as the "culprits.... making this problem in our community" [gatekeepers, urban].

"For a young woman, elderly people say she never used to listen to her parents advice. And for an old woman, they say she was double-crossing her husband".
[secondary school girls, rural]

"She [a woman living with HIV and AIDS] deserves it [to be treated badly] in the sense that she was stingy when she made or had a lot of money she never bothered to share it with anyone including the family.... as the saying goes, "you shall reap what you sow". She was very promiscuous where by everyone in the community was scared of her that she is going to infect their husbands so they were just wishing her to die". [elders, urban]

"Searching for it" [traditional healers, rural]: Girls are accused of tempting men or young boys into risky sexual encounters, in their quest for money (often referred to as "love of money"). An urban businessman recalls his father warning him about HIV and AIDS as a young man, heeding him to "avoid girls. Girls will lead you into...having AIDS". Another young urban man says HIV "makes me fear girls because I think they are the ones bringing the disease". If girls then fall sick with HIV and AIDS,

their mothers are blamed for not disciplining and talking to their daughters.

Girls wearing mini skirts, slit skirts and tight fitting trousers, are seen to be provocative and immoral.

"This girl in a mini-skirt can be infected very easily because she is attracting men through the dressing and their feelings become high...the government should abolish such kind of dressing. A lot of men will be infected by the time she dies".

[woman health worker, urban]

As mentioned earlier, people may recognise that sex work is necessary in the context of poverty, and indeed even encourage or direct it, but if the women or girls then fall sick, they are to blame for their infection.

"Me, I have sisters who go out. They say they have to do the work of prostitution - that is why they were born. The disease came for these people. So these people don't realise anything before they are sick, but come to regret when sick in bed". [women farmers, rural]

Thus representations concerning the spread of HIV and AIDS conceptualise women as active transmitters of disease and thereby more guilty. Men, on the other hand, are portrayed as passive recipients of disease and are rendered innocent since their biologically driven need for sex justifies them sating their desires.

For women, the consequences of being deemed guilty are more severe - blame, violence, divorce, social isolation, gossip, abandonment and neglect are more likely to follow in the footsteps of guilt with women than with men.

"The disease from women": The language used for the sexual transgressions of women is stronger than those used for men. For example, urban elders discussing what names people call women with HIV, explain how women would be called derogatory names openly, "because they used to bitch around and children who used to see what the woman was doing have also followed suit". Asked what words

are used for women living with HIV and AIDS, urban gatekeepers said, "bad words. There are no good words talked to a woman with HIV/AIDS".

A barber in town calls HIV the "disease from women". Another rural man makes out that women are the disease, saying of a sex worker in a bar, "this disease that has come - I don't want to sit next to".

Women and Pollution: A widespread belief in Zambia is that when a woman has a miscarriage or aborts, she needs to be cleansed by taking herbal medicine and refraining from sex for a period (see Gausset 2001, Bond and Ndubani 2000, Mogensen 1995, 1997). This disease has different names in different language groups. In Lusaka, it was referred to as *kafungo*⁷² or *kapopo*⁷³, and in Mbabala, as *kafungo*⁷⁴, *kasowe*⁷⁵ or *kasuko*⁷⁶. In the polluted state, she is able to infect anyone she has contact with (children, other family members, visitors, sexual partners), although it is not contagious beyond contact with her. The contact need not be sexual - transmission routes include sitting on the same stool, sharing the same toilet, eating food she has put salt in.⁷⁷

"If a woman aborts and still continues to serve food before taking or bathing in African medicine, the rest of the family will have *kasuko*, TB or AIDS." [traditional healers, rural]

As implied in the above quote, *kasuko* "has the same symptoms as TB⁷⁸ and AIDS" [traditional healers, rural].

The blame for acquiring *kafungo* lies with women, who are polluted and contagious until cleansed. Once again, the "arrow of accusation" [Douglas 1991] points at women.

"They say men who are HIV-positive must have slept or had sex with a woman who just aborted. They say he has AIDS as well."
[woman health worker, urban]

In using the old to understand the new, existing values, norms and power relations are brought forward from the past and thereby maintained. By anchoring HIV and AIDS to *kafungo*, the concept of disease as punishment for women's sexual misdemeanours is perpetuated. It seems HIV is a disease of women, spread by women.

Sexual Cleansing: Another form of pollution which affects women, and which was discussed by rural respondents, is the polluted state after the death of a spouse. Amongst some ethnic groups in Zambia, including the Tonga, if a spouse dies, the surviving spouse needs to be cleansed by a relative of the deceased in order to be rid of the spirit of the dead spouse. Herbal medicine is also used in order for the surviving spouse to become part of the community again. In the polluted state of waiting to be cleansed, the widow or widower has a spoilt identity - is open to witchcraft accusations (because of possessing a dead person's spirit) and can run mad and die - referred to as *chibinde* in Tonga. In our own data, and other research (see Colson 2000, Malungo 2001), there is evidence that because of the HIV epidemic, sexual cleansing practices have changed, with other rituals supplanting sexual intercourse.

"If a man dies or a woman dies of HIV/AIDS, the families of the living spouse sit and discuss how to cleanse the living spouse which does not involve sexual cleansing, because they fear one might get the infection".
[men farmers, rural]

However, our own research and Colson's, suggest that the substitute practices are not as powerful as the act of sexual cleansing. Thus the spoilt identity can extend beyond the substitute cleansing, and leaves room for witchcraft accusations against the surviving spouse. Women seem particularly vulnerable to this form of social stigma. There is also more pressure on women to be cleansed, than on men to cleanse, since she is "seen or told to be living with the dead spirits on her body" [man politician, rural],

⁷¹ With support from the counsellor, she managed to share her results with her husband, who "just kept quiet" and continued to stay with her.

⁷² Nyanja or slang term for the disease.

⁷³ Bemba for the disease.

⁷⁴ Tonga for the disease. This is the term we chose to use in this report. Mogenson (1995, 1997) uses the term 'kahungo' which respondents said is an Ila term for the disease.

⁷⁵ Tonga - meaning 'to throw it' and referring to a dead premature foetus.

⁷⁶ Tonga - meaning 'dust' and referring to a cough that is associated both with *kafungo* and HIV.

⁷⁷ When a woman is menstruating, many groups in Zambia prescribe that a woman should not at that time put salt in the food she cooks. Salt symbolises both purity and sexual heat.

⁷⁸ The relationship between *kasuko* and TB is explored in the next section.

whereas men are sanctioned to make their own mind up. Women are then caught between the risk of transmitting HIV - or being infected with HIV - and the stigma of not being properly cleansed. For some women, the latter is more important.

Gossip:

Gossip is one of the most pervasive forms of stigma. Gossip takes place in the market, the taverns, in schools, at funerals, among neighbours, in the village, in church, at the waterpoint, among friends, relatives and schoolchildren.

"People with HIV are the talk of the area"
[HIV-positive man, urban household]

If someone comes from town to be cared for in the village, people gossip. If someone loses weight or gets a skin rash or has TB, people gossip. If the teacher looks sick, the pupils gossip; if the preacher gets sick, his congregation gossip. If a wife dies, her family gossip about the husband; if parents die, neighbours gossip about the children.

Gossiping means people are talking about the possibility that the person in question has HIV and AIDS.

"People in your community don't usually talk about HIV people openly but they would gossip about them behind their backs and this usually takes place at the water points when they are about to draw water....."
[school children, urban]

"Some go to the village when they see that there is no one to look after them in town. So at the village they will start gossiping when they see that person, saying, "Look at him! He is slim, he is from town. Lets go and see him" so they start talking in the village saying "That person has AIDS". They gossip in groups"
[business woman, rural]

Gossip instills fear in people and families who know or suspect they are living with HIV and AIDS. A fear that they will be found out, exposed and shamed. For women, as already noted, this is an acute concern. Worrying about gossip is one of the most recurring anxieties that people and families

living with HIV and AIDS face, and these anxieties can impede treatment seeking for opportunistic infections (see next section), being tested for HIV, disclosure, health and even life survival.

"The friends sometimes are ones who like gossiping about their friend behind their friend's back. When the friend is sick they say bad words about the friend. That is why sometimes people find it difficult to disclose even to their closest friends for fear they will spread the issue". [gatekeepers, urban]

Popular discourse about HIV and AIDS is riddled with rumours about people who are suspected to have HIV and AIDS. This drives and shapes stigma. Yet, stigma also *stops* people talking about HIV and AIDS. There is an inherent anomaly here - because of stigma people talk *and* don't talk about HIV and AIDS.

At funerals, particularly in town, most of the gossip is about the cause of death, the cause of illness and whether the person died from AIDS.

"The burials and the funerals are the same although some who are not family members will gossip and speculate that it is HIV/AIDS"
[pregnant women, urban]

"There is silence but people, after burial, gossip about the cause of death"
[Bar owner, urban]

A few people even speculate that gossip plays a role in preventing the spread of HIV. This is parallel to the argument that stigma is 'good' because if people don't want to be stigmatised, they will avoid being infected with HIV.

"Definitely this [staying silent and not disclosing] will lead to a lot of people getting infected because there will be no gossip around. All will be thinking he is fine because by then the symptoms will have not been showing, especially if the victim has money and hasn't disclosed all the people or girls will not mind sleeping with him for the money"
[TB patients, urban]

Both in the household study and the community research, people recalled their experiences of gossip. A rural health worker, talking about caring for her brother who had died from HIV and AIDS, said, *"He lost some weight. People really talked but I had to be strong to take care of my brother. I firstly did not realise it - that people talked a lot - not until I heard a few comments from my neighbours. Anyway I lived with that until he died"*. A couple living with HIV and AIDS in the household study recall their experience of hearing others gossip about the husband's TB status. The wife said she used to hear her neighbours gossiping as she was passing but she "just kept cool and quiet". She says, *"I heard people say a lot of things but I never told him"*.

Households and people living with HIV and AIDS coped with gossip, as indicated in the previous two stories, mainly by withdrawing and remaining quiet. However, in the household study it was evident that if people knew they were HIV-negative, that armed them with the courage to challenge stigma.⁷⁹

Although most people did not realise how detrimental and hurtful gossip is, people with direct experiences of HIV and AIDS often expressed how hurtful words can be and how gossip can lead to self-isolation.

"I remember my friend from Chilenje, he had these diseases from women, he got thin and so people were making fun of him that he has it. No wonder he has slimmed. And so he told me, that in the heart he used to feel bad sometimes [because of] the words people used to tell him". [barber, urban]

"After seeing the patient, we go out and start disseminating the information about his condition. So there will be some people who will hear about it - they will go and tell him. They will say, "Why are you allowing people to see you? This is what people are talking about you!" Then for the patient that will be very bad".⁸⁰ [health worker, rural]

Loss Of Livelihood:

Stigma can cause people living with, or suspected to be living with, HIV to lose their livelihood, particularly if they are involved in selling goods or providing services.

"At the market, if the person is looking to be sick and she is selling at the market, people will not buy her goods especially if she is selling cooked food. So, she feels bad and this will make her think too much over her problem". [women, rural]

This stigma can result in the loss of livelihood, when marketeers who get sick, can even become scared of being seen at the market, for fear of ridicule. In turn families who depend on the income of the marketeer also suffer.

Stigma and discrimination also affect people in more formal employment, who risk losing their jobs because of sickness, as reported by one of the Hospice staff.

"Most of these patients that we have, have been really mistreated at the place of work and have ended up losing the job. They have been in the Hospice for a long time and absent from work. As a result they end up being retrenched, they end up without an income and need to feed themselves...so the people that they were looking after are affected and everything around is bad if someone has left employment. They go down very fast and die". [nurse, urban]

A young man in one of the urban sites reflects on how his household had discriminated against a housemaid, who eventually quit the job.

"There was a time our maid was HIV-positive. By then I had little knowledge of HIV, but she was so open she told Mummy. Since the day when I knew she was HIV-positive, I couldn't eat whatever she cooked and I prepared food on my own. But it was bad to isolate her. You know everyone used to isolate her until she left and stopped working". [young man, urban]

⁷⁹ See next section for an example of this.

⁸⁰ This respondent earlier had explained how someone living with HIV and AIDS that he knew did not want to have visitors for this reason.

"The Stigma Trajectory" - Stigma at Different Stages⁸¹

Stigma changes and emerges over the course of a single illness trajectory. Four phases were identified by Alonzo and Reynolds [1995]: at risk, diagnoses, latent and manifest. We added two more phases - namely the first onset of symptoms (soon after infection) and burial. The trajectory helps to examine how these phases interact with stigma. (See Table 3 below)

Condoms and Stigma

Condoms are linked to sex and HIV and in many minds, to 'promiscuity'. Attitudes to condoms reflect the stigma that surrounds HIV but also reflect the complexity of relationships and risk-taking. In some circles, using condoms is synonymous with being unfaithful, even with prostitution.

"I think having good prevention, looking for condoms, it is just bringing problems. The only best way is a man knows your wife and your wife knows the man. Looking for condoms is not the best way - it is just bringing prostitution". [men farmers, rural]

Within marriage, the idea of using condoms implies the infidelity of one of the partners, and the additional fear of HIV.

"...as a man who is married and really loves your wife, you know she is faithful to you - you don't need condoms, you would rather have it live, and may be you are planning to have a child. Now this unfaithful woman infects you with HIV." [Gatekeepers, urban]

Talking about condoms can still be problematic, with many urban respondents mentioning a television advert, which made them embarrassed. One health provider pointed out how talking about condoms to an elder is the same as "insulting" him, especially if the peer educator is a young person. One headmaster told of how he openly talks about condoms in at his school when discussing HIV and AIDS, but when he is at home, "Sometimes when they are talking about the condoms on the TV, I feel shy about it".

There are many myths about condoms which have been perpetuated by media stories, and which fuel negative feelings towards them. Stories which were

mentioned in the study included: "proof from Kenya" that showed many people have been infected through using condoms; lubricants used on condoms are not good for the body and also mean they are really for people who have sex with dogs⁸²; condoms are a way of the government trying to control the population; and many women know how to deliberately pierce a condom to ensure that it is not effective.

Among sex workers, condoms are more easily discussed. Sex without a condom is more expensive because of the "risk to life". Not surprisingly, poverty plays a huge role in the level of condom use among sex workers and it is recognised that rich men have the power to decide whether to use a condom or 'go live'. Despite many negative views towards condoms, if someone is known to be HIV positive, their absence of condom use becomes part of the blame levelled against him or her. And, although condoms have become associated with HIV, these associations can be positive, especially in town, where condom use was associated with responsible sex and as an important care and prevention option for HIV-positive people.

Indeed, in the household study, most men and women living with HIV and AIDS reported using condoms since finding out about their status. For women, however, condom use was still fraught with difficulties. One HIV-negative woman said that she used condoms with her HIV-positive husband, who sometimes forced her to have sex, but she "had fear in case the condoms came out or was damaged". Two HIV-positive women fell pregnant soon after learning of their status, though neither wanted to have sex at that stage - let alone get pregnant - and both wished to use condoms. In one case, the husband refused to use condoms, in the other; the couple never discussed their status with one another.⁸³

An urban sex worker was a strong advocate for condoms, explaining how sex without a condom was much more expensive because you "put your life at risk of AIDS" and how you need to protect yourself so you can look after your children. She also condemns the sugar daddy syndrome partly

because condoms are often not used when older men have sex with younger girls. She says that her fellow sex workers often discuss condom use - "When we go home, after resting and sleeping, we ask each other how much each one of us made with or without a condom. Everyone is free to say". She relays how sex workers will have sex without a condom if they need the money.

