POSITIVE WOMEN:

voices and choices

A project led by positive women to explore the impact of HIV on their sexual behaviour, well-being and reproductive rights, and to promote improvements in policy and practice

International Community of Women living with HIV/AIDS (ICW)

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– Zimbabwe Report

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by Rayah Feldman, Jo Manchester and Caroline Maposhere

June 2002

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Written by: Rayah Feldman, Jo Manchester and Caroline Maposhere

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Preface

Lynde Francis, Director of the Centre for people living with HIV/AIDS, Harare, Zimbabwe, and ICW regional contact.

This report describes a unique project and process. The International Community of Women living with HIV/AIDS (ICW) developed a project encouraging HIV positive women to share and document our own experiences of living with HIV, particularly in relation to our sexual and reproductive health and needs. We wanted to lead our own research not just showcase it, to own the process not just be subjects of research and to gain skills to advocate for our own health and that of our families and communities.

In Zimbabwe, *Positive Women: Voices and Choices* has been quite outstanding in its process and outcomes. HIV positive women, from resource-poor mainly rural communities, were elected by their support groups to be trained to collect data and analyse the findings. The process of teamwork gave the women skills and self-confidence and they are now strong advocates from their communities, representing the issues of HIV positive women in many fora and making presentations at high-profile, national and international events. In one district a team leader was appointed to a district health committee, in another free basic medical care was negotiated for women in HIV support groups.

This project was a model of partnership between positive women and researchers, between positive women and those who are negative or untested, and between positive women and community leaders and health care workers. Broad-based partnerships are an essential component of an effective response to HIV and positive women have much to contribute to all HIV prevention and care efforts. The participants in the study showed that an HIV diagnosis has an impact on every aspect of women’s lives and that there is a great need for emotional, medical, financial and social support in order for families and communities to better cope with the impact of HIV. The report particularly highlights the importance of peer support and coming together in groups to share experiences, build confidence and learn from one another.

Since the project was first conceived in 1995, there have been welcome advances in medical and scientific knowledge and understanding of HIV particularly with regards to the development of anti-retroviral therapies, which have significantly prolonged life and reduced the numbers of AIDS-related deaths in industrialised countries. Whilst the majority of babies born to HIV positive mothers worldwide are not infected with HIV, the use of antiretrovirals in pregnancy has reduced the risk of transmission in many hospitals in the North to less than two per cent. There is not the range of therapeutic options in many developing countries—yet a short-course of antiretroviral therapy is inexpensive and does significantly reduce the risk of mother-to-child transmission of HIV. However short-course anti-retrovirals are only available through small-scale pilot programmes and as the experiences of the women in this project show that opportunities for positive women to protect their own health or to reduce the risk of their babies being infected with HIV continue to be limited.

The findings of this report are highly relevant to young people whose adult lives will be over-shadowed by the HIV epidemic. In 1999, over 25 per cent of young women in Zimbabwe aged between 15 and 24 were thought to be HIV positive, compared to fewer than 10 per cent of men of the same age. The stories shared by women in this project illustrate women's particular vulnerability to HIV infection. Young Zimbabwean women have the right to have families like the generations before them; they deserve good information and the means to protect their babies from becoming infected with HIV. The experiences of the older women in this project can be shared to inform service provision and education for the next generation in a society reeling from the devastating impact of HIV.

Although this project focused on Zimbabwe many of the issues highlighted are shared by positive women within and beyond Africa. We hope that this report will inspire you to work in collaboration with people with HIV for a united response to the HIV pandemic.

Executive summary

The *Positive Women: Voices and Choices* project was initiated by HIV positive women in the International Community of Women living with HIV/AIDS (ICW). The project aimed to document the reproductive and sexual health experiences of HIV positive women. This was in order to provide information that HIV positive women and AIDS service organisations could use in advocacy for changes in policies and practices that would improve the reproductive and sexual health choices available to women living with HIV and AIDS. This report presents the findings from Zimbabwe, the first country involved in this research.

Project planning and process

HIV positive women were involved in all stages of project planning and implementation, working with a research consultant and a national researcher. Two, and in one case three, team leaders were elected by members of participating HIV support groups in four provinces of Zimbabwe. A total of nine team leaders received training in participatory methods of data collection.

The project carried out a demographic and health survey in April and May 1999, involving 209 HIV positive women from HIV support groups in the four provinces. In-depth interviews were conducted with 59 women from the study areas in September and October 1999. Community workshops were held in each study area to discuss issues arising from the survey and in-depth interviews with support group members, community leaders and representatives of local AIDS service organisations. A team leader review workshop was carried out in February 2000 to review the qualitative data from interviews and community workshops.

The study demonstrated that one-to-one interviewing is an effective form of peer facilitation as well as of research. Following in-depth interviews, team leaders often stayed with the woman they had interviewed, answering questions, sharing information and providing support. The team leaders' training and their involvement in a project that was about their own lives and experiences, helped to build their confidence and raise their profile in their communities. A major achievement of this project was that the research process empowered the team leaders who carried out the footwork for the research.

Sexual and reproductive health

HIV positive women continued to have sexual feelings and many continued to enjoy sexual relationships after their HIV diagnosis. Existing prejudices that HIV positive women should not be sexually active made it difficult for them to disclose their status to family planning service providers and other health workers. Men's attitudes to sexuality and reproduction often posed problems for women's sexual health, especially as women saw themselves as having little control within their sexual relationships.

Some HIV positive women, especially younger women who did not have any children, had a strong desire to become mothers and chose to become pregnant, often in spite of previous experiences of miscarriages or still-births. However, such women often had to cope with negative attitudes towards them from health workers and others. Women who wanted to get pregnant were not given the information they needed to reduce the risk of infecting their partner or child. Only two women had access to antiretroviral treatment to reduce the risk of HIV transmission to their infants; in both cases this was as part of pilot programmes.

Nearly all the women with several children wanted to avoid further pregnancies, but faced discrimination from health workers if their status was known, in that they were not expected to be sexually active. Family planning services that were previously free for poorer women in Zimbabwe are now carrying fees and charges, making them unaffordable for many women. This combination of factors meant that study participants did not have adequate access to contraception, appropriate family planning services or safe abortion. Several women in the study were unable to terminate pregnancies despite a wish to do so and two suffered complications from illegal abortions. The study showed that HIV positive women are unable to access abortions in most health facilities, despite HIV positive status being an exemption to current legal prohibition of termination of pregnancy in Zimbabwe. Women's fear of disclosure of their HIV status reduces still further access to abortion services.

Most women, whether or not they had given birth since their diagnosis, were deeply concerned about the contribution of breastfeeding to HIV transmission to infants and identified a need for information about good practice in infant feeding. Whereas women felt that with support, they could overcome the stigma associated with openly 'not-breastfeeding', the main limitation to breastfeeding substitutes was their cost. Women need better advice on current knowledge regarding safer breastfeeding, and the higher risks associated with mixed feeding compared to exclusive breastfeeding or exclusive substitute feeding.

HIV testing, counselling and care

The study showed that most women had little or no knowledge of HIV transmission or risk before they were diagnosed with HIV. Even when they had knowledge of HIV transmission they did not consider themselves to be at risk, especially if they were married and faithful to their partner.

Most women did not receive adequate pre-test counselling. The decision to take an HIV test was generally made by a health worker rather than by the women themselves—often when a woman, her partner or her child was already ill. Post-test counselling was more common and had a positive impact on the women interviewed. Although disclosure of HIV status to partners and families was very difficult because of the stigma associated with HIV, women normally disclosed their HIV status to existing partners and family. Women were less likely to disclose their status to new partners because of fears of rejection and violence. Some women were deserted by their partners after they were diagnosed as HIV positive; this was more common if their relationship was an informal one. Disclosure to partners was facilitated by support from counsellors. Couple counselling was found to be particularly helpful, but was rarely reported. HIV support groups were a vital source of emotional and practical support for many of the women.

The women were distressed by the discriminatory attitudes and behaviour of the health care workers. In the community workshops, health care workers responded sympathetically to complaints by HIV positive women and offered to deal with the cases of discrimination that were drawn to their attention. The study revealed widespread use of traditional healers who were perceived as more accessible. However, women reported serious complications from abortions brought on by using traditional treatments.

Livelihood

Economic problems for HIV positive women were exacerbated by their lack of land and property rights and employment opportunities and were especially difficult for widows. Women were further impoverished as HIV-related illness and death reduced household income and increased expenditure.

Women's reproductive and sexual health was also compromised by poverty. For many women, sexual relationships were an important means of achieving better economic security, whether by selling sex for money or goods and services, or forming new long-term relationships with men. Their lack of access to appropriate family planning services and fear of disclosure made it difficult for them to practise safer sex or to avoid unwanted pregnancies.

Advocacy

The *Voices and Choices* project aimed to link the findings and the recommendations from the research to advocacy strategies for increasing the reproductive and sexual health choices available to women living with HIV in Zimbabwe.

The study had three limitations. Firstly, the majority of the project participants had been living with HIV or AIDS for over two years. The study may therefore not reflect the feelings and anxieties of more newly diagnosed women. Also women with more established HIV and developing symptoms would suffer more the effects of higher viral load such as poorer pregnancy outcomes and be influenced in their attitudes by this. Secondly, only about five per cent of partipants were under 25 years of age. This means that the study also under-represented women under 25 who constitute the fastest growing group with HIV in Zimbabwe. The findings, therefore, may not adequately reflect the views or experiences of these women. Thirdly, nearly all the women who participated in the study were members of HIV support groups. Women in support groups may be better informed and more confident about living with HIV than women who are not members. In addition, as support groups consist largely of resource-poor women, the study also excluded better-off and better-educated women.

List of recommendations

- ➢ More intensive public campaigns to remove the stigma and discrimination faced by HIV positive people particularly in relation to their sexuality which should be seen as a fundamental human right.
- ➢ More intensive education and training for health workers in the public and private sectors to provide advice and services in confidential, non- discriminatory and respectful ways for HIV positive women and men, from a client centred perspective rather than imposing personal prejudice and ignorance.
- ➢ More effective public and personal communication on HIV and safer sex that associates HIV with risk behaviour and not with particular social groups, and helps people to have a better understanding of personal risk.
- ➢ Reproductive health services to provide support and information specifically targeted at HIV positive women to support them whether they want to get pregnant or if they want to avoid pregnancy. For this, health workers have to better inform themselves, requiring advocacy at all levels of the health service. Advice is needed on the impact of pregnancy and breastfeeding on HIV positive women's own health, treatment of STIs, safer conception for discordant couples, the risks of HIV transmission to infants during pregnancy, childbirth and infant feeding. The various ways to reduce these risks have to be discussed, from condom use during pregnancy to prevent reinfection with HIV or other STIs, short course antiretrovirals, adapted obstetric practices during labour including vaginal swabbing and elective caesarean sections, as well as intensive support to women to either exclusively breastfeed or exclusively artificially feed their infants.
- ➢ Improved advice and access to free, legal, safe and confidential abortion services for HIV positive women.
- ➢ STI-related services (including HIV-related services and education) to be more closely linked to family planning services and more accessible to all sexually active Zimbabweans.
- ➢ Increased advice and access to male and female condoms, and other forms of contraception and protection including emergency contraception. HIV positive women could work with community-based distributors and clinics to include HIV education in contraception advice and distribution.
- ➢ Greater provision of services for men within these integrated sexual and reproductive health services.
- ➢ Improved access to good pre-test counselling to ensure that women understand the test and can make informed decisions whether to go for testing.

- Improved access to good post-test counselling to ensure that women who are diagnosed as HIV positive have support to help them cope with their diagnosis, and that women who are diagnosed as HIV negative are encouraged to practice safer sex.
- Voluntary counselling and testing [VCT] sites to proactively discuss contraception, pregnancy and prevention of parent to child transmission with all young people attending for VCT.
- Approaches to counselling and testing that reduce stigma and discrimination; this includes research into couples counselling and group education, and increased training and resources to expand counselling services.
- Further education and training about HIV among health care workers, including sessions to address their own HIV-related fears and values.
- A more inclusive approach to HIV care and support that would recognise the different support needs of those reluctant to join support groups, such as professional men and women, health care workers and community leaders.
- Comprehensive HIV-related training for traditional healers and inclusion of traditional healers into HIV programmes where possible.
- Further research into traditional treatments for reproductive and sexual health, including HIV and AIDS.
- Further research on ways to assist HIV support groups and their members so that they can meet the huge emotional and practical demands made of them.
- Negotiation and public education with community leaders, women's groups and religious leaders to explore ways to reduce the stigma and discrimination towards HIV positive women from their in-laws.
- Partnering with women's organisations already campaigning for better access to land and property rights, review of inheritance laws and advocacy at the community level to particularly take note of the impact these have on HIV positive women.
- Strategies designed to increase women's financial independence—such as micro-credit schemes, financial support for carers unable to work—and to keep children, particularly young girls, in education.
- Further research into the reproductive and sexual health needs of women under 25 years old.
- Similar participatory research into men's HIV-related reproductive and sexual health needs.
- More studies of this kind, which encourage the active participation of communities affected by HIV and link research to promoting change.

1 Introduction

1.1 ICW—strengthening the voices of HIV positive women

Positive Women: Voices and Choices was initiated and developed by the International Community of Women living with HIV/AIDS (ICW) to provide information about HIV positive women's reproductive health and rights in a way that would:

- allow the voices of HIV positive women to be heard
- open up choices available to HIV positive women
- identify appropriate areas for advocacy.

ICW is an international network run for and by HIV positive women who educate, support and advocate for one another. Established in 1992, ICW aims to reduce the isolation of HIV positive women and overcome the stigma of HIV/AIDS through outreach, networking, skills-sharing, peer-support and information exchange. It works to raise awareness of HIV positive women's issues and ensure that they have input at local, national and international levels in policy-making, service-development and research. Today, ICW reaches women in over one hundred countries.

By 1992, it was apparent that, worldwide, the basic sexual and reproductive rights of women living with HIV were routinely disregarded and violated. They encountered hostile attitudes and discrimination from health care providers and were even refused services and care during pregnancy and birth. ICW members had experienced forced abortions and sterilisation and reported significant difficulties in obtaining advice to make informed decisions about contraception, pregnancy, birth, abortion and infant feeding (See also Tapper and Fransen 2000 p162).

Coupled with these concerns was the frustration HIV positive women felt at the lack of sensitive and relevant research into their experiences. They often felt that they were being viewed as objects of research, rather than being recognised as whole people with distinctive needs arising from their HIV infection. Few studies have addressed the experiences of HIV positive women themselves, particularly the problems they face in making informed reproductive and sexual choices (Selwyn and Antoniello 1994; Bedimo, Bessinger and Kissinger 1998; Krabbendam et al. 1998; Aka-Dago-Akribi et al. 1999; Bennetts et al. 1999).