"Like our business its very easy to get the HIV infection. You would find that you had no money, no customer coming your way almost to morning hours and when the customer comes, he tells you not to use condoms. You cannot refuse since you want the money to buy food or pay school fees for your children and relatives". [sex worker, urban]

Disclosure and Stigma:

In Zambia, few people know their status especially in the rural areas, but live with the suspicion that they may be living with HIV. There is less chance to know your status in the rural area, with VCT testing facilities being very far away. Some respondents believed that testing could make someone die earlier, if they found out they were HIV positive. Others however said that if more people knew their status, then stigma would be reduced and behaviour might change.

"[I] would like to see more testing centres in the district and feel that if there were more centres, people would come. If people knew their status, it would help change behaviour and control the virus". [HIV/AIDS adviser, rural]

Not disclosing is linked to not accepting that you have HIV.

"I have friends who have died. Wives and husbands whom you could literally see that they are suffering from HIV and AIDS but they have never come forward and stated." [pregnant women, urban]

In a way, stigma is there whether someone discloses or not. People are judged by their appearance or

Sex	Symptoms	Testing	Disclosure	Illness	Burial
<ul style="list-style-type: none"> Frequent sex: if someone is seen to be having a lot of sex, gossip and rumours start about their morality and 'misbehaving'. Sex with many different partners: linked to 'promiscuity' which links to HIV and AIDS (in many people's minds) Without Condoms: in town, if not used, leads to guilt (more irresponsible) Sex workers: sex with or by is stigmatised Adolescent sex: stigma higher among rural adolescents than urban Sex equated with infection and death: "He is already dead", "we will see him or her" 	<ul style="list-style-type: none"> A catalyst for stigma: symptoms lead to the beginning of overt stigma Judgements: "we knew this would come" Gestures (finger-pointing, laughing), name-calling and gossip Certain symptoms or infections synonymous with AIDS. For example, herpes zoster Fear about contagion and casual contact intensifies Isolation pronounced Internalised stigma likely: feeling of not being part of society Suspicion of witchcraft may begin especially in rural areas 	<ul style="list-style-type: none"> Suspicion: why someone is going for a test Better not to test: "like digging a grave for yourself" Evidence of sexual transgressions: the mere act of going for a test confirms your 'guilt' Lack of public support: may laugh at people who test: "you will die fast" 	<ul style="list-style-type: none"> Isolation: telling your family and friends can lead to isolation Rejection: others running away from you Blame becomes more harsh Fear of gossip: stops people telling their result Public defamation Never disclose: many people never tell their families, it is easier to keep it a secret Secondary stigma: family is scared of being embarrassed and shamed Little disclosure in rural area: no special services of people living with HIV, HIV not as visible as in town 	<ul style="list-style-type: none"> Mounting blame: "we used to tell you, now you are dying" Shunning more frequent: less encouragement, sometimes abandoned Increased voyeurism: "see how he is finished" Heightened fear of contagion: by friends and family, especially carers Withdrawal of treatment & care: increased economic pressures on family for medicines and other resources Fatigue of caregivers: some give up 	<ul style="list-style-type: none"> Nothing said about HIV: fear, shame, respect, embarrassment OR use cousinship to joke about it Relatives relieved Blame: "you killed our son, now eat him" Funeral rites: shorter, fewer mourners, less money OR use money on funeral, not on treatment Voyeurism at body viewing: how the dead person looks ("very small and grey"), fear bathing dead body Property-grabbing from widows: especially in rural areas Burn/bury clothes: especially trousers, especially in rural site

Table 3 - "The Stigma Trajectory" -Stigma at Different Stages

⁸¹ In the key informant interviews, a matrix of the different stages was used to elicit responses.

⁸² This reference originates from a story in the newspapers in 2002 about a man who forced a woman to have sex with a dog, taking pornographic photos. Women are now taunted about this. For example, one of the women research assistants in town refused the advances of a man as she walked home after work and he reproached her, "So you would rather have sex with a dog would you"?

⁸³ This couple had tested together, after the husband was diagnosed with TB, but received their HIV-positive test results separately. The husband claimed to have told his wife of his status, but the wife claimed they had never shared their results with one another.

sickness, more than by what they tell others. Skin rashes, TB and diarrhoea are all associated with HIV and AIDS and will provoke stigma without actual HIV disclosure.

"The skin also changes, he develops rashes, sores or he becomes dark. Through that we know that he has AIDS".

[traditional healers, rural]

Partly because of stigma most people do not disclose at all, or may only disclose when they are very sick. Husbands fear that if they tell their wives, the wife may run away and leave him alone with no one to care for him. Women fear that if they tell their husbands they will be blamed, or even if they ask him about his sickness, they will be blamed.

"Until you start complaining maybe of the sores, then he will come telling you, you have brought me this disease, you have seen? So there are few husbands who will tell the wife or friends, they will just hide"

[health providers, urban]

The presence of services like VCT, home-based care and the hospice in the urban area did not necessarily make people less afraid of disclosing, but it does mean that there is more visibility of people living with HIV and AIDS, especially through media coverage and outreach programmes, the community are more likely to have heard about someone who has 'gone public' and there is more discussion about testing and disclosing.

"Some of them - like the people under the NZP+⁸⁴ - those are very open about their status and normally they are very open to the community and that's how people get to know about them. Butnormally the community will just judge by the type of symptoms they will present with" [male clinician, urban].

A health worker from the rural site advocates the power of public disclosure.

"People who have come out in the open do

encourage others to come out and it also encourages stigma to be reduced because people look at them and don't see any signs of AIDS". [health worker, rural]



Burial:

Although HIV is rarely pronounced openly as the cause of death (due to fear of retribution or respect for the deceased), at the burial, HIV and AIDS is referred to in veiled terms - within joking relationships (cousinship)⁸⁵, by using other diseases as proxy or through witchcraft accusations. Funerals of people who are suspected to have died from HIV and AIDS are reported to be markedly different from the funerals of people who die from other causes. Either money is withdrawn from treatment before death and saved for the funeral, or the funerals are cheaper and shorter - in one instance, people attending a rural funeral were instructed to disperse immediately after burial. Sometimes people will literally have run out of funds for the funeral.

"There is a difference [with the funerals of people who have died from HIV and AIDS], because sometimes they are buried even without a coffin because they would have no money left as a result of the long illness". [young men, rural]

Coffins⁸⁶ will usually be smaller, cheaper - one young rural man said *"not much attention is given, especially with the buying of the coffin"*. In the villages, people may be buried in a blanket and that

is one motive for sending people living with HIV and AIDS back to the village to die. There is the inference that people living with HIV and AIDS deserve these lesser funerals - although people acknowledge that rich people would still be buried with the full funeral rites. Perversely, rural secondary school boys said, *"Sometimes you can be buried in an expensive coffin because you were a burden to them and now you have died, they are happy it is over"*.

"This is what he wanted hence buried badly without a coffin, thrown like a dog".

[blacksmith, rural]

"Families, who do that, fear that if that person dies in town, there is paying at the hospital and buying coffin. They say, that let him just go and die at the village because there it is easy, you just put in a blanket and bury. That is the idea."

[Person living with HIV and AIDS, rural]

Some people have fears about washing the dead body of someone suspected to have died from HIV and AIDS, although this ritual is conducted by elders who are more immune to contagion. People reported that if someone was suspected to have died from HIV and AIDS, they would be buried with more of their personal items than if they had died from some other disease.

"But the clothes he is been wearing mostly are burnt or put in the coffin, no one will be willing to take those clothes". [sister in charge]

Property grabbing is discussed at the funeral and this can give the in-laws the excuse to hurl abuse at the surviving widow.

Stigma in Different Community Settings⁸⁷



Stigma in the Market Experiences of stigma

- If a marketeer looks sick (thin, skin complaints, coughing), people stop buying from him or her.
- If there are rumours that a marketeer is sick, people shun her.
- People are fearful of eating cooked goods from a marketeer who is sick, in case the food is contaminated.
- If a customer comes who looks sick, marketeers will not let them chose or touch the goods - they will select the goods themselves.

Causes

- The market place is a place of news and gossip: people there talk too much. It is fertile land for rumours that fuel stigma - on the basis of rumours people can be segregated.
- Superstition: to bring luck, some women are believed to add blood to food when they are cooking it to sell, and that if a marketeer has HIV, they could get infected.
- Contamination - anyone or thing deemed unclean is avoided as far as possible.
- Some respondents said that it is how the seller looks that attracts you to buy the goods.

⁸⁴ NZP+ is the Network of Zambian People living with HIV and AIDS

⁸⁵ Cousinship refers to the joking relations established between different tribal groups in Zambia, which allow people to talk more directly than normal about events and issues.

⁸⁶ The word "coffin" has become a form of abuse, a metaphor for impending death. People suspected to be living with HIV and AIDS are referred to as "moving coffins", or people who are thought to have sexually transgressed, are told to "go and buy a coffin" [secondary school girls, rural].

⁸⁷ The pictures used in this section are the ones used during the research to stimulate discussion

Consequences

- Marketeers can lose their only source of income if they are stigmatised.
- When marketeers get sick, they will feel embarrassed even to come to the market.

"There was a time when one of the marketeers in the village became sick. She started to look ill, her skin was turning grey and she had bad diarrhoea all the time. The other marketeers got together to discuss what to do.

Some of them thought that she should be chased from the market; others believed that she would bring their businesses bad luck; some thought they should call in the Environmental Health Officer. But some of the marketeers saw that she was sick and argued that she should be helped, that she needed to earn her living to be able to buy medicine and food. They decided to go to the pastor to discuss the matter further.

After listening, the pastor suggested that the woman be allowed to sell her goods at the very end of the table, and that she should not sell cooked food because that was not healthy. The marketeers agreed."
[pastor, rural]

Stigma at the Bar

The bar was ranked as the place where the most stigma occurs, by respondents in both the rural and urban areas.



Experiences of stigma

- Bars are associated with sex workers. Some women are chased from bars if people believe they have HIV or AIDS.
- People will not want to share the chibuku⁸⁸ tin with someone they feel is infected: they may leave the bar, buy separate drinks, or deliberately exclude the sick person.

⁸⁸ Chibuku: opaque beer brewed from maize

- If someone is stigmatised in a bar, they will just be drinking alone.

Causes

- Fear of contagion: traditionally men drink beer from a shared container. If someone is sick (especially with suspect TB or HIV), or believed to be sick, they are excluded from the drinking circle. Some men think HIV comes through saliva.
- When people drink, they don't care what they say. They can be cruel, they can mock, they can tell someone 'you have AIDS'
- Strangers often come to the bar - if they are not known, people may not trust them. They might be sick.
- Bars are associated with immorality and promiscuity, and drinkers are often accused of being immoral.

Consequences

- Women who sell sex to survive can lose their income if they are chased from bars.
- Men may go to bars, in part to forget about their problems, but if they are isolated there they may become depressed. If they then drink at home that can cause problems for the household.

One of the elders went into his local bar with one of his friends who is HIV positive. People in the bar greeted him only and ignored his friend. As they sat down to join a group of his friends, the friends all stood up and said they had to leave to go somewhere. "Finish that tin we have left for you", one of them said. The elder knew that they did not want to share the tin with his sick friend."
[elders, urban]

Stigma from the Neighbours

Some neighbours do not stigmatise: they can be sympathetic and help those who are sick by fetching water, bathing them, bringing food and chatting. A good neighbour is an extremely valuable resource for people and families living with HIV and AIDS.



Experiences of stigma

- Neighbours gossip with each other about sick neighbours. Women are especially vulnerable to this type of gossip.
- When neighbours stigmatise, they don't offer any help, even if they can see there is sickness in the house. In the most extreme cases (especially if it were sex workers who were sick), neighbours would not even give water.
- Neighbouring children were instructed not to play with children whose parents are sick.
- Sharing toilets with a patient who has bad diarrhoea and TB patients is a source of complaint.
- Relatives who are caring for the sick person may also experience that neighbours do not even want to share household items or food with them
- Some neighbours visit sick patients just to see how they look (voyeurism)

Causes

- Proximity: Because neighbours live close-by, they see everything that is going on. You cannot hide from your neighbours.
- Past relationships: if you already have a history of a strained relationship, then neighbours are more likely to stigmatise.
- Fear and lack of knowledge about transmission of HIV.

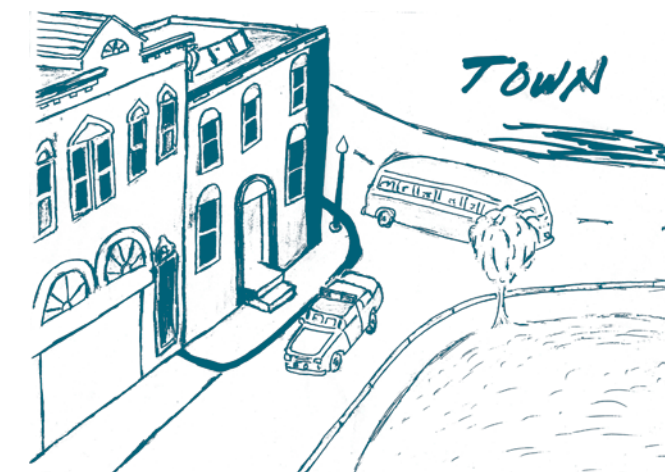
Consequences

- Neighbours are viewed as 'second relatives', who are meant to help out when there are problems. So when neighbours isolate or shun someone, it really hurts.
- The burden on carers and patients is even greater without support from neighbours.

"Usually the neighbour you know, before a person is victim of HIV/AIDS, they might not even be going to them, they might not even be close to them but once they hear rumours that this person has HIV/AIDS they will constantly be going to see how he is deteriorating by the day. Not to see him as per say; it's like they want to see oh "bafika so"[it's arrived] and will go and tell other neighbours to say that person now is at this stage anytime they will die. So they are not genuine neighbours as per say okay and the person with HIV/AIDS will not want to be seen by any person at a certain stage they refuse, they say oh "baisa mukumimona lelo" (we have to come and see you today), they even say I am sleeping or I want to rest or anything just to avoid people seeing them. They like hide themselves away because they know that these people are just coming to see how far they have deteriorated." [politician, urban]

Stigma in Town

In the rural areas people believed there is more stigma in town than in the village. But our research shows that the opposite is true - although certain types of stigma (for example public defamation) are more common in town.



Experiences

- When stigma happens in town, it is in public and many people are likely to witness it.
- Stigma in town is most likely to happen on public transport. People might refuse to sit next to someone on the bus if they look sick.
- Some people don't want to be seen in town talking or walking or standing with someone who is sick.

- Name-calling and public defamation is more intense in town.

Causes

- Even though people in town have access to more information about HIV and AIDS, they still believe it can be transmitted through casual contact.
- People in town are more aware of physical symptoms: they notice skin rashes and coughing and move away.
- There is less chance of retribution for stigmatising because people's networks are not as restricted as in the village.
- Shortage of space - and privacy - in high density compounds can provoke stigma and gossip.

Consequences

- Public humiliation. If you are stigmatised in public, a lot of people will see you. People living with HIV and AIDS may stay indoors to avoid stigma.

"People in town don't care about the person suffering from this HIV/AIDS. To make matters worse when you are passing, there is too much gossiping and finger pointing talking about the person - that this person is dying any time. This behaviour does not help the person at all. It makes him avoid going in town to do whatever he wants."
[men farmers, rural]

Stigma at The Clinic



Experiences

- Health Workers, if you have been sick for a long time, will cut back on medicine for people living with HIV and AIDS, believing you are 'wasting resources'. Some people living with HIV and AIDS

are sent home without treatment or discharged early or referred elsewhere.

- Health workers publicly demean people living with HIV and AIDS for their appearance, wasting their time and hold judgemental attitudes about sexual transmission.
- Relatives are reluctant to take on role as bedside carer since it is very demanding.
- Nurses can stigmatise you by being rough when they are handling you, treating you like a dead body.
- Nurses might expect relatives to do more of the caring than usual, particularly bathing and cleaning up diarrhoea.
- Confidentiality is not always upheld by health workers.
- Extra protective precautions are used if people are suspected to have HIV e.g. double gloves.
- Space and items can provoke stigma within the clinic e.g. being at the TB corner, having an X-ray, carrying sputum bottles, soya supplements.
- If health workers themselves become infected with HIV, they are harshly judged - "they should have known better."

Causes

- Many people spend a long time waiting in line at the clinic. It becomes a place where people talk and gossip
- Some nurses don't know enough about HIV. They think it can be transmitted through casual contact and so they shun people who are very sick.
- Some nurses fear contracting HIV when they have contact with blood or carry out blood tests.
- Health workers can project their own fears about having HIV onto patients.
- Poor working conditions (limited resources, low salary) exacerbate stress and fuel stigma.
- The higher status and power of health workers allows them to dismiss the needs of people living with HIV and AIDS.

Consequences

- Stigma can result in patients avoiding the clinic and going elsewhere for treatment.
- If health workers then become infected, it is hard for them to access help and they are harshly judged by others.

People with HIV/AIDS are treated badly especially at the hospitals by the nurses. Well quite alright as you know HIV/AIDS is a conditional disease. An HIV patient may have diarrhoea, so when you are at the clinic, the doctor will prescribe medicine for you but when the nurse sees in your book and concludes that you are HIV positive, she will shout at you like, " You are just wasting medicine giving it to these people who are HIV positive. We all know that they are dying so it is better to give medicine to those others who are suffering from other diseases. [But] the HIV/AIDS people need care and support just as those who are HIV negative. The other reason could be that the nurses have low salaries so this makes them hates them mostor being over loaded with work, so to relieve themselves from stress they end up shouting at patients. Nurses should treat them good because if they are treated badly at home when they come to the clinic this is where they feel comforted and hope that they are going to be well or healed.
[Young women, rural]

Stigma in The Village



Experiences

- People who are isolated can be made to sleep alone in a hut. Normally people do not sleep alone.
- If their parents died from AIDS, orphaned children may be cast out.
- If a patient is too demanding, they will be left alone, especially during the farming season.
- If a close relative is not caring for you, a patient is more likely to be mistreated.

- Gossiping and voyeurism - people go to "see the slim person from town".
- Relatives who are sent back to the village when sick are resented because of their demands and the drain on extremely limited resources.
- Although witchcraft helps avoid stigma, assigns blame to others and creates hope, being bewitched has become a sign of having HIV and AIDS.

Causes

- The village is a small place and everyone knows what is going on. There is a lot of gossiping in the village.
- Food is a problem in the village - if a sick person demands special food like meat or chicken, there will be resentment.
- There is often not enough money in the village to buy medicine, so patients are seen as stretching already limited resources.
- If fields are neglected because of caring for the patient, the patient is blamed.
- Past relationships: there is resentment if someone returns to the village only when they are sick - only 'now is when you think of us.'
- People believe HIV comes from town - when relatives go to, or come from town, they are blamed for bringing HIV and AIDS.
- There is a lack of information and knowledge about HIV so people fear getting infected.
- No exposure to people living with HIV and AIDS who have gone public.

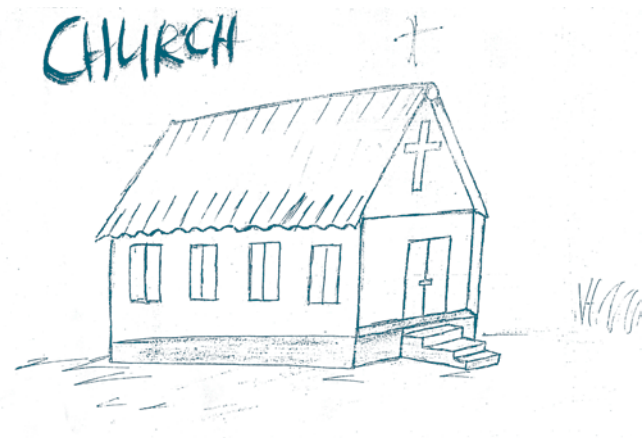
Consequences

- Sick people may be isolated and left alone to fend for themselves.
- Some patients consider suicide.
- Some patients die alone.

"In the village, as for now one thing that I have noticed, if a rich man dies, you know the funeral is going to last for two weeks, because that person has got a lot of food and money unlike a poor person. They just announce at the graveyard, "Ladies and Gentlemen, you know that we are in a difficult situation so you don't need to come and spend nights at the deceased house - we can just disperse from here". Equally, if the person is poor in the village actually even the attendance will be very poor people visiting him. I remember just the previous week we went to visit someone who has rashes all over, and when we reached at his home we found he was all by himself. Why, he has no money to buy food, so what we had to do the deacon I went with, he had to make an immediate budget, then I had to send someone to bring some powdered Milk Biscuits and a bottle of Orange so that at least he can try to help himself." [pastor, rural]

Stigma in Church

The church received the lowest stigma ranking in both the rural and urban areas.⁹ Many people mentioned that the church plays an active role in sensitising people about HIV and caring for the sick - "God's people can't segregate a sick person."



Experiences of stigma

- The church is a meeting place for news - there is a lot of gossiping at the church but often behind someone's back.
- If someone is suspected to have HIV and goes to church, no one will want to sit next to them or want to share their cup during communion.

- If a priest gets sick, people may stop going to that church.
- If a pastor has HIV, some would say he didn't listen to God, but if he was repentant, some may listen to him.
- When a person suspected of having HIV is inside the church, they are 'treated nicely', but once outside the church, sometimes the pastor does not even help.
- Moralising discourse justifies stigma.

Causes

- Fear of contagion - not wanting to sit next to someone with sores or who is coughing.
- Blame - some believe that those with HIV never went to church and did not listen to God.
- Linked to sin - some believe that you can be healed if you repent enough.
- Double standards - acting one way inside the church, and stigmatising outside.

Consequences

- The Church is a place of hope, trust, where you go to find relief and love, if there is stigma there, you feel hopeless.
- For pastors and priests with HIV, stigma means they hide from the congregation and feel terribly ashamed. They are judged very harshly.

"As for me, I don't see any problem if someone with sores in the church comes to sit next to me, but others have seen it differently. They will always want to shift to some other place or bench and not be with this person, which is very bad. [women farmers, rural]

Internalised Stigma

As a result of facing HIV and AIDS related stigma and discrimination, people living with HIV and AIDS often internalise stigma, believing that they deserve to be stigmatised. Internalising stigma leads to people living with HIV believing that they are worthless than others and are somehow to blame for contracting the disease. Belonging to a group ascribed as deviant and which individuals living with HIV and AIDS may have (previous to diagnosis) themselves stigmatised, intensifies self-doubt [Goffman 1963].

Internalised stigma can increase the chance of a person developing depression and low self-esteem, resulting in feelings of despair and helplessness. Many in the community believe it can contribute to an "early death".

Internalised guilt and self-deprecation:

Many people in the community recognise that people living with HIV and AIDS may internalise stigma, and that this can affect how someone feels about himself or herself:

"It is bad, because she or he will say "why do my neighbours not want to visit me when I am sick?" and they will blame herself and himself and questioning on misbehaving, immediately become disturbed." [young men, rural]

Carrying the burden of an HIV-positive status as well feelings of guilt because of being HIV positive, can affect a person's self image: they can believe that they are being punished and have no control over the future. Feelings of guilt were reported to be particularly strong amongst orphans, who after being mistreated and stigmatised in the family, often felt that their parents had died due to something that they had done and that they were being punished in some way (see Clay et al 2003).

Depression, despair, loss of hope:

Internalised stigma can affect a person's mental well-being, particularly if it causes long-term depression

and despair. The resolve to continue to lead a relatively normal life, to contribute to society and to be able to plan for the future, may be hampered by a HIV-positive status and feelings of hopelessness may begin to take over.

HIV-related depression is of course not only caused by internalised stigma. For example, one woman living with HIV and AIDS in the household study, who appeared depressed, talked of the permanency of her status - "this disease that moves with me wherever I go". But the isolation provoked by stigma is what respondents identified as really hurting people and causing the internalisation of feelings of worthlessness. Stigmatising actions - rejection, feeling unwanted, physical isolation - can catalyse thoughts of death and suicide. Talking about the use of separate utensils by TB patients, young rural men said:

"No it is bad, because the patient will feel neglected by other family members thinking "Why have they decided to give me my own plates and cup?" He will think maybe if he dies fast it is to be better for him and he doesn't deserve to live here on earth". [young men, rural]

Looking at a picture of a woman seated surrounded by people who have their backs to her, secondary school boys reflected:

Respondent: "If that woman is not strong she can consider committing suicide because the people she thinks to be near her, when she is sick they are running away from her."

Respondent: "This kind of behaviour is not acceptable at all because, like this woman in the picture, she feels abandoned, depressed and feeling not worth living. And if it was me I will really not feel okay". [secondary school boys, rural]

The feeling amongst people living with HIV and AIDS that they don't deserve care is a recurrent theme in people's personal stories and experiences.

Even if people living with HIV have not disclosed their status to others, the fear of judgement and stigma causes self-harm. The burden of secrecy can lead to illness. People who have 'gone public' about living with HIV and AIDS, have talked about the relief they feel of no longer having to 'carry' this heavy secret. For example, during one of the toolkit workshops, a woman living with HIV and AIDS related how sharing her status with a close cousin was "one load lifted".⁸⁹

A social worker from the urban site showed great insight into the damage caused by internalised stigma and also how the problem of stigma can be tackled.

"Let people know that it's actually normal to be a victim of HIV/AIDS or TB and then we should also try actually to disseminate this information to reach out to as many people as possible and tell them what stigma can do, because we have stories about some victims or clients committing suicide after being stigmatised. So we should actually look at the disadvantages of stigma and let them know that, it's actually normal [to have HIV]. Anyone can get it and of course what is important is to cope with the emotions. Accept the situation as it is because it's irreversible...." [social worker, urban]

Self-isolation

Some people living with HIV and AIDS withdraw from the community as a way of 'coping' with stigma, or as a result of being stigmatised and this in turns, leads to depression and loneliness.

"The person will isolate himself and become miserable" [Secondary schoolgirls, rural].

Being isolated leads to self-isolation. When asked how a person living with HIV might feel in different settings, a group of traditional birth attendants said:

"At school [they would] always feel absent minded and lost. Always fearing people, thinking they are talking about me all the time. They are never with friends who always leave them in isolation to avoid the illness". [TBAs, rural]

For some, self-isolation means withdrawing from everyday life. It was reported that some children stop going to school if they are stigmatised by the teacher, or fellow pupils (see Clay et al 2003), marketeers stop coming to the market to sell their goods if they feel ashamed by the stigma, and, TB patients stay inside their house to avoid gossip.

Secondary stigma

Secondary stigma is experienced by family, especially children, friends and caregivers of people living with HIV. It takes similar forms to primary stigma including exclusion, isolation and gossip. Anyone 'associated' with HIV, risks being stigmatised, sharing the blame for both the infection and the assumed behaviour that led to that infection. Goffman [1963] writes about individuals who are related to stigmatised individuals as "a relationship that leads the wider society to treat both individuals in some respects as one", and how related individuals are "all obliged to share some of the discredit of the stigmatised person to whom they are related".

This is reflected in the following quote.

"In families, it is the same like a thief. If there is a thief in the family, everybody is a thief. So if there is someone with the disease, then everyone is also a prostitute. Everyone has HIV/AIDS. No one gets good remarks when you have AIDS - everything is insults". [traditional healers, urban]

Secondary stigma affects couples: if a husband gets sick, many people assume the wife is also infected, and often go as far as blaming her.

"People will say also the woman is affected with HIV/AIDS and we can't either tell the wife to leave her husband since she is already infected with the disease. Stay away from that couple they are sick". [young men, rural]

In the children's research, the secondary stigma attached to HIV and AIDS translated into anger and blame projected onto orphans by guardians, and resulted in guilt, self-blame and engagement in risky activities (moving to the street, selling sex) (see Clay et al 2003 for a more detailed analysis).

Stigma Associated with Opportunistic Infections⁹⁰

"There are specific diseases where you can say that this is AIDS especially TB, diarrhoea, skin rashes maybe Herpes Zoster. Automatically they say that that person has AIDS" [policeman, rural]

People experience HIV and AIDS in the form of opportunistic infections; this is the practical reality of living and coping with HIV and AIDS in the context of poor environmental health, poverty, limited health services and a high burden of untreated infectious disease. Certain opportunistic infections are closely linked to HIV like diarrhoea, skin rashes and TB.

The bio-medical reality is that Tuberculosis, certain types of diarrhoea and certain types of skin rash (e.g. herpes zoster) are indeed closely associated with HIV infection. Studies in Zambia have demonstrated that around 60% of TB patients are HIV-positive [Elliot 1994] and 85% of patients with a type of diarrhoea called cryptosporidium parvum are HIV-positive [Ndubani et al 1998]. Herpes zoster is strongly associated with early and late stages of HIV infection [Dilys et al 2002].

It is unsurprisingly then that tuberculosis and certain types of diarrhoea and skin rashes are taken by the majority of respondents to be signs that someone has HIV and AIDS. For example, 50 out of 68 key-informants considered skin rashes a sign of HIV and AIDS, and 40 considered diarrhoea a sign of HIV and AIDS.

It is evident from our material that when people suffer from these opportunistic infections, their treatment seeking is impeded and their identity spoiled by the associated stigma. Although some of the stigma predates HIV, HIV has deepened and extended the stigma surrounding these diseases.



The Old Stigmas

Tuberculosis, diarrhoea and skin rashes are all diseases with a long history in Zambia and, prior to HIV, were stigmatised diseases. This is evident both in timelines we conducted with elders in both urban and rural sites about the history of TB, from respondents' comments about "old TB" and "new TB" and from other literature [Ranger & Slack 1992].

From our own material, it is clear there are some core old stigmas that all three share, and old stigmas that are unique to each disease or that two diseases share. The Venn diagrams (see Figure 1) demonstrate this.