At an ICW conference in Cape Town in 1995, it was decided to develop a multi-country study with an explicit focus on the sexual and reproductive health experiences of HIV positive women, and with the aim of directly linking the research with advocacy. This resulted in the *Positive Women: Voices and Choices* project. Underpinning the project was the view that women living with HIV/AIDS have the right to reproductive and sexual health, including the conditions to make informed choices. This report documents the process and findings of this research which was carried out in Zimbabwe from 1998 to 2000.

1.2 Reproductive rights and health

Precisely what is involved in sexual and reproductive rights is still debated, and the project itself did not adopt a specific definition. However, the project's understanding of reproductive rights was informed by the principles outlined by the International Conference on Population and Development in Cairo (ICPD) in 1994 and in the Declaration and Platform for Action of the United Nations Fourth World Conference on Women in Beijing in 1995. These define reproductive rights as '(resting) on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing, and timing of their children, to have the information and means to do so, and the right to attain the highest standard of reproductive health. It also includes their right to make decisions concerning reproduction free of discrimination, coercion and violence, as expressed in human rights documents' (UN 1994, Para 7.2; UN 1995, Para 95).

Good standards of reproductive health enable women to practise and enjoy sexual relationships in safety, to regulate their own fertility safely, reproduce safely and to bring pregnancies to a safe outcome. In order to do this, women require a health infrastructure that enables access to safe contraceptives, safe obstetrical, pre-natal and post-natal care, safe abortion, and appropriate services to prevent and treat diseases of the reproductive system. They also require a social and legal infrastructure that protects them from sexual violence, allows them access to appropriate health information, respects their decision-making capacities, and recognises the health, social and economic support that mothers need.

These reproductive health goals are out of reach for many (if not most) women. Widespread poverty, limited public health services and restrictive legal and institutional infrastructures restrict access to family planning services and abortion. They may reinforce long-standing cultural norms of gender inequality that maintain women's economic dependence on men and restrict their access to education and employment which would help to increase their independence.[1]

For women living with HIV, the stigma, marginalisation and impoverishment that often follow an HIV diagnosis further limit their access to support, information and services, and therefore the quality of their reproductive and sexual health. They have special needs in sexual and reproductive health including information and services to protect their own health as well as to reduce the risk of mother-to-child HIV transmission. Even so progressive a statement as the ICPD declaration (see above) only mentions HIV/AIDS in the context of parent-to-child transmission, [2] and not the sexual and reproductive health needs of HIV positive women themselves. The thinking behind *Voices and Choices* challenged this view and aimed to raise the profile of HIV positive women's sexual and reproductive health needs, rights and well-being.

1.3 Project aims and principles

Aims

The project aimed to explore the impact of HIV/AIDS on HIV positive women's sexual and reproductive decisions and choices by investigating:

- the impact of HIV on their livelihoods, families and relationships
- their access to information and help about contraception, pregnancy, childbirth, breastfeeding, and abortion
- factors affecting their decisions about disclosure to partners and others
- factors affecting their decisions about relationships and having children
- their experiences of health care
- The effects of gender inequality, social policies and economic conditions on the reproductive and sexual health of HIV positive women.

Principles

The project principles were inspired primarily by ICW's commitment to ensuring that positive women were seen and heard throughout all stages of the project. An international meeting of positive women and researchers in 1996 agreed that the project would:

- be led by HIV positive women and ensure their full participation in planning and implementation
- create a model of good HIV-related participatory research and promote a new type of relationship between researchers and HIV positive women
- support and expand existing groups and networks of HIV positive women
- link research with advocacy—where the research identifies important focus points for advocacy
- provide practical knowledge for change by informing HIV positive women, health care providers and policy makers on rights and legislative issues.

1.4 Methodology

Country studies

Positive Women: Voices and Choices was originally planned for six countries. By 1997, this target was reduced to three countries, namely Zimbabwe, Thailand and Cote d'Ivoire. Data collection is complete in Zimbabwe and Thailand and plans are currently in place to hold a capacity-strengthening workshop in Côte d'Ivoire which will explore issues relating to sexual well-being and reproductive rights. The different country studies are based on a common research protocol, which was designed to allow maximum participation in the development of national research and advocacy strategies while enabling common themes to be drawn together in a final international report.

A UK-based research consultant, Rayah Feldman, with the support of a project steering group, developed the protocol. As the situation of HIV positive women varies between and within countries, the protocol was intended to enable local teams of HIV positive women to plan and implement the project as they saw best. The international protocol proposed a four-pronged approach to data collection:

- An overview of policies on reproductive health services in relation to HIV
- A demographic and reproductive health survey of HIV positive women
- In-depth interviews with HIV positive women
- Focus group discussions with HIV positive women.

Data collection in every country was to be carried out by a team of HIV positive women.[3]

Participatory research

There is a growing recognition, in much community-based work, that research should be carried out with the people being studied rather than on them (Jackson 1992; Whitmore 1994; Cornwall and Jewkes 1995). Participatory approaches are also based on a belief that research should benefit the community studied rather than just the researchers and policy makers—that the value of research lies in the changes it brings to communities, rather than simply in the knowledge gained (Jackson 1992; Cornwall and Jewkes 1995).

Voices and Choices aimed to involve HIV positive women at every level in the study, directing and implementing it in each participating country to ensure that it was responsive to their needs. Other studies have involved peer interviewers (Karim et al. 1995) or provided feedback and information on the results to participating women (Santos, Ventura-Filipe and Paiva 1998), but no study of HIV positive women has attempted to include participation at every stage. Bujra and Baylis have commented that, in principle, participatory research "should apply at all stages—the definition of needs, the design of the project, the process of research, the implementation of a project, its evaluation, maintenance, or utilization of the knowledge gained", but that this is rarely achieved in practice (1995).

With the initiative coming from HIV positive women themselves, this project had good hopes of achieving this aim. The study itself used traditional methods of data collection in response to needs defined by HIV positive women, and local participants modified the study design to suit their own purposes. Local HIV positive women were involved in data collection and worked with researchers to analyse the qualitative data that had been collected. The participants in the project were identified through existing support groups, which it was hoped that the project would support and help to strengthen. The project promoted data collection as 'learning together what we know about ourselves' and as an opportunity to express opinions or concerns and receive support and information.

The project was therefore designed and implemented by HIV positive women in collaboration with researchers and can, in many respects, be described as participatory.

Advocacy

The research was intended to provide practical information that would assist HIV positive women, AIDS service organisations and policy makers to advocate for changes in policies and practices that would improve their reproductive and sexual health choices available to HIV positive women.

Ethical considerations

A study of people living with HIV needs to be approached with great sensitivity. The stigma of HIV is such that HIV positive interviewees may fear discrimination, rejection or even violence if their HIV status is revealed. Research on HIV explores the most intimate sphere of a person's private, sexual and emotional life. An interview can become a difficult and emotional experience, regardless of how well a person seems to be coping.

Ethical clearance was obtained from the UNAIDS Ethical Review Committee and from the Medical Research Council of Zimbabwe (MRCZ) and the Biomedical Research and Training Institute (BIRTI) in Harare, and the project was supported by the National AIDS Co-ordination Programme (NACP).

It was important to ensure during the recruitment process that participants understood what their participation in the study would involve. Information about the project, as well as the consent forms were written and explained in Shona and Ndebele, and written consent was obtained from each participant. All staff involved in the project were carefully trained to protect the confidentiality of research subjects and to assure their safety. HIV positive women participated actively as facilitators as well as 'subjects', and their personal experiences gave them a good understanding of many of the issues involved. No names were written on questionnaires, and data were coded and analysed without personal identifiers.

The ethical concerns of the project extended beyond confidentiality to a desire to provide a supportive environment for participants, whether in groups or as individuals. Group and training workshops included good quality food and accommodation, and paid expenses to participants. The training workshops were opportunities to discuss issues and feelings that arose from the fieldwork. ICW was concerned to protect the team leaders' health as far as possible. It stressed the need to have two team leaders in each area to share the workload and provide peer support.

1.5 Structure of the report

The study focused on HIV positive women's reproductive and sexual health as well as the wider impact of HIV on their lives and how this affected the context in which they made their reproductive choices. Therefore, in this report the analysis of the sexual and reproductive health experiences of HIV positive women is preceded by an examination of their family relationships, their livelihood strategies, the healthcare system in Zimbabwe, and the stigma and discrimination that is attached to HIV and AIDS.

Chapter 2 provides an account of the project's methodology in Zimbabwe and the role of HIV positive team leaders. It shows how they and other HIV positive women from their communities participated in the project, and describes the impact it had on them.

Chapters 3 to 5 provide the context for HIV positive women's sexual and reproductive health experiences and choices. Chapter 3 examines how women responded to HIV diagnosis, their decisions about disclosure, and the reactions of their partners and families. It also explores the role of HIV support groups in providing health information and emotional and social support. Chapter 4 discusses how HIV affected women's family and sexual relationships and their economic situation and examines the strategies women have used to deal with these changes. Chapter 5 explores HIV positive women's experiences of the health care system.

Chapters 6 and 7 concentrate on HIV positive women's sexual and reproductive health specifically. Chapter 6 examines women's knowledge about HIV, the HIV prevention methods they used, and their contraceptive practices both before and after they found they were HIV positive. Chapter 7 explores HIV positive women's childbearing choices in relation to their personal circumstances, including the number of their existing children and their relationships. It also examines the effect on their choices of the information and services available to them, including family planning and abortion services. Chapter 8 summarises some of the broad conclusions of the project and the main policy issues it raises.

Names of all participants except for the team leaders have been changed to preserve confidentiality. All the quotations and case examples are taken from in-depth interviews unless otherwise stated.

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[1] For a more comprehensive discussion of these issues see (Dixon-Mueller 1993; Correa and Reichmann 1994; Sen, Germain and Chen 1994; Petchesky and Judd 1998).

[2] While the immediate source of the child's infection is from the mother – during pregnancy, childbirth or breastfeeding – she was probably infected through a sexual partner who may have been the child's father, but not necessarily. We have used the term parent to child transmission [PTCT] to emphasise the role and responsibility that both men and women have in protecting themselves and their families against HIV.

[3] See Chapter 2 for details of data collection in Zimbabwe

2 Voices and Choices, Zimbabwe

2. 1 Introduction

This chapter presents a brief background to the prevalence and impact of HIV in Zimbabwe; it describes the areas in which the project took place and the demographic characteristics of the study population. It also describes the research process involving a team of HIV positive women team leaders, who were involved throughout the project and discusses the impact that participation in the project had on them and their communities.

2.2 HIV prevalence and social and demographic impact

Zimbabwe has one of the highest prevalence rates of HIV in the world (see Box 2.1)

The reasons for high prevalence in Zimbabwe are complex, but include historical causes of family separation such as migrant labour, poverty, poor education and access to health services, and accepted gender norms (NACP/ MoHCW 1998; Woelk 1997; Loewenson 1998; Bassett and Mhloyi 1991). Gender inequality affects women’s economic standing and sanctions double standards in sexual behaviour and male violence against women, which results in women having limited ability to protect themselves within sexual relationships.

Box 2.1 HIV prevalence in Zimbabwe

In 1999, Zimbabwe had an estimated population of approximately 12 million people, of whom 1.5 million people (12.5 per cent) were estimated to be living with HIV. Of these approximately 800,000 were women, 600,000 men and 56,000 children (0 to 14 years old).

Anonymous surveillance screening of women attending antenatal clinics in 1997 reported that 24 to 33 per cent of pregnant women in urban areas and between 7 and 53 per cent of pregnant women in rural areas were HIV positive (UNAIDS 2000:126). HIV particularly affects young people—other surveys have shown that between 22 and 26 per cent of women and 10 to 13 per cent of men aged 15 to 24 are HIV positive. In the 15 to 19 age group, five times more young women are HIV positive than young men.

Many of the key advances made by Zimbabwe in reducing infant, childhood and maternal mortality since independence in 1980, have been undermined by the impact of HIV/AIDS on communities. Life expectancy has been significantly reduced by HIV. In 1983, 85 per cent boys aged 15 years old would reach their fiftieth birthday (only 15 per cent were expected to die before 50). By 1997, only half of boys aged 15 could expect to reach 50. For girls of the same age, the likelihood of dying before 50 increased from 11 per cent in the early 1980s to over 40 per cent by 1997 (UNAIDS 2000).

Peasant households in Zimbabwe were estimated in 1997 to spend $482 million extra on HIV-related illness and death, while the death of a breadwinner due to AIDS was estimated to lead to a 61 per cent fall in production (Kwaramba 1997). Households have sold land and cattle to finance these costs and reduced consumption levels of other household members, including removing children from school (NACP /MoHCW 1998).

Young and old people are increasingly having to take on care roles and even economic production as the middle generation is affected by AIDS. Many children, especially girls, leave school to care for sick family members or to become child heads of households. It is estimated that by 2010, up to one third of all children under 15 will be AIDS orphans. As communities struggle to cope, many children are abandoned by their extended family and their community and end up as street children or sex workers.

Poverty makes households less able to prevent and deal with the effects of HIV as it undermines their capacity to provide for nutrition, health and other needs related to HIV. It leads to poor recognition of health problems, which results in late treatments of conditions such as tuberculosis (TB) or sexually transmitted infections (STIs). It undermines educational enrolment, particularly of girls, and excludes many young people from school health promotion programmes. It may also lead to increased use of sex as a form of payment for goods and services, resulting in wider HIV transmission.

Community support networks have recently been further weakened by high public transport costs, recurrent droughts, inflation and price instabilities of rural produce and basic household goods (Mutangadura and Makaudze 1999). Local community mechanisms, such as burial societies, church group support and savings clubs have been hampered by lack of funds, even though they are regarded as the most effective forms of support.

Home-based care programmes add to the burden of care placed on women and young girls, add a further cost burden to households, and raise problems in the quality of care and the management of HIV-related risks by care givers (Woelk et al 1997). State-based social security and welfare support are minimal, especially in the rural areas (Mutangadura and Makaudze 1999), leading to household coping strategies that have themselves increased stress on households, such as borrowing from friends, support from informal networks, use of savings, sale of assets or remittances from family members.

2.3 Development of the project

The Women and AIDS Support Network (WASN) in Harare agreed to become ICW's partner organisation in Zimbabwe. WASN is an established organisation with a leading reputation on gender, HIV and advocacy and has a long history of organising local workshops involving HIV support groups and members of the community. WASN worked with ICW to identify existing support groups of HIV positive women to participate in the project (see *Identifying support groups*) and provided a secure administrative base for the project. WASN also established a local steering group for the project, which appointed the national researcher, Caroline Maposhere, in 1998.