Core Old Stigmas

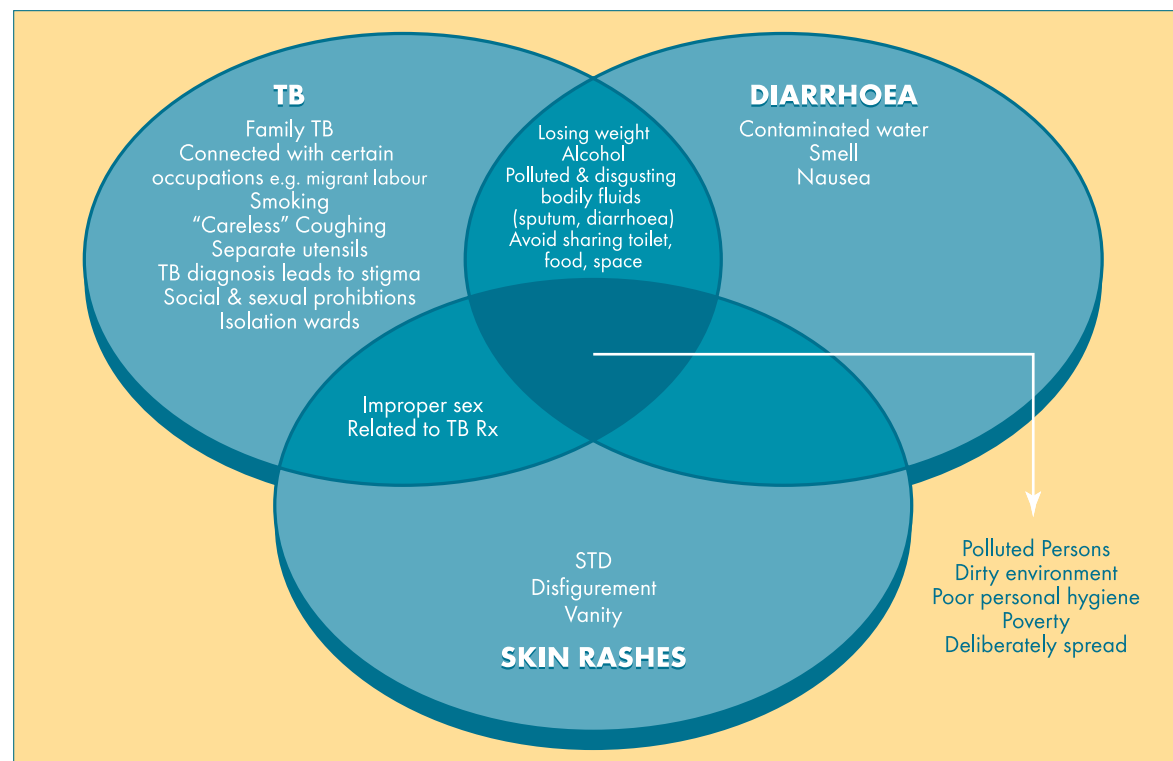
Polluted persons and the risk of infection: Patients of all three diseases are considered to be polluted, and casual contact with them is not advisable given the contagious nature of the diseases. There is indeed a very real risk of infection with TB, diarrhoea and some skin diseases through non-sexual but close contact.

The risk of being infected is frequently used to justify the isolation imposed on patients. Isolation is regarded as an acceptable and, sometimes, an unavoidable preventive measure, even if you realise that this hurts the patient. *"Even if you feel bad, you just avoid them"*, young rural men say about people with skin rashes. It almost seems that the stigmatising action, under the guise of prevention, is an attribute of the disease itself.

⁸⁹ See the Anti-Stigma Toolkit (Kidd R, Clay S 2003) for more details of E's story, and for suggestions about coping with disclosure.

⁹⁰ Within the focus group discussions and the key informant interviews, there was a disease matrix which asked respondents to rate stigma associated with HIV and AIDS, TB, cancer, malaria, skin rashes and diarrhoea, and asked them for each of these diseases "What do people say about people suffering from this disease?", and, "How does it feel for those people who have this disease?".

Figure 1 - Association with HIV and AIDS – The Old Stigmas



"Stigma is like here when my wife was sick. I told her not to be eating with us because she could spread the infection to us."
[young man, urban household]

However, there are deeper moral and psychological judgements made about why a particular person should fall sick and it is these that often justify and result in stigmatising language, actions and experiences. A woman traditional healer, who herself had suffered from TB and knew she was HIV-negative, said people could be stigmatised for just having TB - *"even if it is just TB, they will say maybe you were stubborn, that is why you are sick"*. The implication is that those who "misbehave" are responsible for their sickness, and that those who are sick have "misbehaved". It is almost as though you actively chose to get the infection. An urban sex worker who had had TB said that the community used to say of her when she was sick with TB, *"she is going to die if she is playing with TB"*. The image of *"playing with TB"* is parallel to playing with fire - and bringing trouble upon yourself.

TB, diarrhoea and skin rashes are all connected with contact *kafungo*. This connection is especially strong with TB since one of the main symptoms of *kafungo* is coughing. A woman in this state *"looks like a TB patient and we call this girl that she has macocola"* [woman, urban household]. *Macocola* means to be

tainted, polluted, *'dented'*. As with HIV, this means that "the arrow of accusation" [Douglas 1991] for the spread of TB is pointed at women. In Mbabala, a certain type of diarrhoea is associated with *kafungo* and traditional healers related details about sores around the anus - *tushiya* - that can be treated with herbs in the early stages of *kafungo*. In the late stages, these sores cause diarrhoea and cannot be cured.

"TB is here because these days young women don't listen, they drink a lot of beer, also abort a lot and they are not cleansed".
[man traditional healer, urban household]

"They [people with diarrhoea] might have HIV. They are stinking. They have lost weight. They aborted a big pregnancy". [barber, urban]

Dirty environment, poor personal hygiene and contaminated food: The diseases are recognised as being in part a product of a dirty environment. Skin rashes are associated with poor personal hygiene - not washing frequently or with soap, being dirty.

"Skin rashes are mainly dirtiness people should be washing and sometimes washing in treated water". [politician, urban]

Diarrhoea is dirty itself and is also related to contact with dirt, poor hygiene or buying food *"from the streets"* [young women, urban]. The association between diarrhoea and poor sanitation and water is very dominant in the urban sites, with young children being particularly susceptible to this type of diarrhoea. The dirt in the environment is often metaphorically projected onto the patient and becomes "his dirt" and thereby a reflection of poor character and/or behaviour. People who have diarrhoea are deemed both *"dirty"* and *"careless"*.

TB is also associated with an overcrowded and unhygienic environment - *"our environment is full of bacilli"* [hospice health worker, urban]. TB is due to *"dirty"* habits - *'spitting anyhow'*, smoking, drinking, and *'promiscuity'*.

Skin rashes and diarrhoea are believed to be a reaction to certain types of meat, particularly "bush" (game) meat. There is a strong focus on the risk of getting TB from a TB patient through sharing food with a TB patient and leaving food uncovered at home or in bars and restaurants. This revolves around the risk of TB patients coughing or spitting onto the food, but sometimes this is extended to the risk of blood in food.

"Sometimes TB is like flu. When some germs are expelled they can land on food, you can get it. TB is an air bone disease".
[traditional healers, rural]

"It is not really stigma but another way of lessening the HIV/AIDS and TB disease....is there anyone who would like to eat with a person who is bleeding and that blood is dropping in the food?" [elder, urban]

Poverty:

All these infections are associated with poverty but with TB there is an added twist since TB patients and their families are usually "doubly impoverished" [Ogden et al 1999] - drained by the cost of treatment and managing TB and (often) by the inability of the TB patient to contribute to income. This research and earlier research amongst TB patients in Lusaka [Bond et al 2000, 2002] capture the spiralling poverty of TB patients and their families.

Overlapping 'Old' Stigmas

Weight loss: The wasting associated with TB and diarrhoea is both feared and provokes the process of community diagnosis and name-calling.

Alcohol: Succumbing to either TB or diarrhoea is associated with frequently bars and drinking alcohol, in particular the locally brewed beer and wine.

Polluted and disgusting bodily fluids (sputum, diarrhoea): Even casual and brief contact with the bodily fluids of polluted persons are believed to carry a risk of infection - treading on sputum or faeces, passing where a TB patient has urinated. Contact with faeces is thought by rural pregnant women to carry a risk not only of getting diarrhoea but also TB.

"They [TB patients] should go with hoes when they go in the bush to shit so that they dig a hole and cover the faeces because if one steps on the faeces and had TB then she/he can contract it". [pregnant women, rural]

Other polluted bodily fluids or states, believed to lead to being infected with TB, include the blood (or state) of abortion, miscarriage and menstruation, and contact with dead bodies.

Improper sex: Both TB and certain skin rashes are regarded as manifestations of improper sex.

TB Treatment: Skin rashes are widely acknowledged as a side effect of TB treatment and an indication therefore that someone has TB.

TB: Old Stigmas

In the household study, when asked to describe stigma, most TB patients related it to having TB.

"Discrimination can come when you have TB".
[woman, urban household]

"It is like when you are suffering from TB people will tell you to be eating alone and using your own cups and plates. That is discrimination". [HIV-positive man, urban household]

Family TB: Amongst elders, traditional healers and in the rural site, there is a widespread and old belief that 'TB of the blood' is inherited TB. There are fewer stigmas attached to this type of TB.

"This same TB can be hereditary, can be passed on from the grandparents and the whole line of grandchildren can suffer from it". [gatekeepers, rural]

Social and sexual transgressions: Many people said that TB was airborne and there was an understanding in town that because TB is so prevalent and airborne, it was easy to get. However, very often the inference was that people were pre-disposed to falling sick with TB by a combination of a dirty environment and other physiological, moral and social factors. The air, polluted with TB germs, bacteria and sputum, combine with a person's character (being "stubborn"), physiology (inherited from the family), 'carelessness' on behalf of the TB patient, close proximity (through overcrowding or staying with a TB patient), social transgressions (smoking⁹² and drinking alcohol) and sexual transgressions (engaging in deviant, improper sex). TB is connected with certain occupations - especially working in the mine, charcoal burning and working on flower farms. With the exception of children, falling sick with TB is then largely "due to hooliganism, moving about" [politician, urban].

Social and sexual prohibitions: It is unsurprisingly that respondents cite measures to prevent TB which oscillate largely around: patient behaviour (good personal hygiene, conforming socially and sexually, and withdrawing socially and physically); avoiding contamination through contact with the patient and the patient's food and objects, clothes and family; and the use of a tin for sputum.⁹³ Isolation wards, still used in the rural site and used in the past, were strongly advocated.

Careless Coughing: So often TB transmission is attributed to "careless coughing" or "spitting anyhow" and deliberate spread. The onus here is on individual irresponsibility and society's good. It is the behaviour of the TB patient and his family that

cause TB to spread, and the guilty who are infecting the innocent.

"...the Ministry of Health should at least give proper information to the TB patient on how to spit when they cough, they produce mucus and just spit it any where and then the kids pass by and since the bacteria is still alive and contagious the kid will just get TB instead of giving them bottles". [young women, urban]

Separate utensils: TB patients are nearly always made to eat alone and given their own utensils. Public health messages propagate this prohibition, along with staying in ventilated rooms and spitting into tins.

"It is at the clinic were they tell us a patient with TB should eat alone". [widow, urban household].

Two TB patients in the household study justified this behaviour on the basis that "it is important for sick people to eat alone because they eat slowly" [young woman, urban]. The mother of one TB patient recalled how her father, who had TB, was subjected to the same prohibitions and how these continued throughout his life.

"In the past, when I was young my father had TB, they used to keep them separate. They used to eat alone, even the grass house he used to stay in was burnt, then he was taken to the hospital were he stayed. Even when he was discharged we never stayed or ate together.... The TB my father had, it was only him who was sick and didn't die because of TB but of old age." [woman, urban household]

Symbols of TB: TB diagnosis is accompanied by many visible symbols - having an x-ray done, being given a special card, waiting at the TB corner⁹⁴ in the clinic, sometimes being visited by HBC, going to the clinic on a regular basis (and even daily basis for the streptomycin injections required for relapse TB) and receiving food supplements. These can lead to speculation and stigma.

"You are saying how do people single out that someone has TB? There are many [ways]. Maybe a neighbour comes and they see him on the TB corner, then they go out in the community say that one (ali famankwala ya TB) he's on TB treatment, suffering from TB". [sister in charge, urban]

Unproductive: Being sick and on treatment for a relatively long time, often means that TB patients are unable to contribute to household living for a period. As a consequence, other household members often view them and their children as a burden because they are unproductive.

"It is a problem [TB]. I can give you an example. I have got my sister and because of TB she has no energy to any type of work. Whatever she tries to do, she gets sick. So it is really a problem. She goes to the hospital for treatment and back at home, she can just sit. You know a sick person needs to eat, but has no energy to work for food. Also the sickness takes too long". [man farmer, rural]

"Children of TB patients are a burden because the mother is not productive" [woman, urban household]

Increased appetite: TB treatment is associated with an increased appetite and, in the context of poverty, this is a cause of stigma towards TB patients who want to "eat too much".

"...for us TB patients these drugs we take make us to eat a lot, so when you reach home, you have to eat all the time starting in the morning and people start complaining about your eating habits". [male TB patient, Macha].

Diarrhoea : Old Stigmas

Contaminated water: Diarrhoea is associated with contaminated water, especially in Misisi and Mbabala township. High rates of water contamination from an open quarry in Misisi lead to a high risk of certain diarrhoea infections associated with HIV infection (*Cryptosporidium parvum*), and these infections are a major contributor to illness and death for people living with HIV and AIDS [Kelly et al 1997]. In Mbabala township, diarrhoea



is connected to the 'dirty' water supply from one stream and to poor sanitation.

Smell: The smell of diarrhoea is frequently brought up, for example, an urban barber says about people with diarrhoea, "they feel they are dying. They hate being visited because of the smell in their room". A young urban woman says that people with diarrhoea "feel bad because when you come out of the toilet, you feel stinking, you don't feel good".

Nausea: Young rural women talk about how people feel "nausea" about patients with diarrhoea, and rural pregnant women talk pragmatically about how it just is difficult to clean someone up when they have diarrhoea.

Skin Rashes : Old Stigmas

Sexually Transmitted Infection: Because one skin rash - herpes zoster - is understood to be a sexually transmitted infection, that strengthens the stigma surrounding it. For example, young urban men said, "Skin rashes and she is a prostitute".

Disfigurement: It is feared because of the disfigurement that accompanies it - "it disfigures their natural way" [health worker, urban]. This is parallel to the stigma type that Goffman [1963] calls "abominations of the body" - the various physical deformities. Similar to street children [see Clay et al 2003], people also sometimes find it hard to look at someone with a severe skin rash.