2.4 Project methodology

The project used three methods of data collection, which were phased to succeed each other:

Demographic and health survey

A demographic and health survey of 209 women in four project areas (see Chapter 2) was carried out between April and May 1999. The purpose of the survey was to collect background information about the social, demographic and basic reproductive health characteristics of HIV positive women in the study areas. Most respondents were members of local HIV support groups.

In-depth interviews

In-depth interviews with 59 women, representing all project areas, were conducted between September and October 1999. The women were asked questions about their reproductive health experiences since their HIV diagnosis, starting with the circumstances of their diagnosis, how HIV had affected their lives, especially their sexual relationships, and their decisions about reproduction.

Community Workshops

Community workshops were held in each area between October and November 1999. These were three-day residential workshops in each of the study areas in which HIV positive women could discuss their concerns with community leaders and representatives of local organisations, health professionals, and other professionals with a particular interest in HIV. Records were kept of the discussions in these workshops.

Caroline Maposhere, National Researcher

Data from the survey were coded and analysed using SPSS software. All other data were analysed thematically.

The project covered any costs the women faced as a result of participating in the survey or interviews. Community workshops provided free board, accommodation and childcare and women were also given small daily allowances during the residential workshops.

2.5 Project areas

The project decided to work with groups in four provinces: Manicaland, Midlands, Matabeleland South and Harare. Three of the four project sites (see below) were in rural areas, which were predominantly agricultural, though some women lived in or traded at rural growth points. The project areas included women from the two major Zimbabwean ethnic groups, Shona and Ndebele.

Birchenough Bridge, Buhera South District, Manicaland

Birchenough Bridge is a growth point at the centre of a region of poor rainfall and sandy soil, characterised by semi-arid subsistence agriculture. The rural area around Birchenough Bridge supports small-scale commercial farming on a government developed irrigation scheme of one-acre plots, known as ‘acres’, where intensive cash crop farming is practised. Birchenough Bridge has become a major market centre supporting a good deal of long distance and local trade. Women sell produce from dry or irrigated land, or from the sale of craft products such as mats and baskets.

The project worked with two HIV support groups in Birchenough Bridge, which have now expanded into five separate groups. Most HIV positive women in local support groups who participated in the project live in the poor dry land areas and are mainly subsistence farmers. Men from this district migrate to towns or find work in Birchenough Bridge.

Chirumhanzu, Mvuma District, Midlands

Chirumhanzu support group members sing and dance, welcoming Promise (ICW Programme Officer) during a site visit

Chirumhanzu is a communal rural area dependent on subsistence farming. Its main activities are concentrated around the Catholic mission, St. Theresa, where there is a hospital and a primary and secondary school. A new growth point, Charandura, is developing near the hospital. Many men from this district migrate to towns or mines in Zimbabwe to work. In recent times, visits home have become less frequent because of increases in bus fares.

Women earn a living mainly from farming and from a small crochet and knitting factory called ‘Spider Web’ that provides outwork primarily during the dry season when they have time for non-farm activities. The project worked with three HIV support groups in the area.

Tshelanyemba, Kesi District, Matabeleland South

Tshelanyemba is in a region with poor rainfall and few opportunities for arable agriculture. Farmers are mainly pastoralists and keep cattle or small stock such as goats and pigs. Most men from this district are labour migrants to Botswana and South Africa, who stay away from home for long periods (Bassett and Mhloyi 1991; Campbell 2000). Women trade caterpillars, regarded as a delicacy, across the border with Botswana or in South Africa. Tshelanyemba is served by a Salvation Army mission hospital at which there is an HIV support group that worked with the project.

Harare

Harare is the capital of Zimbabwe with a population of nearly two million people. Women who participated in the project were mainly drawn from support groups in the high density township areas of

Mabvuku and Highfields. Most women who belong to these groups are very poor, unemployed women from the townships around Harare. The population is highly mobile as people move in search of cheaper rented accommodation.

2.6 Characteristics of the study population

This section shows the demographic characteristics of the women who participated in the survey and, where available, of those who were interviewed. As separate demographic information was not collected from all the women interviewed and it was not always possible to match interviewees with survey respondents, some demographic information about some of the women is not available.

Area of residence

Table 2.1 shows the distribution by study area of respondents to the survey and to the in-depth interviews.

HIV status

One hundred and seventy four women in the survey (83.3 per cent) had tested positive after an HIV antibody test and had known their HIV status for over a year. Eight women were diagnosed over 10 years ago. The remaining 35 women (16.7 per cent) suspected they were HIV positive because of the illness or death of a spouse or a child. All the women interviewed had been tested HIV positive except for one woman who knew she was HIV positive when her child was diagnosed.

Table 2.1 Survey respondents and interviewees by study area

Area	Survey	Interviews
Birchenough Bridge	60	14
Chirumhanzu	59	18
Tshelanyemba	30	12
Harare	60	15
Total	209	59

Age

Over 90 per cent of the women in the survey and the women interviewed whose ages were given were over 25. By comparison, the DHS 1999 survey showed 50% of women of reproductive age [15-44] in Zimbabwe are aged between 15 and 24.

Table 2.2 Age of survey respondents and interviewees

Age	Survey		Interviews	
	No.	%	No.	%
15-25	12	5. 7	3	5.0
26-35	73	34.9	13	22.0
36-45	85	40.7	22	37.3
46-55	32	15.3	3	5.0
56-65	7	3.3	0	0
Not available	0	0	18	30.5
Total	209	100	59	100

Means of Livelihood

Survey respondents only gave a single means of livelihood, which can be misleading as many women engaged in several ways of making a living. The livelihood strategies of the women interviewed are discussed in some detail in Chapter 4.

Table 2.3 Means of livelihood of survey respondents

Livelihood source	Number	%
Employed	21	10.0
Farming	101	48.3
Husband employed	17	8.1
Vending	18	8.6
Other	52	24.9
Total	209	100

Education

Although nearly all women surveyed had some schooling, many had not completed primary school (Grade 7), and many of those who attended secondary school did not reach Form 4. Only one woman had no formal education at all.

Table 2.4 Education of survey respondents

Level of education	Number	%	DHS
None	1	0.5	6.7
Primary	129	61.7	40.2
Secondary	78	37.3	50.2
Not available	1	0.5	2.8
Total	209	100	

Children

Table 2.5 Number of living children of survey respondents and interviewees

Living children	Survey		Interviews	
	Number	%	Number	%
0	14	6.7	9	15.3
1-3	87	41.7	25	42.4
4-6	81	38.8	14	23.7
7-9	20	9.6	3	5.1
10-12	7	3.3	0	0
Not available	0	0	8	13.6
Total	209	100	59	100

By comparison, the DHS 1999 survey shows that 30% of women aged 15-44 had no children "ever-born".

Over one third of women who participated in this study had at least one child who had died. The survey did not provide data on the ages or the circumstances of their children's death although women did discuss this information in the interviews.

2.7 Developing the study

HIV support groups

HIV support groups to which women in the study belonged were linked to mission hospitals, clinics and home-based care services. These provided a venue for the meetings or other assistance but normally provide no funding.

These groups provide a variety of support, especially emotional support. Members help one another to come to terms with an HIV diagnosis and share their experiences of disclosure. They talk about the burden of caring for partners and children, and share their feelings of grief and loss and they comfort and support one another when a loved one dies. The groups sometimes help with practical support such as care and domestic work for members who are ill or help with funeral fees.

In addition to mutual support, typical activities include discussions about positive living, income generation and information sharing. Special activities such as peer education may be initiated by host organisations. Groups supported by non-governmental organisations (NGOs) tend to organise more varied activities. Mashambanzou, a Harare-based organisation, runs an HIV hospital ward, a drop-in centre for people living with HIV/

AIDS, and a centre for income generating activities (Jackson 1992). However, activities and functions overlap so that groups carrying out small income-generating activities such as knitting or sewing also provide an opportunity for information sharing and mutual support.

Most groups initiated by established AIDS service organisations or hospitals are larger and more active because of the support they receive from the organisation. Membership of groups is usually between 10 and 30 people. Members often form new groups in a new locality so that people do not have to walk long distances to meeting points. Most support groups are mixed sex though there are more women members (Jackson 1992 pp136-9). People on low incomes are especially attracted to support groups for income-generating activities. There tends to be fewer members from higher income groups.

The frequency of meetings depends on each group's activities. Discussion groups may meet only monthly, while groups running income-generating projects may meet daily or weekly as members will be employed on production activities.

Voices and Choices deliberately set out to work with established support groups in the hope of making the project more sustainable and effective by building on existing structures.

Table 2.6 Mortality of survey respondents' children

Children died	Survey	
	Number	%
0	135	64.6
1	53	25.4
2	14	6.7
3	6	2.9
4	1	0.5
Total	209	100

Identifying support groups

In January 1998, WASN organised a programme for a representative from ICW and the international research consultant to visit HIV positive women in support groups in several areas. These visits were an opportunity not only for the members of the support groups to be introduced to ICW and the ideas behind the project, but also for ICW to get a feel for how support groups operate in Zimbabwe, and of the women who attend them. ICW was concerned to find out whether HIV positive women in Zimbabwe felt that the project would be relevant and of potential benefit to them. ICW was aware of the dangers of designing a project that was not built on the expressed needs of Zimbabwean women but on an agenda of HIV positive women internationally. However, the women interviewed were enthusiastic about the project and felt it would answer concerns they had expressed often but did not have the opportunity to be heard.

At initial meetings with support group members, women were invited to discuss issues about reproductive health and whether they wanted to take part in the project. All the support groups approached were enthusiastic about participating.

> ***'At first when I heard that ICW wanted to do research on reproductive health and sexual issues, my first reaction was that they come again with the research which we are tired of and that we were not going to benefit again. Just coming to us as positive women taking the data they want and vanish in the air. But when they told us that this project was going to be owned and managed by positive women I was very happy.'*** **Otilia Tasikani, Team leader**

Selecting team leaders

Once the groups were selected, they were re-visited and members were asked to elect two team leaders from each group who would be trained to collect data and who could share the workload and support each other. The team leaders gave significant input to the interview and survey questions, and to identifying focus group topics for the community workshops (See *Community workshops* below). The connection between team leaders and support groups was intended to give members of the groups a sense of ownership of the project, and to enable feedback to them at every stage.

The nine team leaders were Dominica Banire, Annatolia Chamuka, Etta Dendere, Nyaradzo Makambanga, Mavis Moyo, Mary Musesengwa, Joyce Mwedzi, Joyce Nyathi and Otilia Tasikani. They were all actively involved in their local support groups and were all willing to be open about their status. At the time of the study they ranged in age from 33 to 50. They had all been personally confronted by the issues of HIV and reproduction. They had all had children and some had lost a child to HIV or other illness and several had been diagnosed during pregnancy.

Team leader training

The team leaders had no formal research experience and training was an essential component of the project. The national researcher ran numerous training workshops on reproductive health and rights and basic research skills for the team leaders. These were invaluable for team building and mutual support as well as for information. Training continued through all stages of the project and involved ongoing discussion of the research process. This also enabled the team to modify the protocol where they felt it appropriate.

It was clear from the first residential training workshop that the project would demand a great deal of time and energy from the team leaders. They had concerns about their own health, the care of their children while they were away from home and the additional workload of the project. This was balanced by their enthusiasm to learn new skills and their desire to help other positive women through the project.

However, the deaths of a number of women who participated in the project were very painful and difficult for the team leaders, and some of the interviews were very emotional. Team leaders afterwards said that they would have appreciated some training in counselling.

Team leaders and National Researcher during TOT workshop
***Front row:** Otilia Tasikani, Nyaradzo Makambanga, Caroline Maposhere, Mary Musesengwa, Joyce Mwedzi.* ***Back row:** Dominica Banire, Mavis Moyo, Joyce Nyathi, Etta Dendere, Anatolia Chamuku*

2.8 Data collection and analysis

The demographic and reproductive health survey

The framework for the survey was developed by the research consultant and national researcher. During a training workshop for the survey, the team leaders developed further questions on sexual health and health care and piloted all questions through practice interviews. They then discussed and rephrased them, searching for appropriate wording in Shona and Ndebele. During their training, the team leaders learned how to ask sensitive questions and discussed the meaning and significance of confidentiality. The training process enabled them to identify the key issues to be explored in the research and to feel capable of dealing with the complex issues involved.

> ***'Outreach leaders went to the HIV positive women whom the leaders lived with, learned from the women and loved them. In this process, collection of data through individual interviews was done. The team leaders worked with the information they knew, worked with the best and influential leaders for the focus group discussion, and collected essential data by probing in in-depth interviews. At the end of these interviews a workshop to present results was organised and carried out for both men and women.'*** **Etta Dendere**

The women who responded to the survey were almost all members of local HIV support groups. Fifty two women initially interviewed were also support group members, but after a review workshop with team leaders for data analysis, seven further interviews were held with women who were not in support groups.

In-depth interviews

The team leaders were trained in community-based research and interviewing for the in-depth interviews and subsequent community workshops. The commencement of interviewing was staggered so that each area started one week after the previous one over a period of four weeks. This enabled the researcher to supervise the initial interviews, advise on possible improvements and provide de-briefing and support.

The interviews were not just a data collection exercise. Team leaders often stayed another hour with the interviewee giving information and talking through problems. Sometimes interviewees later went to the team leaders' homes to talk further. They felt that in this and other ways the project had supported the women who participated to become more aware of their choices and reproductive rights. One team leader described how the study had affected one woman who had several children and who was diagnosed HIV positive after her husband and youngest child died. She was considering being inherited by her husband's brother as the best way to support her remaining children but rejected this strategy when she learned more about HIV through the study.

> ***'After being interviewed for the project she participated in the focus group discussions. She was so keen to know more of HIV transmission and reproductive health. Now she has changed her mind and has made an informed decision. For her, HIV status and widow inheritance do not tally any more.'***[1] **Anatolia Chamuku**

The rootedness of the team leaders within their support groups and communities helped them develop a high level of trust and rapport with the women they interviewed. However, as fieldworkers, the interviewers probably required more supervision and support than was available with just one national researcher working with the team leaders. Most interviews were not tape recorded but notes were kept by the team leaders, resulting in some gaps and unevenness of data. The researchers tried to compensate for this by means of a week-long review workshop with the team leaders and the national and international researchers (See *Team leader review workshop*).

Community workshops

The project's original plan was to have residential workshops for HIV positive women to provide an opportunity for focus group discussions, information sharing, peer support and action planning among HIV positive women. The team leaders adapted this idea to community workshops in which HIV positive women could discuss their concerns with other members of their communities. Findings from the survey were presented and used as a basis for discussion. Talks on HIV and reproductive health were also given by the national researcher, local health professionals and WASN staff. The workshops were facilitated by the team leaders and the national researcher.

In all workshops, over half the participants were HIV positive women from support groups and they also included male and female representatives of community-based AIDS service organisations, peer educators and home-based care groups, village community workers and church leaders. In one area, several people came from the hospital, in another participants also included health workers, village headmen and ZANU-PF officers. In Harare, it was more difficult to get local leaders to attend community workshops, and so nearly all the participants there were women from HIV support groups.

During the workshops, small focus groups discussed a wide range of issues, including cultural practices that influence reproductive health decisions, health care delivery services, gender violence, community support structures, and other issues of great concern to HIV positive women, such as abortion and infant feeding. The workshops were also used for dissemination of information on HIV prevention and sexual health and to develop strategies to meet some of the needs identified in the discussions. They thus served as the first stage of a local advocacy process.

The community workshops provided the first local advocacy and have resulted in some changes locally, including the provision of free treatment to members of HIV support groups in two areas, and negotiating a policy of non-discrimination against people living with HIV/AIDS in Harare. Further local advocacy has resulted from the higher public profile of people living with HIV/AIDS as a result of the workshops. For instance, in Birchenough Bridge, a woman who took part in the community workshop was encouraged to complain to the hospital authorities after nurses very publicly breached her confidentiality; they have since apologised to her.

Team leader review workshop

In February 2000, after data collection had been completed, a week-long workshop was held in Harare with the team leaders, national researcher and the research consultant. Its purpose was to use the team leaders' local knowledge and memory of the interviews to fill any gaps in the interview data, and to clarify some of the issues raised by the data.

The workshop proceedings, which were tape recorded, consisted of discussions in Shona, Ndebele and English reflecting on and amplifying many issues raised in the interview narratives and workshop reports. Each interview was reviewed for clarity and accuracy after a commitment to collective confidentiality had been discussed and agreed.

Many issues were discussed, including the expectations men and women have of different types of sexual relationships, as well as other concerns such as property inheritance and cultural practices that have implications for HIV transmission. Team leaders also reflected on the research process, evaluated its strengths and weaknesses and shared their personal feelings about the project. In this way the team leaders contributed immensely to the analysis of the data and were able to share the knowledge they had gained from their experience of fieldwork.

Limitations of the study design

The women interviewed were almost all members of HIV support groups. The membership of support groups consists largely of poor women and the study therefore excluded wealthier and better educated women by focusing on support group members. Comparison with the 1999 DHS survey shows that the study sample was less well educated and older than women in the general population. Nearly a fifth of the women who look part in the survey, though only three of the women interviewed, were over 45 years. Only about 5 per cent of the women in the study were under 25 and most of the women had been living with HIV/AIDS for over two years. This means that the study under-represented more recently diagnosed women, and women under 25 who constitute the fastest growing group with HIV. The findings of the research did not therefore reflect their reproductive health needs. However, these women are more at risk of illness because of poor access to public health services and social welfare facilities, and therefore more in need of good advocacy and support.

2.9 Advocacy

A national advocacy workshop was held in Harare at the end of 1999 with team leaders, the national researcher, steering group members, representatives of WASN, health care professionals and others to discuss preliminary findings from the project and future directions for advocacy. A further advocacy planning and training workshop on issues arising from the project took place at the end of 2001 to develop an advocacy strategy and plans for its implementation. A wide range of organisations from different sectors in Zimbabwe have been involved in planning this workshop.

2.10 Project impact on team leaders

The impact of the project on the team leaders' confidence and skills has been considerable and clearly reflects the time and effort spent on training and support. The words of just some of the team leaders demonstrate what they felt about their involvement in the project.

> *'From the beginning of this project positive women were involved in deciding the issues which will be researched on that was very encouraging. During the process I realised that I was being empowered. I have really changed, gained confidence and I have also gained status in the community. I am now invited to workshops and meetings whenever there are women's issues being discussed.'* **Otilia Tasikani**

> ***‘As a woman living with HIV I have benefited a lot. I have learnt skills to be a good team leader, researcher, mobiliser and advocacy worker. I have learnt to probe through story telling and to be the ears of the positive women. I have been trained in PRA [Participatory Rural Appraisal] and am now able to facilitate workshops. I have gained knowledge on HIV/AIDS and have learnt that most women’s reproductive health problems are somehow the same. I know I have the right to communicate with my partner.’*** **Etta Dendere**

Most of the team leaders now feel confident to speak out as HIV positive women on behalf of their peers, and are doing so beyond the project itself.

> ***‘I am now able to arrange and facilitate a workshop. When we did the advocacy workshop I was very nervous but Caroline (national researcher) asked us to do our own presentations without any assistance and to present to the stakeholders we had invited. I presented my paper without shyness and I said to myself I have done it.***
>
> ***Because of this workshop I have attended many others. We helped UNIFEM to do a research in the community. They came to us for they knew that we had undergone PRA training. I and two other team leaders were also selected to be in the task force, which is writing a book on positive living. This book will be written by people living with the virus themselves. I am very happy to be part of this task force because there is going to be a chapter that will deal with women’s specific issues only. When I first started this project I did not know what sexual and reproductive health means and now I understand my body much better.’*** **Otilia Tasikani**

As a result of their training and experience of working on the project, team leaders increased their public profile both locally and in HIV organisations, especially within the Network for Zimbabwe Positive Women (NZPW). Some of the team leaders became well known as HIV activists within their communities, which may help other people living with HIV/AIDS to acquire a less stigmatised public profile. Several team leaders have become more prominent in their communities since working for the project. The team leaders in Birchenough Bridge were elected to serve on their local Constitutional Reform Committee. Three have taken up positions in a community working group on health and one has been appointed to her local hospital board to represent people living with HIV.

Team leaders’ attitudes have also changed, particularly in relation to women’s rights.

> ***‘The value of a woman is never discussed in public national meetings. Cultural or traditional values have been used to deny women’s equal status.’*** **Etta Dendere**

They are using their new knowledge and ideas to work with and educate their peers.

> ***‘Before the project we did not know that if you are forced to have sex by your husband it will be rape. We did not know that you have the right to report to the police. Some of the women in our group did not know how they got the virus but after we have gone through the ICW Survival Kit (ICW 1999) we managed to teach them about transmission and how to prevent the virus.’*** **Nyaradzo Makambanga and Joyce Mwedzi**

2.11 Challenges and constraints

The project faced some unanticipated problems that were not easily overcome. Practical concerns that the project protocol had not adequately catered for included the women’s need for some public identification with the project to help them do the work in their own communities. The project eventually provided uniforms to address this.

Other practical problems were more challenging. The study was conducted during a difficult economic and political period in Zimbabwe; for example, fuel shortages resulted in some trips either getting cancelled or taking longer because of time spent in fuel queues. The scale of the project was, with hindsight, unrealistic, stretching across the whole of Zimbabwe. The project did not have its own vehicle or driver. Nevertheless the national researcher forged a team, collected data and ran workshops amidst political and economic stress. She often felt very isolated and sometimes only her enthusiasm and unwavering belief in the capabilities of the team leaders helped her to keep the project going.

Team leaders in uniform

2.12 Conclusion

Apart from the findings generated by the research, the project was also valuable as a process of peer-education and in raising the profile of HIV positive women in their communities. It has had a great impact on the team leaders and has also been an educational experience for support groups and individuals who have been involved with it. However, team leaders who have gained some prominence need ongoing support to carry out their new roles successfully. Successful advocacy for reproductive rights of HIV positive women will also require organisational support to implement recommendations from the research findings. We hope that *Voices and Choices* will become part of an ongoing process in which the voices of HIV positive women will be heard and listened to in Zimbabwe.

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[1] See Chapter 4 for a discussion of widow inheritance.

3 Dealing with an HIV diagnosis

3.1 Introduction

This chapter includes a brief background to HIV testing in Zimbabwe (see Box 3.1). It discusses the circumstances in which women found out that they were HIV positive and their feelings when they discovered they or another member of their family had the virus. It examines the issues involved for them in disclosing their status, the reactions of partners and family members to disclosure, and the role of HIV support groups in helping them deal with their diagnosis.

Box 3.1 HIV testing in Zimbabwe

At the time of the study, free HIV tests were only available in the public health sector if recommended by a doctor. Private sector testing was unaffordable for most people. Voluntary counselling and testing sites run by some NGOs and a social marketing project predominantly in urban centres, provided subsidised facilities at a charge of Z$50 to Z$100, which was also beyond the means of most Zimbabweans. Some VCT sites now offer free testing to those who explain that they cannot pay, but clients still incur substantial travel costs. Since 1996, Zimbabwe has developed a national HIV/AIDS policy that specifies the need to offer pre-test counselling by trained and competent counsellors (National AIDS Coordination Programme and Ministry of Health and Child Welfare 1996, 1998).

There are HIV sentinel surveillance sites in all provinces of Zimbabwe as well as in the urban centres of Harare, Bulawayo, Gweru, Mutare, Kwekwe and Chitungwiza. Sentinel surveillance monitors the rate of HIV infection among pregnant women at the designated sites on an unlinked and anonymous basis. HIV prevalence rates among pregnant women derived from such anonymous surveillance are used for planning and monitoring purposes to make estimates of current and future extent of HIV infection among the adult population (National AIDS Coordination Programme and Ministry of Health and Child Welfare, 1998, *HIV/AIDS in Zimbabwe: Background, Projections, Impact, Interventions*, Harare). Because these tests are carried out anonymously, women are not informed of the result nor are they offered any counselling or practical support to reduce the risk of transmitting HIV to their unborn baby. With increased publicity around the risks of parent-to-child transmission, women have had the option of attending VCT sites to find out their HIV status if they can afford the costs involved.

Named ante-natal HIV voluntary counselling and testing is not routine or available free of charge and is normally only offered when recommended by a doctor. However, there are now a few selected pilot ante-natal care sites offering HIV testing as well as short-course zidovudine (AZT) or Nevirapine to pregnant women who test HIV positive and their infants. Such pilot programmes are optional and only women who wish to be counselled and tested take part.

Table 3.1 Years since HIV diagnosis for survey respondents and interviewees

Years	Survey		Interviews	
	No.	%	No.	%
Less than 2	30	14.4	6	10.2
2 – 5	90	43.1	27	45.8
6-10	31	14.8	14	23.7
More than 10	8	3.8	0	0
Not applicable*	35	16.7	0	0
Not available	15	7.2	12	20.3
Total	209	100	59	100

* These women had not been tested but believed they were HIV positive because of the illness or death of a spouse or child. (see Table 3.2).

Table 3.2 Circumstances of HIV testing

Circumstances*	No.	%
Own sickness	26	44.1
Husband/boyfriend's sickness or death	22	37.3
Ante-natally or following pregnancy (due to woman's sickness during pregnancy or other pregnancy problems)	12	20.3
Child's sickness or death	4	6.8
Other factors	4	6.8
No circumstances given	2	3.4
Total	N=59*	100

*These categories are not mutually exclusive

3.2 Women's experience of testing and diagnosis

Almost all the women interviewed, and 76 per cent of the survey sample, had been tested for HIV and had known their HIV status for over a year (see Table 3.1). Eight women were diagnosed over 10 years ago. Thirty-five women (16.7 per cent) suspected they were HIV positive because of the illness or death of a spouse or a child. All the women interviewed had been tested HIV positive except for one woman who knew she was HIV positive when her child was diagnosed.

Women interviewed rarely sought testing themselves both because of the cost and because they did not generally anticipate that they were HIV positive. Many people had no idea at all that they were at risk, or did not perceive that their or their husband's ill-health had anything to do with HIV. Only seven women in the sample asked for an HIV test, five because they were sick and two to resolve their anxiety. All seven women knew about HIV and suspected that they were at risk. Only one of them expressed any serious hope of obtaining a negative result. She went for a test without telling anyone after her husband discovered his second wife was HIV positive. She hoped she would be found negative as she had not slept with him since he took a second wife 'but it was not like that'.

Testing often followed a husband or boyfriend's sickness or death (22 women), but in many of these cases women were also sick themselves. Women who were tested when they were ill (26 women) often described how they were 'constantly' or 'perpetually' ill.

Testing during pregnancy or after delivery was mainly offered because of pregnancy complications, such as miscarriages or because a previous baby had died, or because the women themselves were very sick during pregnancy. Only one woman seems to have been routinely tested during pregnancy rather than in response to symptoms. Two women who were tested after delivery were sick themselves.

Several women said that their partners refused to be tested and explained this in terms of denial. Only one woman interviewed refused the test herself, and this was because her child had been diagnosed HIV positive.

> ***'I already knew that I was carrying the virus as I had passed it to my child'.***

3.2.1 Testing, counselling and information

Most women seemed to perceive HIV testing as simply another medical intervention. They reported, in quite a matter of fact way, that they were tested when they were ill, or the hospital called them for testing when their husband was sick, or that the doctors 'decided' to test them.

Occasionally women were advised to go for a test by people outside the health care system or not directly involved in their care. One woman's employer sent her to a private clinic in Harare for an HIV test after she was suffering from a bad cough and went back with her to get the result in order to provide support.

In interviews, women rarely distinguished between the advice to be tested and pre-test counselling. Because of this, it is not always clear whether counselling took place in every case. Most of the women had been tested for HIV before Zimbabwe introduced a policy for voluntary counselling and testing, and some women may have been tested and given a positive diagnosis without pre- or post-test counselling. For example, one woman who was interviewed said that in 1992 she gave birth to her first child and both she and her child were very sick.

> ***'When the child was nine months old the doctors decided to do an HIV test. I was not afraid of the test as I knew that my child would be negative'.***

In this case, it would seem that the woman had not been properly counselled before the test. Despite the lack of counselling and information, very few women criticised the way they were tested and only one woman, in Harare, complained about lack of counselling. She was angry that the doctor who had done the test did not tell her anything.

> ***'He just said, "You are HIV positive" and didn't tell me anything.'***

While some hospital staff referred women who tested HIV positive to counsellors and support groups, most women received little or no information about HIV/AIDS from health workers—either when they were tested or subsequently. Counselling was mainly used in the early stages following a diagnosis and counsellors were very important in informing women about local HIV support groups. Several women who had received post-test counselling said it provided support and information.

3.3 Women's reactions to diagnosis

Although many of the women's feelings about HIV have changed since their initial diagnosis, their first reactions to their own or a family member's diagnosis were almost uniformly surprise, shock, horror, fear of death, and fear of how other people would react. Such reactions are very normal when receiving a diagnosis of HIV especially if there is no treatment available. The depth of fear felt by these women also reflected the stigma that is attached to HIV and the fact that women are often blamed and rejected by their partners, friends and relatives—especially in-laws.