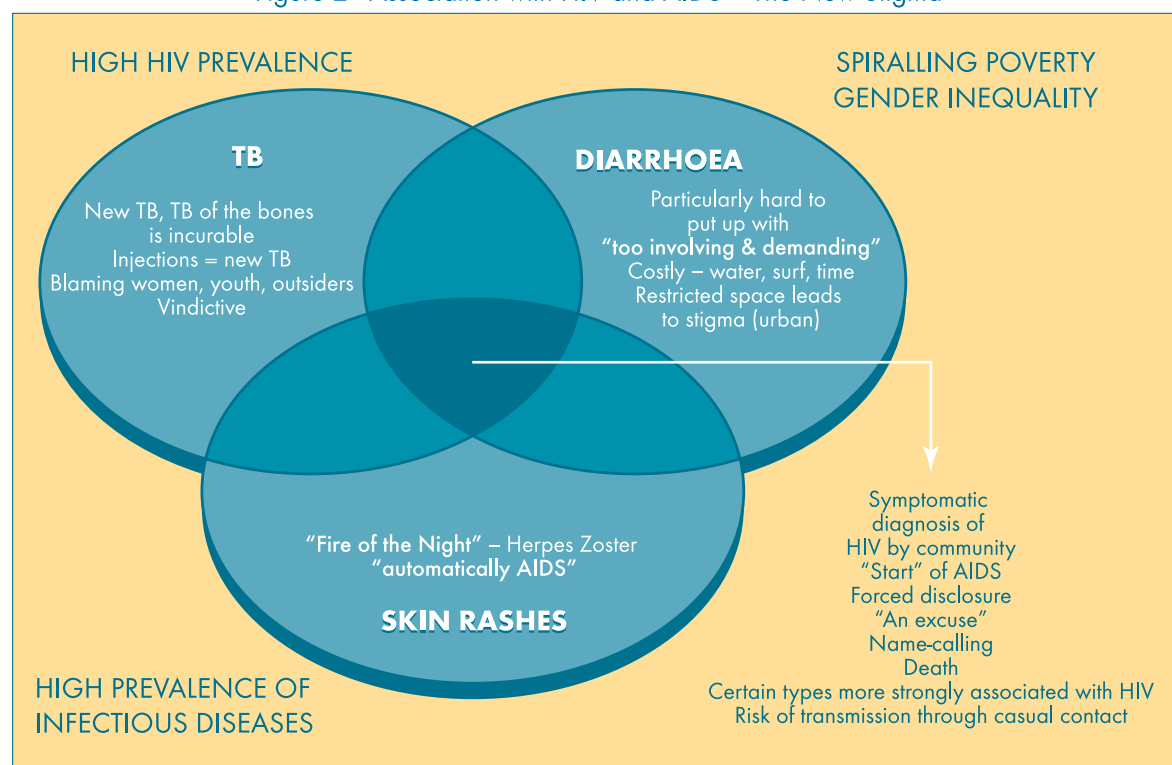
Vanity: Skin rashes are also related to cosmetics used by women, and by implication, to vanity.

⁹² Cigarettes and marijuana

⁹³ Other preventive measures mentioned include: clinical referral, disclosure of TB status, cleaner environment (household and community) and preventive TB therapy.

⁹⁴ In Zambia, in most health centres, there are designated "TB corners" where TB patients wait to be monitored and receive drugs.

Figure 2 - Association with HIV and AIDS – The New Stigma



The New Stigma - Association with HIV and AIDS

Twenty years into the HIV pandemic in Zambia, the old stigmas associated with TB, diarrhoea and skin rashes are either accentuated or layered upon new stigmas because of HIV. The Venn diagram (see Figure 2) indicates the different dimensions of this HIV-related stigma, pulling out core stigmas in relation to HIV and the three diseases, and unique stigmas or stigmas that only two diseases share. If the previous diagram were imposed upon this, the multi-layered stigma would be apparent, particularly in regard to TB, which overlaps with HIV very powerfully [Bond and Mitimangi 2002].

Core Stigmas

Community Diagnosis: People with tuberculosis and certain forms of diarrhoea and skin rashes are closely observed by others in the community who "wait and see" if anything "is behind the disease" [TB patient, urban household] or if "you have been up to something" [rural marketer]. If these infections occur in combination with one another, reoccur, persist and are particularly severe, the community will often diagnosis the patient as having HIV. These infections are therefore signs of HIV and AIDS.

"...when you just have TB, they will say that one it is AIDS. Wait and see in three months,

these people become like those people with leprosy, they won't even want to associate with them. There is too much stigma in the community...". [health providers, urban]

The overlap between these three opportunistic infections and HIV can sometimes be so strong that the distinction falls away altogether. This is particularly true of TB. One young urban woman TB patient is emphatic that diarrhoea, skin rashes and TB "are AIDS".

"I no longer really understand what TB is". [clinical officer, urban]

"Skin Rashes and HIV - they put these diseases together". [pastor, rural]

"People with diarrhoea are dirty people and have AIDS". [widow, urban household]

As a pastor pointed out, the problem is that people with these infections - especially TB - then think they have HIV.

"The major problem we find here is that people have started mixing the two diseases. TB and AIDS when someone suffers from TB, they say it is AIDS, hence bringing trouble to that person, he will think it is truly AIDS". [pastor, rural]

These infections are regarded as indicative of the "Start of AIDS" or "the beginning of the disease", and assumptions about death and "bad" behaviour flow from the onset of symptoms. This is captured in the following responses from a church elder concerning skin rashes.

Interviewer: "What are people saying about this disease [skin rashes]?"

Respondent: "They say the symptoms for HIV virus has started".

Interviewer: "What do they say about people suffering from this disease?"

Respondent: "They say he/she is HIV positive hence death is near".

Interviewer: "How does it feel for people who have it?"

Respondent: "They feel shame for their bad behaviour since those are signs for HIV/AIDS".

These diseases are perceived to almost metamorphose into one another, eventually leading to AIDS, with the progression of diseases consolidating the community HIV diagnosis.

"Nowadays if a person is suffering they first identify that its malaria but as it develops later on it is known as TB or eventually you may know that this is HIV". [bar owner, Misisi]

Forced Disclosure - "This disease is not hidable" [traditional healers, urban]

For people living with HIV, or for the many Zambians who do not know their HIV status, opportunistic infections like TB, chronic diarrhoea and certain skin rashes force them into a public arena where assumptions, moral judgements and stigmatising behaviour flow from merely having these infections. Even if TB patients hide, a woman divorcee commented with some irony, people will think they have AIDS [urban household]. In a sense, for those that are HIV-positive, their disclosure is forced. The quote from a conversation between urban traditional healers captures this.

"This disease is not hidable. It still shows what one was doing..... There is no way he can keep it as a secret when he has symptoms showing purging, some rashes, some sores,

and continuous malaria". [traditional healers, urban]

TB patients are put under considerable moral pressure to reveal their status. As the following quote shows, public good is pitted against private pain and stigma and the need to get well and get help is pitted against the need to hide.

Interviewer: "Why would you not tell others you have TB?"

Respondent: "Because when you have TB then people will start laughing at you, saying you have HIV. That is why we wouldn't want people to know. But the best is to let them know so that people can help you out and to avoid transmitting it to many people". [TB patients, urban]

Apocalyptic language: The language used for these three opportunistic infections becomes a vehicle for inferring that someone has HIV and is increasingly moralising, virulent and apocalyptic. Patients with these infections are regarded as "victims of AIDS" [gatekeepers, urban] who may spark off a chain of deaths within their own family.

"This world has been destroyed because of others! The symptoms are in the form of herpes zoster". [elders, urban]

"They feel very sad if diarrhoea continues and suspect something else - HIV/AIDS - which is highly there in all communities especially this time due to promiscuity which is rampant". [redcross helper, urban]

"TB is a killer disease which spreads like bush fire!" [politician, urban]

Name-calling⁹⁵: Often name-calling starts when these infections begin - "They call them by those names....normally at a stage when the disease tries to show" [pregnant women, urban]. All three are called "kanayaka" in the urban sites.

"People start nicknaming the person when the diarrhoea is continuous". [elders, urban]

⁹⁵ See Language and Stigma

"If it is a teacher [with skin rashes], there is too much gossip like "Kanayaka ba sir". He used to moving around with a lot of schoolgirls now he is in for it". [school children, urban]

Neighbours talk a lot of things about me and people in the community called me "kanayaka". [man, TB patient, urban household]

Death: In the context of HIV, all three diseases are associated with death. High mortality is particularly attributed to TB, which is seen as "killing a lot of young men and women" - "it finished a lot of our children" [elders, urban]. Many respondents also felt that TB and diarrhoea now "kill fast".

"They say diarrhoea is AIDS...They say it is death" [headman, rural]

"They say of skin rashes that she or he is HIV-positive hence death is near". [church elder, urban]

"TB patients have AIDS so they don't get better until they die". [HIV-positive married woman, urban household].

Certain types more strongly associated with HIV:

There are different types of tuberculosis, diarrhoea and skin rashes within local taxonomies.⁹⁶ Some types are more strongly associated with HIV than others with a distinction made between "normal" or "ordinary" TB, diarrhoea and skin rashes - which are not related to HIV - and other types which are related to HIV (see Text Boxes 6 and 7). As an urban politician explained, in relations to skin rashes, there is a tendency to "differentiate the rashes", observing whether it is a rash that disappears with treatment or not and speculating over what the cause may be. The same happens with TB and diarrhoea. The types related to HIV all carry more moral implications and are also considered to have become more prevalent since the advent of HIV.

⁹⁶ See Ndubani et al 1998 for an analysis of popular taxonomy of diarrhoeal disease in Misisi compound. They write that moral implications are only associated with wasting and long-standing diarrhoea which derives from an infraction of sexual prohibitions (miscarriage) and is only treatable by traditional healers.

⁹⁷ Although people would often distinguish between "negative" and "positive" TB cases, and would sometimes try to draw conclusions about HIV status on the basis of this distinction, there is little consistency in the data over whether 'negative' TB or 'positive' TB is equivalent to HIV. What was more significant was being assigned a "status" and becoming a "case" - which holds parallels with HIV.

One woman traditional healer explained to me that "TB of the Bones" was HIV-related because "of the HIV/AIDS viruses which make the joints of the patient weak" [urban].

Text Box 6: Types of TB⁹⁷, Diarrhoea and Skin Rashes associated with HIV

TB: "New" TB, "TB of nowadays", "TB of the bones", incurable, relapse (injections)

Diarrhoea: chronic, continuous, long-standing, persistent, severe.

Skin Rashes: herpes zoster, changes in skin colour, dry skin, kaposi sarcoma, severe or "sores all over the body" [urban elders, rural doctor, young urban men], boils, "syphilitic rash" [HBC co-ordinator, rural]

Text Box 7: Types of TB, Diarrhoea and Skin Rashes not associated with HIV

TB: "real", "normal", "genuine", "just" TB; TB of the lungs; TB that was "there in the past"; curable, "TB of the blood" - family TB, "TB of the air"

Diarrhoea: poor water, ordinary diarrhoea (related to contaminated water or contaminated food particularly bush meat or the rains), acute diarrhoea (cholera)

Skin Rashes: common, normal rashes, rashes also related to TB treatment, to food especially certain types of meat, cosmetics.

Relapse TB is associated both with HIV and with not adhering to social and sexual prohibitions.

"Causes of TB relapse? If you don't follow the don't". [pregnant women, urban]

Risk of transmission through casual contact:

People's fears around casual transmission of HIV are fed by both the fear and the real risk of casual, non-sexual transmission of TB, diarrhoea and skin rashes. In the case of skin rashes and diarrhoea, possible transmission routes for these diseases become possible transmission routes for HIV.

"There are some girls here, they will not mix, with someone who has AIDS...some think AIDS is like skin disease. This is what they believe. They don't believe that when they met [had sex] they can contract AIDS, even shaking

hands is a problem. They would prefer talking to him at a distance". [retiree, rural]

".....may be the patient has diarrhoea, people can't eat with him because they will eat his dirt, fear to be infected with HIV/AIDS". [pastor, rural].

"If a person who has AIDS develops diarrhoea he purges on clothes. If you wash those clothes without wearing gloves you will contract the disease". [traditional healers, rural].

In the case of TB, the link is more complex. People do not usually have fears of catching HIV through a TB patient coughing or through sputum, but they do worry about catching TB this way. And if you catch TB, you are very likely to have HIV. Also TB can be caused by casual contact with a woman who has aborted or miscarried. It would seem that this association - between TB and *kafungo* - has strengthened since the advent of HIV.

"The first information they have about TB - maybe it is something within the family. If it takes longer than that they said it is related to HIV. Then people with HIV - people we cannot eat with them, we cannot use the same toilet with them because people fear to get infected. They think [that] those with TB and HIV cannot be cured". [teacher, urban]

TB and HIV

"An excuse": TB diagnosis is regarded "an excuse" made by health workers, patients or relatives, or "a scapegoat" - a diagnosis, like witchcraft, which people can hide behind during illness and at funerals.

"He used to think he is man enough now he is going to see and that's not TB that's HIV he is using TB as an escape code". [peer educator, urban]

"At the hospital they say she has TB when they mean AIDS". [young women, rural]

"I have never seen at a funeral were they would disclose that this one died of AIDS, they don't disclose, they will talk of other diseases, like was bewitched or say its TB, which has killed that person". [pregnant women, urban]

"TB of nowadays": Much of the discrimination towards TB patients emanates from the strong belief that "TB is AIDS" and that "TB of today is due to misbehaving" [widow of TB patient, urban household]. Symbols of TB automatically become symbols of HIV. Although some respondents do distinguish between TB and HIV and understand that TB is not necessarily related to HIV, for most having TB is synonymous with having HIV. Six out of 13 of the household respondents said that TB patients were describe as AIDS patients

"....the problem is a lot of people do combine these two, synonymously...it is not very clear as to draw a line or a boundaryso people fail to differentiate, between a TB patient and a HIV AIDS patient". [NGO manager, urban]

A TB diagnosis at the clinic transforms into a HIV diagnosis in the community.

"In community, it starts with malaria and in the end they test it at the clinic say that it is TB and when they go home they deny him and say TB is AIDS". [HBC caregiver, urban]

Incurable: People with TB are "unfortunate because it is associated with HIV" [orphanage teacher, urban]. This association means that there are always a number of possible outcomes - and creates confusion over whether TB is curable or not, as captured by the apparent contradictions in the responses about TB from a nursery school teacher:

They say it is a killer disease but it is curable.....They really pity them [TB patients] and say those who move about will finish since AIDS has no cure. They feel very miserable and expect to die anytime, treatment must be done without delay. [nursery school teacher, urban]

"Arrow of Accusation" [Douglas 1991]: TB follows the same pattern of blame as HIV - young people, women, people in towns, sugar daddies are viewed as out of control, not listening to elders or tradition and responsible for the spread.

"These days TB is more common because people don't listen they misbehave, they sleep

anyhow, and drink a lot smoking that is why we can't control the disease now. You find a young girl sleep with an elder man and the young man sleeping with elderly women". [48 year old HIV-negative man, ex-TB patient, urban household]

Vindictive: TB patients, similar to people living with HIV, are often accused of spreading their infection on purpose.

"Here may be this person wants to murder a lot of people, this is what we can think in our minds. Again, this thing (TB) they don't say that this is how I am suffering. A person will know that he is not okay but he will still move up and down". [traditional healer, rural]

Diarrhoea and HIV

Particularly hard to put up with: Diarrhoea is particularly hard for carers to put up with since it is "very involving & demanding" [rural male TB patients], demands time (washing the patient and linen), space and money (for surf) and is considered disgusting. Only particular close relatives will tolerate diarrhoea. Diarrhoea also demands that the carer should be of the same sex in order to wash the patient.

"Others feel it is a burden because that person has diarrhoea and a short time later he/she messes her/himself again. It is very involving and demanding". [male TB patients, rural].

"...distant relatives especially if you start developing diarrhoea, they really isolate you. Only your mother can stand that, and may be your young brother or elder sister can care for you". [pregnant women, rural].

Skin Rashes and HIV

"Fire of the Night": Herpes Zoster is often referred to as the "Fire of the Night" or *mulilo wa kutulo*. This refers to the fact that the rash can appear overnight and "burn" your skin. The urban traditional healers said it also has connotations with witchcraft that is inflicted during your sleep in retribution for adultery. Out of all the rashes, it is herpes that is the most strongly associated with HIV. Talking about herpes zoster, a widow whose

husband had died from HIV says, "Once you see the rash, you just know you are positive" [urban household].

Experiences of Stigma Related to Opportunistic Infections

Many of the core experiences echo with the experiences of stigma directly related to HIV and discussed earlier in this report. Some experiences are unique for one or two diseases. The Venn diagram in Figure 3 portrays the experiences of stigma in relation to these three opportunistic infections.

Core Experiences

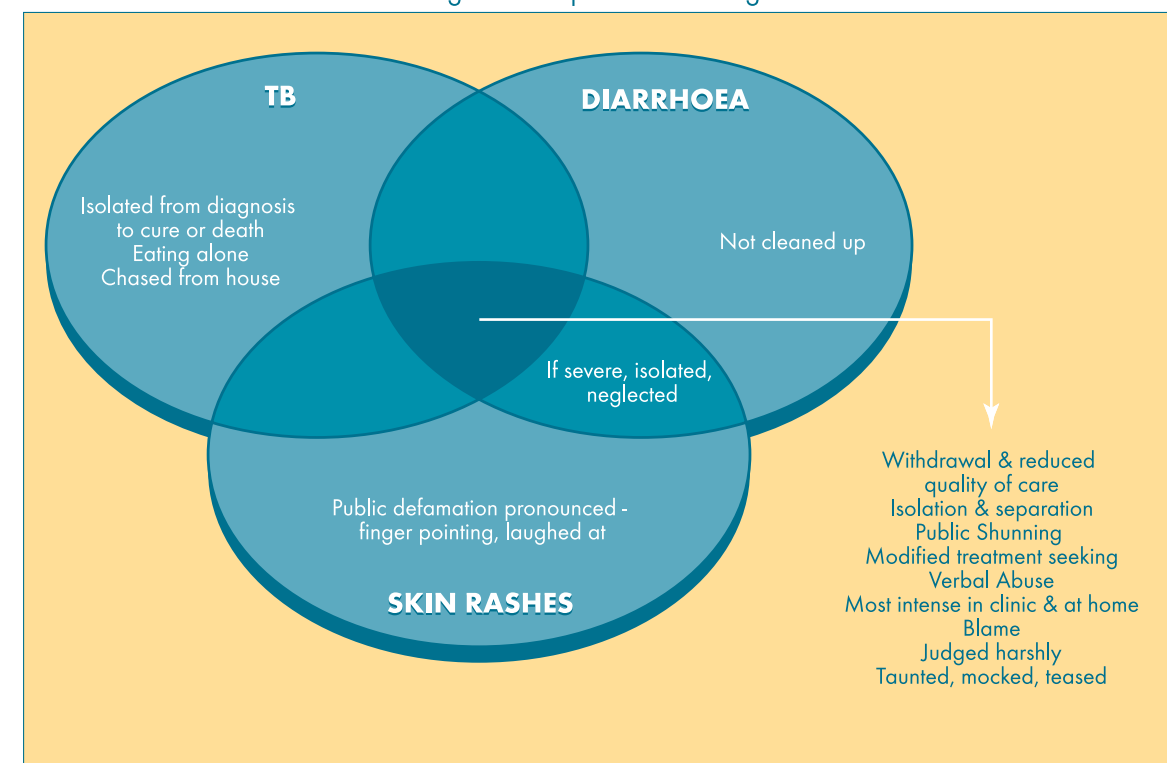
Withdrawal and Reduced Quality of Care

Pushed between treatment options: Patients with diarrhoea are taken by carers to the hospital or clinic and then sent home. An urban male marketer explains that "people shun the patient [with diarrhoea] and so they would rather take the patient to the hospital". However, nurses at the clinic, relates a taxi driver in the urban site, "the moment they get the message that this person has chronic diarrhoea they will discharge that person and you start nursing that person at home". Young women from the same site claim that health workers don't want to "waste" medicine on people they know are HIV-positive.⁹⁸

Not deserving of treatment: When opportunistic infections are diagnosed by the community as being related to HIV, carers in the household can withdraw treatment. Stories of neglect - particularly around chronically patients with diarrhoea and TB patients - abound, and the critical importance of special services for people living with HIV is highlighted as reflected in the following:

"..on the issue of TB a lot of people in our community are suffering others are sick but no one cares for them. No one gives them water, people from home based care if they try to pass by to the patient's place that's when they receive help. Only a few Catholics who were trained to help if they don't give report there

Figure 3 - Experiences of Stigma



that person will just be suffering without anyone cooking porridge. He stays hungry just like that". [bar owner, urban]

nursing her. After all she was married and they were all doing business moving from one place to another disturbing people's properties". [women TB patients, rural].

Text Box 8: Not deserving of treatment

In one relatively well-off urban household, the father (a traditional healer) and the mother repeatedly claimed they could not find the money to transport their HIV-positive daughter to the clinic or to buy medicine. Once, when their daughter suffered from relapse TB, the mother came to the clinic to try to collect drugs for her daughter and did not return with her daughter - who by this time weighed 25kgs - to get treatment until a week later. The counsellor thought the family was probably both tired of spending money on their chronically ill daughter and also that they hoped that the research study might assist.

Similar to children, there are stories of TB patients not being given food in a household.

"...another friend with TB who used to stay with the brother, he wasn't given food. He used to get Soya from the clinic. So because of hunger, he started drinking beer. Because of beer drinking he was chased from the house". [man, urban household]

Not cleaned up: Elders in the urban site said one of the problems they faced was "cleaning up the patient when they had diarrhoea". There were reports in both sites of patients not being cleaned up when they had diarrhoea, and, in a couple of cases, dying covered in excreta. This reflects how diarrhoea is sometimes so hard for health workers and carers to cope with. The more severe the diarrhoea, the more likely that the patient is neglected. This is also true of severe skin rashes.

Carers give up: Carers can lose hope and give up caring for chronically sick patients, especially those with diarrhoea and TB. "People give up easily and run away because it takes a long time to nurse the sick" [gatekeepers rural]. Close relatives of a woman TB patient deserted her at the mission hospital, using the following justification - as relayed by her fellow TB patients.

"...the sister and brother left, they said that we are going because we are fed up this person [who] doesn't even have a child to help

"Then the last comment is people with AIDS suffering from diarrhoea, people don't want to look at them or may be help". [youth development officer, rural].

⁹⁸ The young women also pointed out the irony of patients coming to the clinic where they hope they will be comforted and healed, but instead being shouted at and refused medicine.

Isolation and Separation

Restricted space: Space is restricted by the desire to hide from stigma, the need to be near a toilet (in the case of diarrhoea) and prohibitions on where you can go when you have TB.

Deprived of contact: People report that they avoid touching those with skin rashes, sitting next to them on buses or sharing a toilet or basin with them. People may even avoid touching things that people with a bad, peeling rash have touched.

"Maybe you've got deep rash, some of them go to that extent like the skin is peeling off, they are scared of those things, they think maybe you might touch those things maybe were the skin has peeled off so maybe that sent the odour". [politician urban]

People report refusing to eat with, share utensils with, drink from the same beer container or even share soap or drink water from the home of a TB patient. TB patients are usually instructed not to have sex during treatment.

Indeed, all except one of the TB patients in the household study recalled how their family were frightened of sitting near them and always ate separately; and some recalled how their spouse, siblings or children used to hide in their rooms because they were afraid of being infected.

"When I had TB my wife used to say that I should not sit near her since TB is infectious....She used to tell me that I should stay a bit far from her because she didn't want to get sick".

[HIV-positive man, urban household]

Public Defamation and Rejection

This is particularly related to skin rashes, which give licence, especially in town, to staring, finger-pointing, being openly, laughed at.

"if its a man or woman who has HIV/AIDS selling [in the market] people start selecting where to buy by saying to their friends "you don't go and buy there!" Or "there, can't you see the way that person is looking - the skin greyish as if someone hasn't applied lotion on the body! Lets go we buy somewhere else".

[young women, urban]

TB patients are often made to eat and sleep on their own from being diagnosed until they finish treatment. One 23 year old man who had suffered from TB and who tested HIV-positive, was told by his wife that he should *"die with TB on his own"*, and whilst he was sick with TB, she forbid him from being near her. Once he recovered from TB, although they continue to have sex together (using condoms), he is still made to eat alone and have separate utensils.

Many TB patients experienced being rejected by neighbours and, if they were involved in selling in the market, people would refuse to buy items (especially food items). One young man withdrew from the market when he had relapse TB and had to go for daily injections, choosing instead to sell from outside his home which was a more sympathetic environment than the market. Even in church, TB patients are not always welcome.

"In some churches when they find someone has TB they will advise he/her to go home, people from there will come to pray for you at home, rather than go to church when you are sick".
[peer educator, urban]

A TB diagnosis can instigate family rejection, particularly for women and for more junior or marginal household members. In a household study a young man staying with his brother in Misisi, was chased from the house by his brother's wife when he revealed his TB diagnosis.

Reduced Treatment-Seeking for Opportunistic Infections

"It is TB, skin rashes and cancer [that are most associated with HIV]. Most people who have these diseases are shy to talk about their diseases, which makes them stay away from the clinic or the hospital to receive treatment".
[peer educator, rural]

There is evidence in our material that when people fall sick with these infections, they will hide their illness to avoid stigma. Respondents also point out the vicious cycle of stigma leading to neglect, depression and avoiding or lack of treatment. As a result, *"TB kills fast"* [traditional healer, urban].

"TB patients feel neglected. They get depressed and many give up. Some don't even want to go to hospital".
[NGO manager, urban]

When suffering from skin diseases, patients *"don't feel ok because when one has skin rashes he/she will not feel like a real person [and] cannot go out into the field to greet friends"* [politician, urban]. They isolate and withdraw themselves from public places and from friends, wanting to hide their skin and their condition.

When discussing the management of diarrhoea, respondents talked about using nappies (*"wrapping like a baby"* [rural community health workers]), and washing the bed, the linen, clothes and the patient. Although respondents often advocate the use of gloves and disinfectants, they often do not have gloves to use. It is managing diarrhoea that seems to sometimes push carers to the limit, as reflected in the following quotes.

"Man also suffers. If he is sick, purging all the time, his wife won't take off his trousers. His male relative will do that. People complain because of dirt purging stuff. They wish a patient death at this stage".
[traditional healers, urban]

The association between TB and HIV may push people back to traditional healers in a quest to avoid diagnosis and the stigma of regular trips to the TB corner, and healers may exploit this.

"The TB of nowadays has no cure at all especially of modern medicine but when such a patient is taken to a traditional healer, he or she can be cured". [traditional healer, urban]

In the rural site, stigma contributes to how long it can take people to get diagnosed with TB due to the cost of transport, long distances to reach the clinic or hospital, and dominance of traditional beliefs.

"TB is high, but also it is difficult identify a TB person sometimes you can find that may be a person can be coughing almost a year".
[woman marketeer, rural]

⁹⁹ With whom she shared a house.

Because of the strong association between TB and HIV, TB patients would sometimes avoid diagnosis, not disclose their diagnosis, delay or drop out of or hide treatment. One HIV-positive woman in Misisi said, *"People don't say they have TB because they fear to be isolated".* *"Of late it is a problem, people do not want to be told they have TB"*, explained a rural clinical officer. In the household study, 4 out of 13 TB patients said they had hidden their TB status because they were afraid of being isolated and told they had AIDS, and six said they had been ashamed but they overcame their shame to get treatment because *"if you hide you will just die"* [woman traditional healer, urban household].

"I don't share my TB results with people because when they know that you have TB they stop drinking or eating with you thinking that you have AIDS".
[HIV-positive man, urban household]

Only three were not ashamed of their TB status and that was because they had *"just TB"* and knew they were HIV-negative.

"I was not feeling ashamed because I knew it was TB of the air". [woman, urban household].

"I was tested [for HIV] and found negative and the people I was staying with knew that I had TB only so I was not called names".
[HIV-negative man, urban household]

Indeed, it was evident from the household study, that if you knew you were HIV-positive this deepened the stigma associated with opportunistic infections and, conversely, if you knew you were HIV-negative, you were more able to push the stigma away. For those TB patients who were HIV-negative, this knowledge seems to give them the confidence to challenge and deflect stigma. For example, two women who had had TB in the household study discussed their experience of relatives to their husband gossiping about them being sick. The HIV-positive women said she simply hid herself away - *"I used to stay in the house so I never heard what people gossiped about me".* The HIV-negative woman relates how *"my sister in marriage⁹⁹ and neighbours used to say a lot of bad*

things....she is going to die, she has no relatives here only in Ndola. So one evening I went outside the house and started insulting and telling them off. That's when they stopped gossiping about me". As a stone-crusher in Misisi said simply of HIV-related TB, "since they know the cough is different, they feel bad".

Self-Stigma and Opportunistic Infections - How it makes a patient feel

The impact on patients of the stigma of opportunistic infections is mainly considered by respondents from a psychological angle, with little mention of the physical impact (e.g. scratching, pain, dehydration). Respondents cite a range of emotions as the impact of having these infections including: panic, fear, feeling powerless, depression, withdrawal, self-isolation, shame, embarrassment, feeling bad, feeling rejected, expecting to die anytime, contemplating suicide, constrained, defeated, lonely. It "weighs them down" [priest, rural].

"They [people with skin rashes] feel they are not part of the community".

[person living with HIV, rural]

"Feel troubled in the heart because the person will feel it's just that they don't like him/her, that is why they are treating her like that".

[man TB patient, rural]

"He [person with diarrhoea] feels bad due to the words said by the fellow friends".

[peer educator, rural]

Talking about his experience of having TB, a 35-year-old HIV-positive man relates how neighbours "didn't answer me well" and "used to isolate me", and how this behaviour gave him "a pain in my heart". The wife of a HIV-positive TB patient never told her husband what the neighbours were saying about him to protect him from their words. A HIV-positive woman who had had TB portrays the dehumanising dimension of stigma related to TB when she pleads, "TB patients are also people because it is not that when someone suffers from TB

is not a person" [urban household]. A man who had insisted his wife sat separately from the family when she had TB, later developed TB himself and experienced the same treatment. After that experience he said, "It is not good to isolate a person when you know that he has TB because before he started treatment you were eating together. So it is better to just give him/her a side plate but you sit together".

TB patients absorb the prevention messages they are given, often imposing self-isolation on themselves. So they both create the distance and are distanced.