> ***'I felt like committing suicide or running away from my family because my husband was always accusing me of having brought the virus to him.'***

> ***'I sat down and for a moment I thought I would go mad.'***

Many women had to deal with their own diagnosis while grieving the death of a partner or child. Emotional upset was also often linked to disbelief and anger, especially with their partner when they realised that HIV represented his infidelity. One woman expressed a double betrayal, when she realised that her husband had known his HIV status and concealed it from her.

> ***'To be told that we had HIV was terrible to me. I spent a lot of time thinking this man was deceiving me. That is when I realised that once I had a terrible rash and my husband was shocked, but we said, "no it's an ordinary disease", not knowing that he knew what it was.'***

Some of the women said that at the time they felt like they wanted to die and that they continue to feel great distress.

> ***'I felt like dying on the spot. My husband started drifting away from me and at last he died. People's attitudes towards me have changed. They are always looking at me because I am always sick and losing weight drastically.'***

Most of the women described feelings of loneliness and hopelessness.

> ***'I am so worried about my life. I have no future now. It is so painful to live for nothing but waiting for death at any time. My life has become a real burden. I am always sick, unhappy, and know no peace.'***

The degree of shock that women expressed when they were diagnosed also seemed associated with their prior ignorance or knowledge about HIV. One woman who was tested with her husband said:

> ***'We took the result very easily and were not shocked or surprised since my husband had been ill for a long time.'***

Several women in Chirumanzu mentioned how they were helped to come to terms with their diagnosis by their counsellor. There appeared to be less stigma associated with HIV in communities that had good counselling services and active support groups. One woman's story shows how community attitudes, including non-discriminatory treatment, local support groups, and counselling can work together to help women through the whole process of diagnosis.

> ***'When I got ill when I was pregnant, that is when the support group members taught me and gave me advice on HIV/AIDS. I then decided to get tested for HIV. I did not have problems in accepting my situation because I got some post-counselling. I also got the same treatment as the other patients in the hospital.'***

3.4 Implications of disclosure and non-disclosure

How and whom women told about their HIV status depended on the circumstances in which they became aware that they were HIV positive. They had to weigh up the social risks of disclosure against the mental and physical health risks from not disclosing (Cf.Bassett and Mhloyi 1991; Crawford, Lawless and Kippax 1997). The women's stories reflect a considerable tension between the need for the comfort of telling someone, and the fear of rejection or stigma. Those who could not tell could also not be comforted, though a few described telling counsellors who gave them support. Even though there is almost no family in Zimbabwe not affected by HIV/AIDS, no one was open about their diagnosis to the community at large.

The decision was not always left to the woman. In one case, health workers breached a woman's confidentiality by telling her relatives; in another, the woman's partner told other people first.

> ***'He was devastated by the news and (even before the respondent was tested) was telling everyone that we all had AIDS.'***

Another man told people that his wife was a 'horrible prostitute' after she was tested for HIV when it was already known that he was HIV positive.

Deciding to disclose to partners

The women talked about disclosure mostly in terms of seeking emotional or practical support, but they also saw disclosure to their partners as necessary to protect their own and their partners' health. So, despite their fear of rejection by their partners or in-laws, only one woman who had a partner at the time of diagnosis did not disclose her status to him (see Table 3.3). Two women said that counsellors helped them to tell their partners after they had been tested. However, few men appear to have told their wives or girlfriends when they discovered their own HIV status unless they were already very sick.[*]

Disclosure to a partner was not always an issue. Sometimes women's partners already knew their status and nine women were tested and counselled together with their partner. The partners of 19 women (a third of those interviewed) had died, or they had separated, before they knew that their wives or girlfriends were HIV positive (see Table 3.3). In some cases, where boyfriends had left them, women expressed regret that they could not tell their former partner.

> ***'My boyfriend and his family ran away as soon as I gave birth and I did not have his address, which therefore meant that I could not tell him of anything. That is how we separated, it really pained me and I went to the extent of getting ill and admitted to hospital because of him.'***

Table 3.3 Disclosure to partners at time of diagnosis

Pattern of disclosure	No.	%
Partner knew because tested together *	9	15.2
Told partner (two after counselling)	21	35.6
No partner at the time (died, separated, single)	19	32.2
Did not tell partner	1	1.7
Not available	9	15.3
Total	59	100

[*] Some of these partners subsequently died

Twelve women had new partners since they knew they were HIV positive. Out of these, six told their new partners. The interviews did not reveal the circumstances of their disclosure or how difficult they found it. The main reason for disclosure seemed to be to persuade the men to use condoms. However, only three of them did use condoms, the other three men refused to believe the woman's disclosure.

Four women who did not disclose their HIV status to new partners were afraid to lose the emotional and economic security the relationship brought them. However,

Box 3.2 Maria's story

Maria was diagnosed HIV positive after her boyfriend died. She was working as a sex worker and first went to traditional healers for treatment as she was afraid of being identified in the hospital and having her HIV status revealed. She later formed a new non-paying relationship, but did not disclose her HIV status to this partner in case he rejected her. Her paying partners used condoms, but the non-paying boyfriend refused as he wanted to have a child.

> ***'Personally I did not want a child but I wanted to please him. I later on decided to abort, but I feared because I did not have the right place to do it successfully since I did not want any one to know that I was HIV positive.'***

Maria continued to be very anxious to ensure that no one in the maternity services knew that she was HIV positive. She did, however, tell a friend who referred her to a support group.

not disclosing created problems, including pressure to have children and, if they did not use condoms, the risk of either partner being infected or re-infected with HIV and STIs (see Box 3.2). Women who were sex workers did not disclose to their paying partners but routinely used condoms with them.

Disclosure to relatives and friends

Most women had someone whom they could tell. Women whose husbands died, whose partners left them or abused them, or who were not in permanent relationships at the time were likely to turn to relatives and friends for emotional or practical support (see Table 3.4).

These women usually first turned to female relatives. Depending on their age and circumstances, some women told their older children or their parents, particularly their mothers. Several women also confided in their sisters. Two women told their brothers and received support from them.

Relatives were confided in both for emotional support and for practical advice and help. One woman whose husband accused her of infidelity and of ‘having brought the virus to him’, eventually told her sister and they ‘cried together’. A young widow said that she told her mother because she had no husband or friend to tell. A woman, who had been deserted by her partner, also told her mother. Her mother took her and her children back to live with her and also told her about the Mashambanzou support group and cooperative.

Table 3.4 Disclosure to others

Person to whom disclosed	No.	%
Parents (mother 5)	7	11.9
Other close family (sister 5) brother, aunt	9	15.3
Child(ren)	3	5.1
Friend/s (including specified HIV positive friend/ support group members 2)	10	16.9
No one	2	3.4
Not available	28	47.4
Total	59	100

In no case did women choose to disclose to their in-laws, and three women said they were afraid to confide in their relatives.

Friends could also be an important source of comfort and, even more than relatives, were a means of getting information about support groups and other HIV-related services. Friends provided information about support groups to seven of the ten women who disclosed to them. Given the high prevalence of HIV in Zimbabwe, both relatives and friends were likely to have information and networks that could provide support to newly diagnosed women.

Disclosure to no one

Some women were already so isolated because their partners or other significant family members had died that there was almost no one close left to tell, but only two women told neither their partner nor relatives, fearing rejection from both. Their stories show how traditional expectations of marriage could serve to alienate relatives and in-laws from orphans, and put more pressure on young women to keep their status secret from those on whom they depended economically (see Box 3.3).

Elizabeth’s words (see Box 3.3) express the anguish she felt at keeping her status secret. Her story also shows that where disclosure is felt to be impossible and no support is available, talking about HIV may become restricted to situations of conflict and hostility, thereby sustaining stigma. Voluntary disclosure helps to spread awareness in families and communities that anyone can be HIV positive and so can contribute to a destigmatisation of HIV infection (Health and Development Networks 2001).

3.5 Partners' and families' reactions

Initial reactions within couples frequently involved mutual blame and quarrels. Only ten women said that their husbands accepted their HIV status without recrimination. By contrast 23 women, over half of those whose partners knew their wives' or girlfriends' diagnosis, reported a hostile reaction from their partners, or one of disbelief or denial.

Acceptance by partners

The interviews suggest that where men knew about HIV they were less likely to blame their wives. One woman said that her husband 'scolded' her until peer educators came to the house and explained to them about HIV/AIDS. In Birchenough Bridge, half the women said their husbands accepted their HIV status, the highest level of partner acceptance in the four study districts. A woman in Birchenough Bridge said simply:

> ***'My husband accepted it because he knew about HIV/AIDS. He also had a lot of friends who talked about the virus.'***

Box 3.3 Disclosure of HIV status

Sarah was left with two children from two partners who had both died. Because *lobola* (marriage payment) had not been paid she could get no support from her last partner's family and became dependent on her own parents for a plot to cultivate and a place to live. They believed she was only being treated for TB. She was afraid to tell them the truth in case they would be unwilling to keep her. She had told no one except her counsellor, but after her interview she joined a support group.

Elizabeth lost both her parents and her sister to AIDS while still in her teens. She got married knowing she was HIV positive. Her relatives had refused to help her and her young brothers after her parents died as her father had not paid *lobola* and she appeared not to be in contact with them. She was desperate to keep her status secret. Even after the death of their first child, she became pregnant again and remained afraid to tell her husband for fear of being deserted.

'At the moment I am six months pregnant. I had to have a child to please my husband. It is not my choice, my husband paid *lobola* and he must have a child… If I had money I could buy AZT. I have heard that it reduces the risk of transmitting the virus to my baby. I cannot ask my husband for money to buy AZT as he will want to know what I will use it for. But now I am tired of living a life of lies. I am hoping to tell him before I deliver this child.'

Elizabeth's husband later had an affair with another woman, and it was only in the course of a bitter row with her that Elizabeth disclosed her status, brandishing it as a weapon with which to wound the other woman.

In Tshelanyemba, only one of twelve married women reported that her husband accepted her diagnosis. Team leaders commented that she was very well respected in the community and her husband did not want to lose her by making unfounded accusations. The couple was counselled together when they were given the test result. At first they could not talk, but then they realised:

> ***'We had to be strong and face reality so we had to talk about how we would live from then on.'***

The woman reported her husband as saying that 'the virus knows who brought it home', whether it is her or him, and it was more important that they now use condoms—since she had told him that she had been given lessons on how to conduct sexual relationships safely. In Chirumanzu, only one woman said that her husband accepted her diagnosis.

> ***'We were together when we were told, and so my husband was very ashamed and he begged for an apology because he had really wronged me.'***

Every case of partner acceptance involved men taking responsibility for their actions and either having some knowledge of HIV or being willing to seek information together with their wives. Some men were supportive, with several encouraging their partners to seek out more information or health care.

Denial or disbelief

The men who could not accept or cope resorted to denial—of their own or their partners' status—or, more commonly, to overt hostility. Sometimes the reaction was one of simple disbelief because the woman looked healthy. However denial manifested itself, it meant that such men were unable or unwilling to offer any support to their partners and even tried to prevent them from seeking support elsewhere. Sometimes it included pressure not to return for test results or criticism for having been tested at all.

Men's denial could result in them refusing to use condoms whether or not they were HIV positive themselves. One man, who later died, could not accept that he was HIV positive and refused to use condoms when having sex with his wife. One woman married her husband's brother after her husband died. Her second husband refused to believe that she was HIV positive, or that his brother had died of AIDS, and he insisted on her having his child. Only when both he and the child became sick did he begin to acknowledge that his wife was HIV positive.

Hostility

Many reactions from men were more overtly hostile and specifically included blame, sexual violence, coldness or desertion. Blame and accusations of infidelity against the women were described most frequently by women in Tshelanyemba who were all married. These were also the women who reported the greatest unhappiness following their HIV diagnosis. Other women also described quarrels and a loss of love including a refusal of sex in their relationships. Focus group discussions revealed that refusal of sex by either partner is often perceived as hostile, and indeed two women viewed their husbands' lack of interest in having sex with them following their HIV diagnosis as evidence of 'not caring' (Cf.Watts et al. 1998).

When women refused sex because they were angry, or tried to insist on condom use for safety, some husbands were sexually aggressive towards them. One woman said that she was often forced to have sex after her diagnosis. She and her husband quarrelled over condom use, even when she was pregnant and feared re-infection. Beatrice fought her husband to refuse sex.

> ***'I never wanted to do it again, but my partner wanted to do it. To me it was the end of our sexual relationship. My husband would sometimes force me to have sex with him and we would wrestle until I won. Since he was now weaker, I would always win the fights. He would use nasty words like "you harlot, you are refusing because you see other men out there". Both of us were actually being treated for an STI when we were having these conflicts.'***

A third woman refused sex with her husband after he took a second wife, but was raped by him and became pregnant. All the men in these examples were themselves HIV positive.

At least six men left their partner following her disclosure. All but one of these were non-marital relationships.[1] A man in Chirumanzu refused to accept responsibility for his girlfriend's status and deserted her while she was pregnant with his child.

> ***'He did not accept it. He said, "Where did the HIV come from?" From that time he began to disappear from me, yet I was already pregnant and he had infected me. That is how the relationship ended. His relatives do not even want to hear that he is responsible for the pregnancy, worse to hear that he too has HIV. All these developments are very painful to me.'***

Hostility from in-laws

Hostility often came as much or more from in-laws as from husbands. One woman described how her husband supported her in the face of the in-laws' anger.

> ***'At first, my in-laws were blaming me, but before his death he talked to his relatives saying that there was no need to blame me. He actually asked them whom they wanted the disease to fall on instead.'***

When the husbands were still alive, the in-laws would encourage them to blame their wife for 'bringing the infection' to the home. A woman in Chirumanzu described how she and her partner quarrelled so much that they eventually went to his aunt to mediate, but she simply blamed her for infecting her brother's son. Women were routinely rejected by their in-laws if they were widows. A woman in Tshelanyemba became sick and was tested after her husband died.

> ***'My father-in-law chased me away saying that I brought a deadly disease to the home.'***

Sometimes the in-laws' anger was because a widow refused to remarry within their family, in which case she risked losing control of the marital property.[2] A widow with six children in Birchenough Bridge said that her in-laws tried to evict her from her husband's land. Fortunately the village headman intervened and would not permit it.

Gender inequality and blame

Blame and hostility were not always one way, but the way women described the hostile reactions of their partners or in-laws revealed the gender inequality inherent in their relationships. Women could be punished, blamed and abused, but they had little redress against their husbands or lovers. Whilst blame and recrimination were often mutual, and some women did challenge their partners' behaviour, they had few resources with which to do so. One woman said she considered divorcing her husband.

> ***'But he would never understand why. He would cast all the blame on me and suspect that I am being unfaithful to him.'***

The sexual double standard, which enabled women rather than men to be stigmatised, was also sustained by women's economic dependence on men for their own and their children's wellbeing, especially in rural communities where women's rights to land derived from their husbands.

3.6 Helping each other to cope—benefits of support groups

Many women described how HIV support groups helped them with emotional and social support, and provided information that helped them to come to terms with their HIV diagnosis.

> ***'The people whom I met at Mashambanzou gave me the strength to go on. They were always cheerful and they were always laughing. During my first days I could not believe that they were HIV positive. How can one be so happy when she knows that she is going to die?'***

> ***'I never told anyone but just joined a support group because of loneliness.'***

One woman was advised to join a support group after harrowing experiences and two attempted suicides.

> ***'That is where I got all the help I wanted. I moved from denial to acceptance.'***

The HIV support groups were also important because of the collective strength and sense of identity that they fostered in many of the members. This enabled some of them to be more open about their status and, as the experience of the project showed, to be willing to engage with other members of the community in workshops, and to challenge discrimination and traditional practices such as widow inheritance.

Although income-generating activities in support groups were very important to some women, in the interviews the women stressed the information and support they received from their groups more than the financial benefits. Support groups were often the sole source of information about how to live with HIV/AIDS. Women said that they got information about the HIV virus itself, and about how to 'live positively', including information on how to eat well, look after their sexual health and feed their babies. Income-generating projects included knitting, sewing and vegetable cultivation in a group garden. Groups also offered practical help in getting benefits from government agencies or in getting free medicine. Group members in Harare and Chirumanzu were able to receive free medicine at the clinic on showing their membership cards. The Mashambanzou support group gave destitute women letters to help them receive welfare payments. Over time, the need for support could change and women did not necessarily remain in support groups for a long time.

Team leaders reported that some people felt ambivalent about being a member of a support group. This included women who were reluctant to be identified as HIV positive and would only come when they most needed to, or would not join one at all. For example, one team leader described how a young woman secretly went to a support group after she had been very ill and diagnosed with HIV and no one else knew her status. As she began to recover and gain weight she stopped going to meetings.

Group dynamics were also difficult and sometimes people left because they did not get on with or did not trust other members. The team leaders described how negative attitudes to support groups and their members could change.

> ***'In Birchenough Bridge the support group was started by sex workers and so it was associated with all sorts of bad things until one of our members died and people heard us praying in the funeral and saw us doing good work there. Then many other people started to join this group because they saw that this was not a group of prostitutes but helpful people such that even some people who were not HIV positive joined us.'* (Review workshop)**

While more women than men joined support groups, one woman described how she persuaded her HIV positive husband to join a support group. Some men in Chirumanzu participate in the gardening project, which is run by one of the groups there.

Although HIV support groups are assumed to be inclusive, income and status differentials often restrict their membership to poor women. Better off or better educated women are less likely to join them because they perceive their needs as different and do not want to be identified with the other members because of their positions in the community. Team leaders knew HIV positive people such as school teachers who felt they could not go to support groups for these reasons, but still wanted more information about living with HIV (Review workshop).

3.7 Conclusion and summary

Decisions about testing were made by health workers rather than by the woman themselves, often when a woman, her partner or her child was already very ill. Women were frequently blamed and accused of bringing HIV to their husbands and families and often suffered discrimination as a result of their diagnosis, either from their partners or from in-laws if they were widows. There was some suggestion that couple testing and counselling helped reduce the blame and conflict that often followed a positive HIV diagnosis.

Most women were offered little information about HIV before they were diagnosed; post-test counselling was more common and had a positive impact on the women interviewed helping them to see that life could go on after an HIV diagnosis.

In spite of the stigma associated with HIV, women normally disclosed their HIV status to existing partners and family. Women were less likely to disclose their status to new partners because of fears of rejection. Male violence and fear of rejection, especially by in-laws was a big issue and women were less likely to disclose their status to new partners. Disclosure to partners was facilitated by support from counsellors or HIV support groups. Support groups were a source of emotional and practical support for many women after initial diagnosis.

Otilia and Joyce N—
Groupwork during TOT workshop

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[1] See Chapter 4 for a discussion of marriage and sexual relationships.

[2] See Chapter 4 for discussions of women's rights to land, inheritance and widow remarriage.

4 Changing relationships and livelihoods

4.1 Introduction

This chapter examines how living with HIV has changed the lives of the women who participated in the study, in terms of their relationships and family lives, and their economic situation. It explores what has influenced those changes, and what choices have been available to them. It also examines how HIV has affected where they lived, whom they lived with, and how they earned their livelihoods. All these factors are important in shaping their sexual and reproductive choices.

4.2 Relationships

In the study it was difficult to classify relationships (see Box 4.1). This report employs terms which women used in the interviews about their partners e.g. husband, boyfriend, and have described women as married, widowed or divorced, if they said they were. In the review workshop there was a good deal of discussion about different types of sexual

Box 4.1 Marriage and sexual relationships in Zimbabwe

Nearly all Zimbabweans have been married at one time in their lives. By the end of their childbearing years, over 99 per cent of Zimbabwean women have been married. Marriage in Zimbabwe may be carried out according to customary law or civil law; customary marriages are not necessarily registered. Couples who cohabit without marriage payments having been made or completed, but have or expect to have children, are normally regarded as married. 'Marriage includes both formal and informal unions. Informal unions are those in which a man and woman stay together intending to have a lasting relationship, even if a formal civil or religious ceremony has not yet occurred' (Central Statistical Office, Zimbabwe, 1995 p69). In practice it is not always clear how permanent each partner in an informal relationship expects it to be.

The median age at first marriage is 19.8 years for women and 25 years for men (Central Statistical Office, Zimbabwe, 1995). Twenty per cent of married women and eight per cent of men are in polygamous marriages (husbands having more than one wife).

As labour migration and family separation became common as a result of colonialism, patterns of sexual relationships have changed. 'Husbands formed other liaisons in town… Men who could not afford to maintain urban wives opted for more casual arrangements… Some women migrated to meet the demand for sexual services created by the… settlement of men without their families'. Other pressures and opportunities for sexual relationships exist in rural areas as well as towns, especially rural growth points and army camps, and relationships may range from long-term cohabitation to single encounters. In virtually all cases, women expect some benefit, whether material or social or both, from sexual relationships including marriage (Bassett and Mhloyi, 1991 p151).

relationships. Where it was not clear from the interview transcript, team leaders pointed out whether an interviewee's particular relationship was long-term, casual, or a recognised marriage. They felt that the main difference between a non-marital, long-term relationship and marriage was that traditionally marriage involved a relationship between families rather than between individuals. This made it more difficult for a husband to abandon his wife than for a man to leave his non-marital partner.

Changes in relationships since diagnosis

Table 4.1 shows nearly three quarters of the women interviewed were married at the time they were diagnosed with HIV, the other women interviewed were single or in non-marital relationships. The study did not show if any women were divorced or widowed from earlier relationships.

Table 4.1 Relationship status at time of diagnosis

	Tshelanyemba	Chirumanzu	Birchenough Bridge	Harare	Total
Married	12	12	11	8	43
No relationship or non-marital relationship	0	6	3	7	16
Total	12	18	14	15	59

Table 4.2 shows the changes in the relationships of the women interviewed in the study. When they were diagnosed HIV positive, 43 women (73 per cent) were married. By the time of the study only 13 (30 per cent) of these women were still married to the same partner and 28 (64 per cent) were widowed. Out of the 15 women who were single or involved in non-marital relationships at the time of their HIV diagnosis, 10 (66 per cent) had lost their partners through death or separation.

Only three women in the sample had married after they discovered that they were HIV positive. Two of them married new partners after earlier relationships with other men had ended; the third woman married her husband's younger brother after her husband died. Table 4.2 possibly under-represents the number of non-marital relationships that widows had entered into following their husbands' death as some women were reluctant to talk about them. Nevertheless, it appears that most widows did not form new relationships.

The ending of married women's relationships was mainly due to the death of their husbands. Widowhood in Zimbabwe has become increasingly common as a result of the HIV epidemic (Tagwireyi 2001). Although we have documented a great deal of blame and anger and subsequent marital strife, husbands did not often leave their wives and wives almost never left their husbands because they were HIV positive. Only two married women divorced after their HIV diagnosis. Because marriages, especially where *lobola* has been paid, involve connections between families rather than just between individuals, marriages as institutional arrangements seemed fairly resilient to the impact of HIV/AIDS as long as both partners were alive.

From the women's point of view, however, this resilience may have simply expressed the lack of choice available to them. It was difficult for women to leave their husbands even if they wished to do so. Women without husbands have lower social status than married women and are treated with less respect by their families. Several women interviewed said that they considered leaving or divorcing their

Table 4.2 Changes in relationships of women since HIV positive diagnosis

Relationship at time of diagnosis	Change to relationship by time of study	Number	Comments
Married			
	Same Marriage	13	
	Widowed	28	1 remarried; 3 formed new non-marital relationships
	Divorced	2	1 formed new non-marital relationship
Sub-total		43	
No relationship or non-marital relationship			
	Same partner	3	
	Married new partner	2	Both women were single at time of diagnosis
	Partner died	2	Both formed new non-marital relationships
	Separated	8	3 formed new non-marital relationships
Sub-total		15	
Not available	not available	1	
Total		59	

husbands when they found out that they and their husbands were HIV positive, but that there was no point because they would be blamed. They would also lose access to their children and the family land and home, and would have to return to their own parents or survive on their own.

It was easier for husbands to leave wives, especially if they had set up another household elsewhere with another woman, but this was not common. Two women in Tshelanyemba described their husbands going away and staying with other wives after they were diagnosed. Usually, given the earlier sickness of men in the relationships which were described to us, men tended not to leave their wives after they knew their own HIV status. Indeed, two men who were labour migrants and were mainly away from home, came back when they were sick to be cared for by their wives.

The women's accounts suggest that more casual relationships were particularly threatened by a woman's disclosure of her HIV status because of men's fear of infection. Several women's boyfriends deserted them when the woman was diagnosed or because their child became sick. It was also easier for relatives of a woman or her partner to break up a non-marital relationship than a marriage when they found out the woman's HIV status. However, HIV was only one of several reasons why relationships ended. Men also left because the woman became pregnant and/or because the man was already married to someone else.

4.3 Emotional impact of HIV

Changes in quality of relationships

The continuation of marriages after an HIV diagnosis conceals the initial anger, pain and emotional turmoil that women described and which have been discussed in Chapter 2. Three women felt that their married life had significantly deteriorated; they had stopped having a sexual relationship and felt that their husbands no longer loved them.[1] Over time though, couples tended to come to terms with their diagnosis and most of the women whose husbands were still alive at the time of the study described how their husbands came to accept that they were both HIV positive, helped either by support groups or by counselling. Most of them said that they were taught about safer sex and that their husbands agreed to use condoms. Resuming a peaceful relationship after an HIV diagnosis seems to have depended on couples being able to talk to one another. This is illustrated by Juliana's story (see Box 4.2).

Box 4.2 Juliana's story

Juliana's husband took a second wife who became sick and was found to have HIV. Although Juliana refused to have sex with him after he married the second wife, she found that she too was HIV positive. She attempted suicide after her diagnosis and then again after her husband forced her to look after his other wife. It was after this second attempt that her sister advised her to go for counselling and she was told about an HIV support group.

> ***'That is where I got all the help I wanted. I moved from denial to acceptance.'***

Later her co-wife died. Juliana continued to refuse to have sex with her husband and stopped taking the contraceptive pill.

> ***'As I was not having sex, one day my husband came and forced me to have sex with him. He raped me and I became pregnant.'***

Juliana had an incomplete abortion and was taken to hospital. At this point an HIV positive counsellor intervened and spoke to Juliana's husband about the effects of his behaviour, asking him whether he wanted to lose Juliana too. It was only then that her husband found out she had been pregnant and had had an abortion.

> ***'He apologised to me. That is when we started to have a serious discussion about sex after 16 years of marriage. We decided to use condoms. We are now more in love than we were before and we go to Support Group meetings together when he is there.'***

Juliana's story illustrates the crisis that HIV can present to a relationship and how skilful counselling can have an impact on men's behaviour. It also shows how support can help women assert themselves and can ultimately lead to better communication. Juliana's story throws light on a process described by many women in which the marriage relationship was only able to continue acceptably after men took responsibility for their actions.

Struggling with loss

Women not only had to cope with the loss of their husbands and lovers and the crisis that HIV provoked in their relationships, they often had to confront multiple loss in their families. A few women experienced the death of their parents from AIDS as well as that of their partners and children. At the time of the study, nearly half of the women had a sick child, or had lost one or more children to HIV/AIDS, or both. Over a third of the women in the survey had lost at least one child. One widow whose child was sick expressed the pain felt by many when she said she 'did not feel strong enough to have him tested'. When women's children became sick or died, they would blame themselves rather than the child's father. One young woman who was deserted by her boyfriend and left with a sick child after she was diagnosed during pregnancy said:

> ***'I always felt guilty knowing that I infected the baby.'[2]***

Poverty could make loss and bereavement harder to bear. One of the most poignant experiences was that of Juliet who did not know where her child was buried as she had been abandoned by her boyfriend and had no money for funeral expenses so her child was given a pauper's burial.

> ***'It always pains me when I hear other mothers at my support group saying that they are going to put flowers on their children's graves. It always reminds me of my poverty.'***

4.4 Economic impact of HIV on households

Growing poverty

Women described the difficulties of making ends meet after they and their partners found they had HIV, even when their husbands were still alive. It became much worse if their partner died or they separated from boyfriends who had been helping to support them. Those who lived from farming found that they no longer had enough energy to carry out long hours of manual work. Women, whose husbands got ill or died, lost what income they had provided while they were employed. Many women complained that their main problem was being able to take care of their families and to find money for basic needs such as rent, food, milling maize and school fees let alone for health treatments or special foods for babies. Sometimes women could not even afford transport to health facilities. Lack of income was a constant source of worry to them. Financial problems resulting from HIV were exacerbated by the recent harsh economic situation in Zimbabwe (see Box 4.3).

Box 4.3 Poverty in Zimbabwe

The Zimbabwe Poverty Assessment survey found that poverty was primarily rural (72 per cent of households) and more common in women-headed households (MPSLSW 1995), which constitute a third of all households in Zimbabwe. The incidence of poverty increased from 40.4 per cent in 1990/1 to 63.3 per cent by 1995/6 (Kanyenze 1999), associated with unemployment, drought and low pay. The 1995/6 Central Statistical Office Income and Expenditure survey (Central Statistical Office 1998), using consumption measures of poverty, found that it is more severe in rural areas (80 per cent of households) and in female-headed households, with half of rural households having inadequate resources to satisfy food needs. Widows were the most poverty prone. Recent surveys indicate that there has also been an increase in urban poverty in the 1990s.