Witchcraft¹⁰⁰ and Stigma

It is important to explore witchcraft and the role of traditional healers to further our understanding of stigma because stigma for a variety of reasons, is leading to accusations of witchcraft to explain HIV infection, as well as pushing people to seek help from traditional healers

People from town may go to the village in the quest for traditional medicine to treat both HIV symptoms and other chronic illnesses (for example epilepsy or infertility). Traditional medicine and kin support are embedded in the tradition of the village. "In the villages", young rural women explain, "we mostly go to ng'angas". Traditional healers often manage chronic diseases - as a rural pastor put it, "they divide the diseases - some for hospital, some for the ng'angas". It is not that witchcraft and traditional healing are exclusive to the village - indeed, in Misisi there are many traditional healers [see Ndubani 2002]. But, there are many other treatment options in town.

Witchcraft pushes stigma away: Some respondents - including interestingly traditional healers - said that families and patients are hiding behind witchcraft explanations. This is a common perception in rural Zambia [Bond and Ndubani 2000, Bond 1998, Musingeh 1990].

"...it is a hiding area because they will always give you some way forward which is some comfort even if she/he knows that the witchdoctor can't [cure her]".

[traditional birth attendant, rural site]

"They say she has died of AIDS. But her families hide it. They hide in the name of witchcraft". [traditional healer, rural]

Although there is a very deep rooted and genuine belief about witchcraft in general, and as one cause of HIV and AIDS, most respondents recognised witchcraft as a strategy to hide HIV and buffer stigma. It is easier for the family to ask for and to receive support for a relative who is being bewitched. In turning to traditional healing, they are following a much trodden and very familiar path which gives them hope (in the form of the possibility of cure) and allows them to discuss cause of the illness more openly with others who can, in turn, offer advice, recommending herbs or healers. People who are bewitched are "being assisted, because people go and tell them try this ng'anga maybe you get alright, try this one, maybe you will be alright" [teacher, rural].

It is easier for the family to then care for someone who is bewitched - "These people who are bewitched are well looked after" [headman, rural]. It is often a kinder and more encouraging way to handle the patient as reflected in the following quote.

"They say maybe they will not tell him directly to say he is suffering from HIV/AIDS but only advise him to go and see the witch doctor for African medicine. Where by they know that he contracted the virus but they are sort of encouraging him". [young men, rural]

By assigning HIV to witchcraft, "Close families escape stigma in that manner", explains a doctor in the rural site. A NGO manager in the same site agrees - "close relatives will always feel sorry for the person...the friends maybe in the community who knew about his behaviour, when [he] starts shouting the symptoms, they will just know. It is a scapegoat going to bang'angas".

Many rural respondents told us "it is not their fault they are bewitched" [business lady, rural]. There is no shame attached to being bewitched - "they wouldn't be taking it as if it is a shame" [pastor, rural], and "being bewitched goes along with sexual propriety" [agricultural officer, rural]. Being bewitched is also more "normal" than having HIV, which is reassuring and comforting - people who are bewitched "never feel like those with AIDS; they take it as normal to be bewitched. Their body is not like 'the carriers'" [TBA, rural].

In other words, being bewitched helps people cope with external and internal stigma. One of the advantages of traditional healers is that they do not often tell you that you have HIV since "the witchdoctor does not see the HIV virus and will continue saying you have been bewitched and assure you some medication" [TBA, rural]. It is a way of avoiding a HIV diagnosis at the hospital and a way to "avoid death" [NGO manager, rural].

Traditional Healers are a more discrete treatment option: Living largely amongst their own kin in scattered villages and in poverty, people may find that traditional healers are a closer and more discreet treatment option. For people living with HIV and AIDS it is a way to avoid stigma on the way to and at the hospital or clinic.

"Here [in the village] that person belongs to us he is part of us. We feed him. We don't even say he has AIDS. We say he is bewitched. But when you take him to the hospital and sees that they don't treat him well, they can call him names". [blacksmith, rural]

"Sometimes people fear to be seen. They don't want to tell the people what they are suffering from. If they go to the hospital, they fear that people will see them, because at the hospital many people usually go there. Hence they go to the bang'anga". [person living with HIV, rural]

Traditional Healers may be less stigmatising: Healers were though reported to be good listeners - even "counsellors" - and, in stark contrast to sometimes harsh treatment at the hospitals and clinics, are much more likely to adopt a respectful,

¹⁰⁰ In the rural focus group discussions and key-informant interviews, the following questions on witchcraft were included: What do they say about people who are bewitched? How does it feel for people who are bewitched? Why would people who are HIV-positive prefer to go to the traditional healers rather than going to the clinics or hospitals? In both rural and urban sites, both in-depth interviews and FGDs were held with traditional healers. In the rural site, through the training workshop with research assistants, we quickly realised the significance of witchcraft in relation to stigma and the widespread use of traditional healers, and that is why we added these questions. With hindsight, it would have been good to ask the same questions in town.

welcoming approach, without judging or condemning. And they are much more likely to blame the "witch", not the patient. *"It is not your fault. It is the fault of the uncle who is bewitching you"*, [research assistants, rural workshop], and as a result people feel *"sympathetic because the blame lies with the witch"* [clinical officer, rural].

Traditional Healers may lack confidentiality: There was evidence, however, in the rural material that traditional healers did not always maintain confidentiality, with a number of respondents claiming, *"witchdoctors never keep secrets"* [gatekeepers, rural].

"...the father ...might take the son to the witch doctor and this witch doctor won't keep it as a secret, he will go on and tell others, "that man came brought this sick person and has suffered from this disease"". [women farmers, rural]

Some traditional healers claim they can cure HIV and AIDS: Traditional healers in both sites said they were able to diagnose HIV and AIDS and treat the symptoms. Some of them said they were able to cure HIV, especially in the early stages, or give medicine to prevent people being infected with HIV. One rural healer also said that witches could make people sick with AIDS symptoms.

"...witches have tricks others can bewitch a person in line with AIDS having AIDS symptoms. People can even say that, that person has AIDS when he is just bewitched". [traditional healer, rural]

Rural Traditional healers struggle with managing HIV: However, traditional healers also said they found it hard to cope with HIV and AIDS. In our discussions with them, they repeatedly said they had difficulties managing HIV and AIDS because of poverty, the difficulty of diagnosis and that HIV could not be cured.

"Here in the villages we have a problem of helping people living with AIDS. If there is

something you can do - please come in because people are dying. A person who has AIDS wants nice things [but] where are you going to find them? There is no food. Some die when they were not supposed to die. At least a rich person is sustained. You can give him medicine but is he going to eat? If he dies, we just bury because there is nothing we can do.....These people must be taken to the hospital because those people know how to go about it". [traditional healers, rural]

"Some people say that even if you help him you are wasting your time because that person will die. They say that he was bitten".¹⁰¹ [traditional healers, rural]

"AIDS is difficult to treat. Even just finding out to say that this is AIDS. It is difficult. You just need to encourage that person. He has to be treated in a way that he doesn't know that he has AIDS. There is no person who can cure AIDS it is difficult". [traditional healers, rural]

Urban Traditional Healers cope better with HIV and AIDS: The healers in town are more likely to be registered with a traditional healer's association and to have been engaged directly in HIV and AIDS workshops.¹⁰² The healers in Mbabala had not had this opportunity and they have more fears around casual transmission of HIV, use more stigmatising language and their bio-medical knowledge is more limited.

Urban traditional healers are helped by increased access to VCT, knowledge of status and openness in the urban sites. One traditional healer relayed how *"a lot of them come to me to seek help and they say that they are HIV-positive. They come to my working place."* Although he is not able to cure them, he says he is able to *"stop some of the diseases attacking the body"*, and that *"one of the patients is now five years since the time he discovered he is HIV-positive by the medicine I give him"*. This suggests that if patients know about their HIV

status and are able to share it with traditional healers, healers are more able to help them.

Drawback of using of witchcraft as an explanation: Certain types of illness lend themselves to accusations of witchcraft and there are always different motives lying behind witchcraft accusations [Douglas 1991]. It is evident in our material that witchcraft accusations are a strategy to push blame away from the close family and the individual, to channel blame about HIV infection to the in-laws and a reflection of stress and strife within the household. The latter is evident in accusations made by sons against their fathers, a pattern also recently recorded by Colson [2002] amongst the valley Tonga. Respondents mentioned accusations being thrown at uncles, grandmothers, in-laws and fathers. These accusations are very openly made at funerals.

".....sometimes the son can tell his father and they will keep the secret, but afterwards the son will start saying, I am having dreams my father is the one who is bewitching me, the father gets confused because he remembers it is the son who revealed that his HIV positive, so like this the father can also blow it to others and this also becomes a problem". [women farmers, rural]

"It happens, you find that when the wife dies the relatives of the husband are blamed, that it is the husband who brought the disease, and again there comes the issue of bewitched, either say the uncle of the man has bewitched her because they don't want her". [women farmers, rural]

This has the effect of putting the locus of responsibility into the realm of external control [Schussler 1992], and could give people a sense of "false confidence" [Turner 1963] that the disease is effectively managed without internalising the connection between behaviour and HIV infection. Witchcraft accusations also have the potential to cause family rifts, anguish and financial strain¹⁰³ [Bond 1998].

In both sites - but more especially the rural - there were respondents who saw traditional healers as charlatans who were mainly *"after money so they will cheat"* [gatekeepers, rural] and that seeking treatment from them for HIV and AIDS was *"wasting time and money"* [NGO manager, rural]. They were accused of *"taking advantage of sickness"* [business lady, urban] and demanding extortionate fees (for example, three cows).¹⁰⁴ In the face of poverty, no special interventions for people living with HIV and AIDS and the failure of traditional medicine to effectively manage HIV, the danger is that rural traditional healers may themselves become scapegoats.

Being bewitched as a sign of HIV and AIDS: While witchcraft and turning to traditional healers may have been, and still may be in some cases, a way to cope with or protect with stigma, this is rapidly changing. The strong association between HIV and witchcraft can mean that being bewitched, similar to having TB, is now stigmatised since it has become a sign of having HIV as reflected in the following quote.

Interviewer: *"Are people who are bewitched treated badly by others?"*

Respondent: *"Yes, they mistreat, because they think it is a virus. They are bewitched but people think they have a virus....they look at the kind of life the sick person led. So even when the person is truly bewitched, still more people won't believe, saying "This one who used to move like this! No, this is a virus!"* [Person living with HIV, rural]

This portrays the dynamism of beliefs about witchcraft and HIV. Witchcraft has metamorphosed into another sign of HIV and AIDS.

¹⁰¹ "Bitten" in this context means bewitched and has become synonymous in Zambia and Malawi with being infected with HIV (see Bond 1998, Probst 1996).

¹⁰² A woman traditional healer in the household study, living in Misisi, had attended three HIV and AIDS workshops and her knowledge of HIV and AIDS was very sound and detailed. Empowered by her various experiences - including the experience of nursing her brother and her niece who had AIDS, having herself had TB and having tested HIV-negative - and her different sources of information (including her knowledge of traditional medicine and inclusion in the first ZAMBART household study), she has little fear of casual transmission of HIV, makes few judgements about people living with HIV and AIDS and has a very strong combination of skills.

¹⁰³ Accusations of witchcraft sometimes result in witchfinders identifying witches and fining them hefty amounts (see Yamba 1997).

¹⁰⁴ In the community meeting we had at the beginning of our rural research, villagers turned on the traditional healers present and started slating them for exploiting HIV and AIDS. We felt very uncomfortable by this attack on healers, since it wasn't our intention to point fingers at them or alienate them, and one staff member from Kara Counselling pointed out the positive role of traditional healers in order to diffuse the situation.

Building on Existing Care and Support

In some ways providing care seems to be the opposite of stigmatising actions, yet they are not mutually exclusive. It is possible to advocate against stigma and yet stigmatise, and, moreover, it is possible to stigmatise and to care. In spite of so much reported stigma, many members of the communities in both the rural and urban sites are caring for relatives when they fall sick, often in the face of absolute poverty. Respondents showed high levels of awareness about the needs of people living with HIV and AIDS, ranging from 'healthy' food and nutrition, medicine, spiritual support and emotional care.

"It's not good for persons suffering from HIV/AIDS to leave them on their own, not caring about them. What is needed is to be with them all the time, give them the care and support they need, giving them food to improve and prolong their lives...where exactly is our passion and Christianity if we are saying some of these words and not putting them into practice". [traditional healers, urban]

Food and diet: When asked about caring for people living with HIV and AIDS who are sick, food was one of the first factors mentioned by many respondents. People recognise the importance of food and diet as a way of helping a sick person live longer. They mention 'healthy foods', mineral salts, 'foods that build and protect the body', beans, meat, fish, vegetables and chicken.

"When you have a balanced diet with a lot of vegetables, good environment, care from the family looking after that patient, and also the friends, can help that person live longer [than] a hundred years". [gatekeepers, urban]

"When you have this disease, whatever you want in terms of food should be there for you to eat, that way you live longer". [young men, rural]

Families will try hard to ensure there is enough food to sustain a patient. These concepts of the special dietary and nutritional needs of people living with HIV and AIDS in the context of poverty are both

"poignant" [Blinkhoff 1998, Bond 2000] and an added burden on patients and families. Indeed, the lack of food, particularly in the rural area during a period of seasonal hunger, was one of the factors that fuelled the feeling of 'burden' experienced by carers of patients.

"Looking after the patients is very expensive for you to get what he needs. You will sell your things in order to buy food hence this leads to poverty". [primary school pupils, rural]

"They [people living with HIV and AIDS] are being kept well - it's only that they get hungry so fast, they don't want to stop eating and they demand nice food and where do they expect you to get that food? For example, like me I am a widow and old...what can I do? "Nothing". [stonecrusher, urban]

"The family also tries to provide the balanced diet, so that the person can survive. They struggle by all means to find the money". [secondary school girls, rural]

Emotional Support: The communities acknowledge the importance of emotional support, referring to: providing moral support; not leaving someone alone or uncared for; and how essential it is to talk to a sick person, to be gentle with them and to show them 'a soft heart'. Women are reported to have softer hearts (in this regard) than men. Such support is confirmation that you matter, that you 'count'.

"Those who have this disease want to be pleaded with and showing them all the love and care and even showing them soft hearts. Even when they know that they are dying, it gives them so much strength". [pregnant women, rural]

"Firstly, give that person encouragement so that that person feels loved and counted in life". [TBAs and CHWs, rural]

It is this awareness of the need for emotional care and support that can directly challenge the hurt and pain caused by stigma and isolation. Respondents

talk about how love and care can extend lives and how the patient needs comfort, so that he or she does not feel neglected by their family, and how important it is not to scold a patient.

"... not telling them off over their past behaviour or anything that would make the person angry. They need to be free minded always". [TBAs and CHWs, rural]

A teacher in the urban site sees illness as the opportunity to show your love.

"I have a nephew with TB. Thus I show him the love that I have never showed him". [teacher, urban]

Spiritual Care: People also recognise the role of spiritual beliefs and care, in helping to sustain a sick person. Prayer, reading the bible and getting strength from God were all mentioned as an important part of the care for a patient with HIV and AIDS. Even if there is belief that someone may have 'sinned' in the past, most people believe that they can turn to God for comfort.

"Yes, even if one was not helping you, showing off before he or she was sick, people in this state they need care. [We should] encourage the HIV/AIDS patient not to lose heart and tell them they should always pray to God. God himself sent his only begotten son to come and save the sinners and he also healed the sick. We should emulate this example from the Bible". [gatekeepers, urban]

Faith also plays a key role in helping to sustain the carers, as this group of health providers described.