Peasant households in Zimbabwe were estimated in 1997 to spend Z$482 million extra on HIV-related illness and death, while the death of a breadwinner due to AIDS was estimated to lead to a 61 per cent fall in production (Kwaramba 1997). Households have sold land and cattle to finance these costs and reduced consumption levels of other household members, including removing children from school (NACP/MoHCW 1998).

Poverty also makes households less able to prevent and deal with the effects of HIV through undermining household capacities to provide for nutrition, health and other needs generated by illness including TB and STIs. It leads to late attendance for treatments, undermines education enrolment, particularly of girls, excluding them from school health promotion programmes.

Gender inequality in land and property rights

In Zimbabwe, generally women gain rights to land and other important resources through men—usually husbands and fathers. Women without partners are therefore at a particular disadvantage and many widowed HIV positive women find themselves with little or no means of livelihood. Widows were often left far worse off than they had been during their husbands' lifetimes because of their lack of land and property rights (see Box 4.4) and the practice of widow inheritance. Traditionally, if women wanted to continue staying in their former husbands' home they would need to be inherited by his brother. Although this practice is changing, there is still considerable pressure to be inherited as a means of continuing to stay at the husband's homestead. Otherwise in-laws may keep the children of the marriage and take all the household property, ignoring the wife's contribution to the family's possessions (Dengo-Zvogbo, 1994; Moyo, 1995).

Among women remaining alone, only widows who were able to stay on their husbands' land (see Box 4.4) and in the family home remained economically secure. A quarter of our interview sample now lived with their parents or siblings, rather than with a husband or long-term boyfriend. In Chirumanzu, only 5 out of 10 widows had managed to remain in their marital home. One widow was forced to leave her marital home after she refused to be inherited and her in-laws took all her husband's property including his shoes and the couple's bed (Review workshop).

Box 4.4 Women's land rights and inheritance in Communal Areas

Just under one third of Zimbabwe's population live in towns. The remainder are predominantly engaged in agriculture. Over half the population are subsistence and peasant farmers who live on land designated as Communal Areas, which constitute about 40 per cent of the country's land area. There is extreme land shortage in some areas and about 20 per cent of the population in the Communal Areas are landless (Moyo, 1995).

Rights to land and inheritance in the communal areas have, with some exceptions, been governed by customary law or practices in which women access land through men, for example their husband, father or brother. Land is normally allocated to men by the District Council, although the system is currently under review. Women have no independent legal access to land. Women contribute labour to their husband's land, and married women are also entitled to a plot of land allocated to them by their husbands. However, a study showed that less than a quarter of women actually had access to such plots. Unmarried or divorced women depend on land in their family homes but there is no guarantee that they will be allocated any (Zimbabwe Women's Resource Centre and Network 1994).

Women can challenge their in-laws by appealing to sympathetic local chiefs or to the courts, but many are not aware of this and even success is not without problems. A village head in Birchenough Bridge stopped the in-laws of an HIV positive widow with six children driving her out, stating that they had no right to do so when there were so many children. However, this left the in-laws bitter and angry and so the woman felt that there was no one to help her when she was sick (Review workshop).

In interviews, several women commented that they were literally left destitute when their partner died or left them and they had nowhere to go. They had depended on social welfare payments or financial support from voluntary agencies. This was particularly true of women in urban areas who had no other family from whom to get support. Juliet was helped by her support group to get welfare benefit (see also Box 4.2 Juliana's story). Both her parents and her only sister had died leaving her with no one else to give her support.

Women who could not stay at their marital home would go back to live with their parents or brothers if they had no other means of support, but they might have to leave their children with the husband's family. However, families were not always able to take them in, and the spread of HIV means that this mechanism of support is becoming more fragile. Several women interviewed had lost one or both parents to AIDS. Loss of support from their family of origin could leave women without land, employment, or economic security, and make the need for a male partner to offer both emotional and financial support even more important to them.

Even if women could return to their family home they were likely to be more marginalised as women's status is achieved through marriage and children. Their family home was also often inadequate to meet their needs.

> ***'Now I'm living just like anybody else but life has changed because of my HIV status. My husband died in 1992. Life is hard because nobody is looking after me with the children. I am facing problems getting drugs, because I am always on and off sick. I need food and I am unemployed. I don't have a place of my own. I'm only using one room with three children. It is my parent's home, we are too many with other brothers of mine at the same time all in the same house. The house is too small for three big families. Each one has its children under one roof. I need a place of my own, so that I'll leave my children with a place when I'm gone.'***

Urban widows whose husbands left them a house or who had a pension were somewhat better off than others, but only two women in our study were in this situation. Counsellors and support groups also discussed the importance of encouraging men and women to write wills so that their expectations can be respected in making arrangements for the children.

Women's livelihood strategies

Both rural and urban women used a range of strategies to achieve some kind of economic security. Such strategies included returning to their families of origin; engaging in agricultural work; trade, including cross-border trade; handicrafts; casual labour; selling sex or finding a new long-term relationship (see Table 2.4).

The HIV positive women who were interviewed used the same kinds of strategies as other women to address their poverty, but their problems were exacerbated by HIV in several ways. Firstly, many of their problems were caused by HIV. Secondly, as women with poor health, they actually needed better incomes to sustain their own and their children's health. They needed fresh food for themselves, and would have liked to be able to afford alternatives to breastmilk.[3] However, even though none of them had the means to afford formula they still needed money to afford other foods that would benefit their babies. They often had less energy to work than did healthy women and because of the stigma attached to HIV there were constraints on how they could earn livelihoods. For instance, one woman in Harare left her job because she was afraid of the reaction of her co-workers to her diagnosis. In Birchenough, members of the support group who sold vegetables in the market found that people avoided their stalls and would not buy from them. All these factors increased their economic vulnerability.

None of the strategies described here are mutually exclusive. Women who returned to their parents usually engaged in subsistence agriculture and petty trade. As well as these regular income-generating activities they might also sometimes sell sexual services and participate in income-generating projects in support groups. Some would also find a longer-term boyfriend or a husband who could provide them with financial support.

Occasionally women appealed to local headmen or other authorities to allocate land to them. One of the team leaders described how she left the village where she had lived with her husband and came to another one where she asked for and was given land in her own right, but this was exceptional.

Rural women, living with relatives, were allocated a small plot and rarely had enough land for themselves and their children. To find other sources of income beside subsistence agriculture some grew vegetables that they sold in local markets, worked as casual labour on other people's farms, or wove cloth, knitted and made baskets for sale. Doing 'piecework' (casual labour) could involve having to leave a small child in the care of other people. In Chirumanzu, many women also knitted for a local factory. Women in Tshelanyemba kept small stock and engaged in petty trade across the border with Botswana, selling caterpillars (a delicacy) and vegetables. Urban women were not better off since they had often depended on a husband's income and had to meet higher costs of rent and purchased food.

Women who belonged to HIV support groups with income-generating projects sewed, knitted, or cultivated vegetables within the groups, and the support group then helped to market the produce or finished goods.

Sex and survival

Many women in the study felt pressured to enter new relationships in order to support themselves and their children. Such relationships included widow remarriage, permanent and casual unions and commercial sexual relationships. In the absence of cash, sex, through both recognised and unrecognised unions, became a widely used currency among women to gain access to goods and services. In several cases in the study such relationships, before and after HIV diagnosis, resulted in unwanted pregnancies and/or STIs including HIV. One young woman in Harare became a sex worker after both her parents died of AIDS.

> ***'My father was the first one to die, in December 1993, and in 1994, my mother gave birth to a healthy baby, but she also got sick. She was so ill that she did not breastfeed the baby. As I was the eldest daughter, I was the one who took over all the duties of looking after the family including my mother and the baby. The baby was like mine, and when my mother died I became the breadwinner. As my father had left no pension I had to find ways to look after the family. I had three brothers and one sister. When my young sister was three years, she also became sick and she died. There was no other way to find money. I started to have sex with anyone who could give me money. It was not easy for me but I had to do it because I had to find food for my brothers. All the relatives did not want to help us. My mother's parents were saying they could not stay with them because our father had died without paying*** **lobola** ***for my mother. So we were alone.'***

Some women worked regularly in bars and beer halls as sex workers. In all the urban areas and growth points it was possible to sell sex to bus and truck drivers and others passing through. Where there were businesses, schools and hospitals, there was also demand for sex workers. But sex could be used as a more casual currency too, and some women would engage in sex for money to pay for food or rent.

Some income-earning strategies that women engaged in were not primarily sexual but might involve provision of sexual services. For instance, legal cross-border trade requires passports and customs fees, even if it is small-scale petty trade. Team leaders explained that illegal cross-border trade is known as ‘border jumping’.

> ***‘Border jumping is very risky because if the police get hold of you, you probably have to offer sex, if you are not to be considered as illegal citizens. These days when you tell someone that you are a vendor who sells from one country to another it’s almost the same as saying you sleep with people. It’s a very common practice’*** **(Review workshop).**

Selling sex abroad was also a way of earning foreign exchange, which could then be sold on the parallel market in Zimbabwe, or used to buy luxury items to sell back home.

A more publicly acceptable mechanism of achieving some economic security was to engage in a longer-term relationship. While widows were under pressure to marry their former husband’s brother, only one of the women we interviewed did so, several women returning to their families rather than being inherited. Agnes, who married her husband’s brother, said:

> ***‘I don’t love him like I loved my husband. I am staying with him so that I can stay with my kids. If I refused them I would have been asked to leave the kids because at that time they were still very young. I don’t have relatives. That’s why I can’t leave here. I have nowhere to go. I don’t have a brother, mother, sister. I’m an orphan.’***

Widow inheritance usually included an obligation to have a child in order to seal the relationship. Agnes did have another child against her wishes, despite the fact that she told her new husband that she was HIV positive. Two other women had legal marriages after their HIV diagnosis. They too perceived marriage as a contract to have children in exchange for economic security. One of them, Elizabeth, described in Chapter 3, said:

> ***‘My husband paid*** **lobola** ***and he must have a child.’***[4]

Other women, including some who also worked as sex workers, had long-term boyfriends. Even if their relationship was not yet long-term and the couple did not live together, many women described such relationships in terms of love. Love involved emotional support and closeness as well as sex, but a boyfriend who loved a woman was also expected to provide her with economic support. However, such support was often conditional. Boyfriends might give women money for themselves but not for their children, and women could not demand too much in case the relationship would be perceived as commercial. Non-marital partners, unlike husbands, tended not to want children and several of the women we interviewed were deserted by their non-marital partners when they became pregnant. Women’s boyfriends were often already married with children and did not want further responsibility in an extra-marital relationship (Review workshop).

4.5 Conclusion and summary

Changes in women’s lives and relationships following an HIV diagnosis were shaped by unequal gender relationships and poverty, as well as by the physical effects of the virus. Economic problems for HIV positive women were exacerbated by the lack of women’s rights, especially as these affect widows. Although women are increasingly resisting widow remarriage they have little protection for their property or for custody of their children without it.

This chapter has shown how marriage and sexual relationships form part of women’s livelihood strategies as they offer important economic benefits to women.

Anatolia and Joyce M share the advocacy module

However, these relationships are usually conditional on women bearing children or accepting men's wishes in sexual relations.

Women's relationships often changed dramatically because of HIV, not just because of their own HIV status, but also because of their partner getting sick and possibly dying. HIV was also a cause of separation among unmarried couples though much less among those who were married. Relationships that continued were usually changed by an HIV diagnosis and couples often took a long time to come to terms with it. Counsellors and support groups could help them in this.

HIV positive women often had to cope with grief at the death of parents, babies and children, as well as of husbands and boyfriends, at the same time as coming to terms with their own diagnosis and having to deal with the social and economic impact of HIV on their household.

HIV within a household often increased poverty because of the death or ill-health of one or more of its members. It was often more difficult for women to sustain their livelihood strategies either because of ill-health or social stigma. Women engaged in agricultural work, petty trade, and other informal sector activities. Some income-generating activities were assisted by HIV support groups but were very limited in scope. Sexual relationships as a means of achieving better economic security, whether selling sex routinely or occasionally, or new long-term relationships with men, could pose serious health risks to them unless they were able to practise safer sex and exercise control over their fertility

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[1] See Chapter 6.

[2] See Chapter 7 for discussion about women's concerns about their children's health and future.

[3] See Chapter 7 for a discussion of issues relating to infant feeding.

[4] Some women did wish to have children. See Chapter 7 for a detailed discussion of women's childbearing preferences.

5 Women’s experience of health services

5.1 Introduction

HIV positive women’s experiences of health services are an important but understudied issue. This chapter gives a brief introduction to some of the experiences of the women in the study after they were diagnosed with HIV. Reproductive health is considered in more detail in Chapter 6, but it is also included here in terms of these considerations.

Box 5.1 Sexually transmitted infections (STIs) in Zimbabwe

There is a strong association between STIs and HIV infection. Untreated STIs can dramatically increase the risk of HIV transmission, but many women who are infected with STIs do not know they have them, especially as some STIs do not produce symptoms in women. This means that women can go without diagnosis and treatment for a long time, which has serious consequences for their health. Untreated STIs can cause infertility, pelvic inflammatory disease, ectopic pregnancy, infant mortality and cervical cancer (Burns et al. 1997).

There is a high level of new and untreated STIs in Zimbabwe although there has been a small decline in the rate of STIs to about 67 STI episodes per 1000 people. Urethral discharge and genital ulcers, the STIs which most increase the risk of HIV, constituted 50 per cent of STIs reported in 1997, with a 33 per cent increase in genital ulcers and a 32 per cent decrease in urethral discharges since 1994. Reported STIs have fallen in urban areas by 11 to 31 per cent, but have risen by a corresponding amount in rural facilities. (NACP/STI programme 1998).

In a study of factory workers in Harare, HIV positive men were three times more likely to have an STI than HIV negative men (Machekano et al. 2000). Men report STIs more often than women as symptoms are more evident and stigma associated with STIs in men is less. STIs are often only diagnosed in women during ante-natal screening or when symptoms begin to show after a long infection (Loewenson, Edwards and Hove, 1996).

The National AIDS Coordination Programme has developed cost effective STI treatment and prevention policies and protocols to improve the quality of provincial and district STI and prevention services, with particular emphasis on services for women and early diagnosis and treatment (National AIDS Coordination Programme and Ministry of Health and Child Welfare, 1998, HIV/AIDS in Zimbabwe: Background, Projections, Impact, Interventions, Harare). However, recent studies show that prevention and treatment services remain inadequate. Gregson et al. reported that in rural Zimbabwe one third of sexually active adults had experienced STI-related symptoms but that there were delays in seeking treatment, especially among women. Local programmes promoting safer sexual behaviour and fast and effective diagnosis and treatment of STIs could reduce the extensive HIV transmission in rural communities (Gregson et al. 2001).