"The little we have, we share, the way God gave us, and we thank God, the gift of visiting these people, that is why sometimes gives us the energy... if I am absent my heart will tell me go to that person". [health providers, urban]

Need for external support: Poor households do need support to care adequately for people living with HIV and AIDS when they are sick.

"The rich can afford to buy medicine and to buy food for themselves. Now to the poor, they can't afford it and sometimes the neighbour can't help (not all neighbours are good). The churches help them, any groups or organisations that are working on HIV/AIDS can help". [young women, urban]

Churches in both sites - but especially the urban - provide practical help to families caring for sick people living with HIV and AIDS. Respondents mentioned the fact that churches have built shelters for patients, provided food and clothes and sometimes medicine. In the urban sites, home-based care¹⁰⁵ (HBC) and the hospice are seen as critical in the care and support of people living with HIV and AIDS. As mentioned before, HBC is mentioned as providing care and material and emotional support, particularly when the household cannot cope. Material support includes food aid to TB patients.

"The critically ill without financial capabilities would turn to the Home Based Care who gives them shelter, food, care (nursing) and comfort". [TB patients, urban]

"If someone is very sick, they take that person to Jon Hospice". [young women, urban]

"It's better to be kept at Jon Hospice than at home because at home no one bothers to bring you things like oranges, apples, mangoes etc. But at the Hospice, if you are there as a patient, a lot of gifts will come". [business men and women, urban]

In both sites, and despite the reported stigma at the clinics, the clinic (and the mission hospital in the rural site) are viewed as an important treatment option for patients when they are chronically sick and when you have money to pay for medicine, or when free treatment is possible (like in the mission hospital). Some respondents, including those in the household study, saw clinics as a place of hope, where good care is provided and patients have a chance of recovering.

"We really thank the clinic for the help they give to people with AIDS. Some people take

¹⁰⁵ Almost all the urban key-informants and FGDs mentioned HBC as a source of care and support, compared to only three rural key-informants - one from Macha Hospital (who have a home based caregivers) and two from Choma town where they have HBC. In Mbabala, there is no HBC.

months at the hospital but nurses still don't give up on them. Those who were supposed to die quick, their lives are sustained when they go to the hospital because of the kind of treatment they receive". [pastor, rural]

Text Box 9: "I never stopped"

"My daughter was married - the husband was promiscuous. Last time he had a girl friend and this girl became sick. At this time my daughter was still alright but somehow she was not well. She was in and out of the bed, she could complain of malaria, fever, toothache and so on, not knowing what the cause was. We used to visit her until finally, she was brought to us from our home area. I decided that she should stay with us, for us to observe her. She stayed with us for five years. The husband remained home with the second wife and the girl friend has passed away. I experienced a lot with this daughter of mine where by sometimes she could complain of legs aching. We thought sometimes she was possessed by demons, we took her to the witchdoctor just like that until finally I came to understand that this was not the real problem she was telling us. It was something else. I was convinced that it was AIDS but I didn't tell her directly. "I have taken you to the witchdoctor, hospital and private hospital so that next I think there is something, may be you misbehave sometime back". She responded openly to say, "Let me not hide anything to tell you the truth, my husband had a girl friend and it is the same girl you heard that she passed away. Even if I am going to be treated in any way, I am not sure of being healed, you will just waste your time". I never stopped, I tried my best, and finally she died on June 10th 2002".

Care becomes harder over time: As mentioned before, over time - in the context of poverty - care wanes. This is reflected in the following dialogue amongst community health workers and traditional birth attendants in the rural site.

Question "Does support change over time?"

Respondent 1 "It changes because as you nurse, money is finishing".

Respondent 2 "You lose hope and you stop putting that much effort".

Respondent 3 "You run short of money because of the demand and being too close. You find you have to reduce because you are tired".

[TBAs/CHWs, rural]

Women as carers: "this disease needs women carers" [pregnant women, rural].

There is always pressure on relatives to care for kin. There is a Tonga saying for this "*chalema kusowela kuli bamukamwini*" - "when it is heavy, throw it to the owner".

"There is no way you can mistreat him because he is your child. You can't tell him to get out, where can he go?" [Blacksmith, rural]

Usually, mothers will look after their children, daughters their mothers and sisters will care for sisters and brothers. Rural secondary school girls remarked that good women friends also look after each other "*even in the full blown stage*". An urban health worker, recalled how her mother "*did fine*" looking after her brother who had HIV and AIDS, managing to attend to her personal business and his care. A woman miller shares her experience of caring for her daughter who died from HIV and AIDS, demonstrating the strength of a mother's love (see Text Box 9). Indeed, if mothers did not care for their children when they had HIV and AIDS, this was considered improper, and they could be chastised for their behaviour.

But even with close, blood kin, the care would be determined partly by the strength of reciprocity in the existing relationship and whether it was felt the child deserved the care.

"Just to add on, there is this lady who came from Lusaka, she never brought any things to the mother in the village. Now she got sick [and] she came back here to be nursed by the poor woman who didn't enjoy part of her money". [men farmers, rural]

Women were more likely to care for their husband if he were sick with HIV and AIDS, often despite their anger and blaming. If women in turn fell sick with HIV and AIDS first, they were more vulnerable to be sent to their parents or deserted.

"Those who are married are taken care of by their wife, who as well stands by their side until death". [traditional healers, rural]

"A woman can suffer for her husband but I have never seen a man suffer for his wife". [traditional healers, rural]

In the household study, there were examples of men staying with their wives when they knew their wives were HIV-positive, and even when if their own results were discordant.



Text Box 10: Community Ideas For Interventions To Combat Stigma

- Start with ourselves: changing attitudes to people living with HIV - we need to start with ourselves then we can treat others better.
- Greater Acceptance: People should live positively and accept their status; community members should avoid isolating or saying things that hurt a sick person.
- More Information about Stigma: Stigma can be minimised by the availability of up-to-date information in the communities using posters, IEC materials translated in local languages, door to door sensitisation campaigns involving local families.
- Greater clarity on HIV and AIDS and TB : transmission, prevention and treatment.
- Educating Couples: Women always suffer the blame and do most of the caring while the man is blamed less because he is head of the house, so we need to educate couples to support one another.
- More support for people living with HIV and AIDS and caregivers: support groups for people living with HIV and AIDS and care givers; participatory workshops using learning through drama and songs.
- Greater material help to support Positive Living: The poor should be helped in terms of food and medication. Families need to be supported to care for the sick. Nutritional foods like soya beans (as provided by the Home Based Care) and fruit should be available to support positive living.
- Greater support for Widows and Orphans: Government should look at the plight of remaining spouses, widows and widowers who are HIV-positive; build more orphanages to accommodate the orphans; build projects where youths can spend time; create social amenities as forms of prevention.
- Greater Employment Opportunities: One sex worker in the urban Misisi compound said there was need for education on health issues and creating employment for sex workers, "it's not our wish to be sex workers but it's due to poverty".
- Better Health-care facilities: the government should support health institutions and provide enough drugs and better facilities. Clinics and hospitals need to be able to give proper diagnoses and medication. Misisi compound should have it's own clinic
- Active Role of the Church: the church is where you find refuge and hope of living longer- churches need to educate and preach about HIV and AIDS and stigma in the communities, and to provide practical help like clothing, food and shelter to families affected by HIV and AIDS.
- Collaboration of different organisations to fight stigma like the Neighbourhood Health Committee, Home-Based Care, Clinics, Witchdoctors
- VCT : More centres in the rural areas and the use of reliable testing kits. Health workers should also undergo counselling training.

Stigma needs to be tackled on two fronts. Stigma related to HIV and AIDS would be reduced by strategies that aim to reduce poverty, women's inequality, orphan's powerlessness, and, increase access to special services, health facilities and HIV education and prevention campaigns. But special anti-stigma awareness and education is also needed. Stigma needs to be addressed on an individual level - safe space, time and guidance is needed to get people to reflect on what stigma looks like and how it hurts. Ideally, everyone should be engaged in this process and the involvement of opinion leaders, for example politicians, the church and community elders, is critical to an anti-stigma movement. Certain groups who play a crucial role in the lives of people affected by HIV and AIDS could also benefit from anti-stigma education - in particular, health workers, teachers and the guardians of orphans.

Lock into widespread acceptance of HIV and the need to talk: Anti-stigma interventions at this stage of the epidemic are both timely and crucial, locking into the widespread acceptance of the epidemic, people's need to talk and helping alleviate the impact of HIV and AIDS on communities. As the Central Board of Health aims to roll out successful HIV prevention and care programmes to more districts, aided by global funds, understanding stigma and how stigma can be effectively reduced is going to be crucial to the success of these programmes and services.

Supporting people to cope with stigma: Families and people living with HIV and AIDS can be supported to better cope with the impact of stigma through anti-stigma training, counselling, support groups and learning how to disclose safely. People living with HIV and AIDS need to be given voice in order to challenge the dominant representations circulating society. The empowerment of this group will lead to attitude change in the society at large.

Addressing the additional stigma faced by women: Our research shows that women face multiple stigmas in relation to HIV and AIDS. Any

interventions that aim to empower women, provide real alternatives to selling sex and actively support them in their role as carers will be a step towards reducing stigma, blame and the burden of care. Greater community awareness about women's vulnerability to HIV-related stigma is essential.

Language and Awareness: If people were more able to recognise what stigma is and when they are stigmatising, and how it hurts, they would become more aware of the danger of stigmatising language - including the damage of metaphors and analogies that blame and ridicule certain groups and physical frailty, and the damage of gossip. A greater recognition of stigma and its implications in terms of risk must be fostered within individuals. The influence of norms and values must be emphasised.

Provide and roll out health services and integrated support for people living with HIV and AIDS: One strategy to reduce stigma in poor communities is to provide programmes targeted at households and individuals affected by HIV and AIDS in the form of health services, integrated services and support. Special attention needs to be given to the rural areas to address the desperate imbalance in the distribution of services for people living with HIV and AIDS.

Improve practical management of HIV in households: Interventions that improve practical and medical management of opportunistic infections diseases will reduce HIV-related stigma.¹⁰⁶ For example, the provision of adult nappies for patients with chronic and severe diarrhoea, and even gloves and disinfectants for the carers, could reduce and address verbal abuse, neglect, fears and household stress. And any preventive therapies that reduced the frequency and incidence of opportunistic infections would end up reducing stigma related to these infections.

In-depth and up-to-date knowledge: In order to address fears around non-sexual transmission of HIV and the transmission of opportunistic infections, in-depth and up-to-date knowledge and HIV and AIDS education is needed. This should be

participatory and based on an exchange of knowledge, allowing for people to discuss their versions of the risk of casual transmission (which are continually evolving).

Building on the role of the church in care and support: The church does play a major role in the care and support for people living with HIV and AIDS and have a growing influence on people's behaviour. They are also in the position to lead by example in terms of showing love and support to people with living with HIV and AIDS.

Witchcraft and Traditional Healers: In the rural site, traditional healers need to be exposed to more in-depth information about HIV and AIDS and the healers and the formal health services need to work more closely together in the management of people living with HIV and AIDS. Efforts to build on the different strengths of the different treatment options - for example the encouraging attitude to patients that traditional healers practice and the ability to test for HIV in formal health services - could help reduce stigma. Traditional healers are more able to help people living with HIV and AIDS if they know about the HIV status of their patients.



¹⁰⁶ Other than our evidence of reduced stigma in the urban sites, another testimony to this are special clinics run by Zambart and the District, called "ProTest", which have provided people living with HIV and AIDS in a few Lusaka compounds with access to free treatment and integrated care. Run by specially trained clinic staff with a few additional resources, these clinics have effectively extended the lives of people living with HIV by treating opportunistic infections freely and quickly and by referral to the clinic and community based care. Despite stigma, they have proved extremely popular.

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Appendix One: Study Populations

Table A: Key Informants, Urban and Rural

Urban	Men	Women	Rural	Men	Women
Politicians	5		Politician	1	
Health Workers		4	Headman	1	
Home Based Caregivers		2	Health Workers	4	1
Neighbour Health Committee Member	1		Home Based Care Co-Ordinators		2
Traditional Healers	2		Neighbourhood Health Committee Chair	1	
Orphanage Care Attendant	1		Traditional Birth Attendant		1
Religious Leader	1		Traditional Healer	1	
Educationalists	2	1	District Farm Mgt Officer	1	
Taxi Driver	1		NGO Workers	2	
Barman	1		Religious Leaders	5	
Barber	1		Teacher		1
Sex Worker		1	Transporter	1	
Peer educators	2		Bar Owner		1
Musician	1		Barber	1	
Dramatist	1		Sex Worker		1
Redcross Helper	1		Peer Educator	1	
Secretary		1	Miller		1
Marketeers	1	1	Police Officer	1	
Stone Crusher		1	Marketeer		1
Social Worker	1		Retiree	1	
Nutritionist	1		Gardener (PLWHA)	1	
			Black Smith	1	
			Community Development Officer	1	
Totals	23	11		25	9

Table B: Focus Group Participants

Name of group	Urban No. of participants			Rural No. of Participants		
	F	M	Total	F	M	Total
Pregnant Women	8	-	8	10	-	10
Young Men	-	11	11	-	9	9
Young Women	9	-	9	8	-	8
Health Providers	7	-	7	-	-	-
Traditional Healers	8	10	18	4	6	10
Business Persons	3	7	10	-	-	-
Gate Keepers	3	6	9	1	7	8
TB- Patients	4	5	9			
School Boys	-	10	10	-	10	10
School Girls	13	-	13	8	-	8
Elders	-	14	14			
Women Farmers	-	-	-	9	-	9
Men Farmers			-	-	8	8
TB - Patients (Men)	-	-	-	-	6	6
TB - Patients (Women)	-	-	-	9		9
CHWs &TBAs				3	5	8
Secondary School Boys				-	12	12
Secondary School Girls				14	-	14
Total	55	63	118	66	63	129

Table C: Household Study Respondents (13 households, 15 respondents - 7 women, 8 men)

HH location	Sex & Age	TB status	HIV status	Marital Status	Spouse Status
Misisi	Male (35) & Female (28)	TB Cured	HIV-positive	Married	HIV-positive
Misisi	Male, 22	TB Cured	HIV-positive	Married	Did not wish to test
Kamwala	Female, 40+	No TB	HIV-negative	Widowed	HIV-positive, cured of TB but died later (2001)
Misisi	Male, 22	TB Cured	HIV-positive	Separated	Did not wish to test
Misisi	Male, 21	TB Cured	HIV-negative	Single	N/A
Misisi	Male, 46	TB Cured	HIV-negative	Married	Wife HIV-negative
Misisi	Male (64) & Female (40)	No TB	HIV-negative	Married	Wife HIV-negative
Kamwala	Female, 28	TB Cured	HIV-positive	Single	N/A
Misisi	Female, 23	TB Cured	HIV-positive	Married	Husband does not wish to test
Misisi	Male, 48	TB Cured	HIV-negative	Married	Wife first one to have TB & cured, HIV-positive
Misisi	Female, 35	TB Cured	HIV-positive	Widowed	Dead
Misisi	Female, 28	No TB	HIV-positive	Single	N/A
Misisi	Female, 27	TB Cured	HIV-negative	Married	Husband HIV-negative