5.2 Health problems

General health problems

All the health conditions women described in their interviews were self-defined and were in terms of symptoms rather than of named diseases. These symptoms included sores, rashes, chest pains, coughs, diarrhoea and stomach pain, headaches, weight loss, weakness and tiredness. Even though the women interviewed were not acutely ill, some women complained of constant illness.

> ***'Healthwise everything is quite bad. I am always sick from different diseases and they do not give me any respite. I have a lot of health problems and I am always tired.'***

The diseases named were always those for which women had received treatment and included a range of HIV-related conditions, especially TB, meningitis and STIs. Several women also suffered from fibroids and ovarian cysts.

Sexual health problems

Over a third of women in the survey said that the most common reason for using a health facility was because of STIs (see Box 5.1). Over 60 per cent of women in the survey had been treated for an STI in the last three years. Many women interviewed described symptoms of reproductive tract disorders and had suffered from STIs both before and after diagnosis. They described symptoms of STIs including painful genital sores, itching and discharge. Several women said that they had contracted STIs in pregnancy, though it is not clear whether they were diagnosed with STIs during pregnancy or actually contracted the infections at this time.

Box 5.2 Health services in Zimbabwe

Health care in public health facilities is only free for people who earn less than Z$400 per month. To prove their eligibility for free treatment people need to obtain confirmation of their income status from their local social welfare office. Because this is difficult most people have to pay for treatment.

At primary care centres people are seen by a nurse and referred to a doctor if the condition is severe. Medicines are provided at the clinic, but recently essential drugs have often been unavailable.

Women also complained of irregular menstrual periods since they were HIV positive. More than 52 per cent of women in the survey reported that their menstrual cycle had changed since they knew they were HIV positive and 65 per cent reported irregular periods at the time of the survey. Many of the women interviewed also mentioned problems with menstruation, particularly pain, heavy or continuous bleeding and irregular periods.

5.3 Use of health care systems

Public health facilities

Although 86 per cent of women in the survey reported that they usually went to hospitals and clinics whenever they needed health care, they experienced serious problems with these facilities. Problems included: not being able to afford fees and medication, not enough time for examination, shortage of staff at the facilities and negative attitudes of health workers. Women were very concerned about the imposition of health care charges. Many said that they could not afford treatments. One woman said that health charges 'will honestly kill us'. At some facilities the women interviewed were known by health staff and were not required to pay.

A few women mentioned buying medication directly from a chemist, but this would usually only occur if the drug was not available from a clinic. None of the women had access to anti-retroviral treatments for themselves, although two had enrolled on a programme of short course antiretrovirals (ARVs) to reduce the risk of parent-to-child transmission in pregnancy as part of a clinical trial (see Chapter 7 for a discussion of short-course ARVs in pregnancy).

Traditional healers

Most respondents used formal health facilities when they were sick but, although they received basic health care from local hospitals and clinics, many women also consulted traditional healers or faith healers, especially for STIs or menstrual problems. Women used traditional healers for several reasons. They felt that traditional healers actually treated the condition complained of while in hospitals minor complaints were often dismissed.

> ***‘If women go to the hospital with menstrual problems they just give you some Panadol, whereas if you go to the traditional healer you are treated for an STI without paying a lot’* (Review workshop).**

Traditional healers were also cheaper than conventional medicine and people could pay later, or pay in kind instead of in cash, which made treatments easier to afford. People felt comfortable with traditional healers because of shared beliefs. Women interviewed did not distinguish clearly between traditional healers and traditional medicines (See also Chavunduka 1997). Many talked about treatments with herbal remedies that people would give to friends. One woman, who was very careful not to disclose her status and did not want to go to the hospital, said that she got traditional medicines from friends.

However, the quality of the medical treatment offered by traditional healers seemed questionable. Two women had abortions using traditional medicine because they were unable to get an abortion any other way. In both cases there were serious complications that resulted in hospitalisation. Two women also reported consulting traditional healers to cure their husbands of serious illness, which was later diagnosed as HIV. Team leaders felt that it was important to educate traditional healers about HIV because they treated many people living with HIV/AIDS (See also Bodeker 2001).

Constraints on access to health care

Nearly half of the survey respondents (44 per cent) said that they had to ask for permission from husbands or in-laws to go for treatment, reflecting the subordinate position of women within families. Requesting permission was not elaborated in interviews, possibly because it was taken for granted by both interviewers and interviewees. However, some women described pressure from partners or families not to go back for test results or criticism that they had gone for HIV testing at all. Given that few women had money of their own, it was difficult for women to seek health care without their partner’s consent. This was made worse when partners were not open with each other about HIV. One woman was unable to get ARVs in pregnancy because she had not disclosed her status to her husband and would have had to explain to him why she needed the money.

Other constraints on access were cost, including travel costs to a larger hospital if the treatments were not available locally.

Patience, for example, became pregnant after she and her husband were both diagnosed HIV positive. She knew about use of ARVs in pregnancy to reduce the risk of HIV transmission to her infant, but it was not available in local health facilities. She had a difficult pregnancy with bleeding and was diagnosed with an STI at the ante-natal clinic. She would have liked to give birth by caesarean section but was unable to afford the bus fare to the large hospital where it would be available.[1]

5.4 Quality of care and discrimination in health care

The women's discussion of the quality of health care focused mainly on how comfortable they felt with their care, especially their experience of discriminatory or patronizing behaviour by health care workers (particularly nurses), rather than on the efficacy of treatment. Besides discrimination, discomfort with male nurses was the only other element of quality of care that women commented on, with over 40 per cent of the women in the survey feeling ill at ease when male nurses treated them for STIs. This may reflect much stronger sensibilities about protecting bodily privacy than health providers took account of, especially in small communities where patient and nurse may be known to each other.

Despite a clear anti-discriminatory policy by the government (National AIDS Coordination Programme and Ministry of Health and Child Welfare 1998), in the interviews many women described hostile and discriminatory treatment and nearly half the women in the survey felt that they were discriminated against by nurses.

Nearly two thirds of those questioned said that health workers in general do not treat people with HIV the same as other people. Most of the examples of discriminatory treatment came from maternity and ante-natal care.[2]

Discrimination by health workers was a major issue discussed in focus groups in the community workshops.[3] Women in one support group suggested that discrimination stemmed from health workers' fear of infection, negative and judgmental attitudes, and the feeling that as nothing could be done for people with HIV it was not worth wasting medicines, money or time on them (Meeting in Birchenough Bridge with ICW 1998).

Discrimination took the forms of hostility and rudeness, differential treatment and betrayal of confidentiality. In many cases women experienced more than one type of discrimination. Sometimes women found themselves the object of hostility from other patients but no one reported any health care staff stopping such behaviour. On the other hand, women also gave examples of kindness and recognised that their complaints did not apply to all health workers.

> ***'I had problems with the nurses who took me for a very loose woman and some would tell me straight to my face that my baby would die, while a few tried to comfort me saying the baby might not die.'***

Hostility and rudeness manifested themselves in several ways. Women complained that nurses scolded them, especially when they were pregnant, as they advise HIV positive women not to have children. Sometimes the rudeness took the form of verbal abuse and undermining comments or calling a woman names and telling her she would not give birth.

> ***'We don't need people like you. Do you think you are going to have a healthy baby?'***

One woman said that some health workers were sympathetic while others 'loathe you'. Another said that the health staff behaved as though she was dirty and seemed to be laughing at her. In one community workshop, people said that nurses say of people living with HIV or AIDS, 'it's them again', accompanied by rude facial expressions.

A common complaint was that the medical treatment meted out to HIV positive women was different and discriminatory. Often people living with HIV/AIDS are denied access to a doctor by nurses or they are sent home without treatment or just with painkillers. Women felt that health care workers were 'too lazy' to treat people living with HIV or AIDS. A woman whose wound became infected after a caesarean section was sent home after three days instead of the normal six.

> ***'I was told to go home where there are no nurses or doctors. It was a way of sending me away because they could not cope with an HIV positive mother and baby.'***

In one community workshop, 'being sent to home care' was identified as a major problem that HIV positive people encountered. Women in Birchenough Bridge said that a referral to home-based care on the hospital record was a euphemism for HIV and effectively a statement of refusal to treat.

Women also complained that doctors would not carry out physical examinations on them or do further investigations. Women felt that it was only people known to be living with HIV or AIDS who were handled with gloves, suggesting that universal precautions are not followed in many hospitals in Zimbabwe. One woman said that she was delivered by nurses wearing protective clothing. Other stories tell of women being put into isolation when it was realised they were HIV positive.

Most forms of discrimination by health care workers can betray confidentiality about a person's HIV status, since people can observe that a person is being treated differently. Sometimes, however, health care workers betrayed a woman's confidentiality more directly; for instance when nurses told a woman's relatives that she had AIDS. The woman was angry not only at this disclosure, but also that they said she had AIDS rather than HIV. Women also claimed in workshops that service providers gossiped about them.

To avoid breaches of confidentiality and discrimination, a few women did not disclose their HIV status in health facilities, including ante-natal, maternity or baby clinics. A minority of women expressed satisfaction with the care they had received and did not feel they were treated differently from anyone else.

Part of the problem of discrimination in health care was that the nurses lived in the same community as their patients and knew them and their health problems personally. If nurses know of an HIV positive woman who keeps having babies, they feel free to criticise her. There are also health workers who are HIV positive themselves and who may feel a need to conceal their status by displaying negative attitudes.

> ***'Probably what makes the nurses have such negative attitudes is the fear that we all have, that maybe we will get the disease if we get into contact with these people. But that is not true, hence we advocate that people be trained and given more information on how to deal with patients by support groups like this one. Even professionals these days have***

> ***HIV so if there is discrimination at workplaces because of HIV then lay people can act against these professionals. An HIV positive nurse can be in trouble when people refuse to be treated by her. So we have to fight this discrimination by working together'* (Review workshop).**

Team leaders felt that nurses who had attended the community workshops had really changed their attitudes. Health care workers who attended the project's national advocacy workshop in November, 1999, in Harare, took women's criticisms on board and recognised their responsibility in addressing the community stigma and discrimination in health care (Advocacy Workshop, 1999).

5.5 Conclusion and summary

Women interviewed were very worried about the effects on them of health care charges. They were also distressed by the discriminatory attitudes and behaviour of health care workers. A few women avoided such discrimination by not disclosing their HIV status to health workers in ante-natal clinics and maternity services, although this was not possible if they were seeking treatment for opportunistic infections. It also meant that they could not get care appropriate to their health needs. In the community workshops, health care workers responded sympathetically to complaints by HIV positive women and those attending offered to deal with cases of discrimination which were drawn to their attention. This suggests that there is scope for further education and training about HIV among health care workers.

The study also revealed widespread use of traditional healers who are seen as more accessible, willing to provide services not easily accessible through conventional health services, such as abortion, and to treat chronic conditions such as STIs and menstrual problems. However, treatments offered may be of doubtful value or even dangerous.

Nyaradzo—Team leader rehearsing a teaching session during TOT workshop

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[1] It is not clear whether she wanted an elective caesarean to reduce the risk of parent to child HIV transmission. In Zimbabwe elective caesarians are not usually offered in public services and there isevidence of poorer outcomes for HIV positive women in developing countries who have caesarian sections because of risks of wound infection (Poppa 1999).

[2] This is discussed further in Chapter 7.

[3] Discrimination by health care workers is explored at some length in Health and Development Networks 2001. See also Faugier and Sargeant 1997.

6 Exploring sexual and reproductive health

6.1 Introduction

The project offered an opportunity to explore how HIV positive women viewed and looked after their sexual and reproductive health before and after their HIV diagnosis. This chapter examines women's knowledge and practice of both HIV and STI protection, and contraception.

6.2 Recognising the risk of HIV before an HIV diagnosis

This section examines the extent to which women's knowledge about HIV influenced them to take preventive measures against infection before they found that they were HIV positive. Over 90 per cent of the women interviewed said that before they knew their HIV status they had not used protection to prevent either STIs or HIV. At first sight, this would appear to be a very high proportion in view of the high prevalence of HIV and STIs in Zimbabwe and the public education efforts that have been made in recent years. Sixty-one per cent of women in the survey said that they had been treated for STIs in the previous three years. Many of them were by then already HIV positive, but several women interviewed had also had STIs before they were diagnosed with HIV.

Why did women not use protection? The explanation is to be found not just in their limited knowledge about HIV, but in an understanding of how they related their knowledge about HIV to themselves and an understanding and other aspects of their lives. These include their expectations of their sexual relationships and the degree of control they felt they had in them, as well as attitudes towards condoms and to the control of disease more generally.

Knowledge and awareness of risk

Over half the women interviewed said they had known nothing of HIV prevention before they found they had HIV.

> ***'We did not use any protection because we did not know and were ignorant of it.'***

Loewenson et al. (1996) looked at the impact of changes in family structure in Zimbabwe on the communication of information about reproductive health. They noted that such changes have disrupted traditional mechanisms of sex education. Young girls were formerly taught about sex by grandmothers and aunts. Now, in Matabeleland, and possibly elsewhere in Zimbabwe too, some women in towns are being paid to teach young girls about sex. However, all the issues that they deal with revolve around male pleasure and do not include assertiveness or HIV education (Review workshop).

Nevertheless, many women acknowledged that they had *heard* of HIV, but either they knew nothing or very little about transmission or, more commonly, they did not see how this knowledge applied to them. Their knowledge seemed very vague and incomplete.

> ***'Before I was told about my HIV status, I only knew that there is AIDS but did not know all the facts about HIVor AIDS. So I did not try to protect myself from AIDS because I did not know about it.'***

More commonly, women distanced themselves from HIV so that it would not apply to them. This is very common in dealing with difficult or unacceptable knowledge and has been much discussed in relation to HIV/AIDS (see, for example, Ray et al. 1998; Ratcliffe 1999). Distancing oneself from HIV was easier for those who saw themselves as keeping to the strict rules of marital and sexual relations in Zimbabwe. Those perceived to be at risk were frequently seen as other types of women, who did not keep to these strict rules. HIV was frequently viewed as an *attribute* of these types of people rather than as an infectious virus.

Some people had thought that AIDS could not affect a woman who only had one partner.

> ***'When I gave birth to my first child, I was always in and out of hospital. The child was not responding to the treatments she was being given at that time. When the child was nine months old the doctors decided to do an HIV test. I was not afraid of the test, as I knew that my child would be negative. I was thinking AIDS was for people who have many sexual partners. At that time I had only one boyfriend. He is the one who took away my virginity.'***

Several of the women interviewed thought that HIV did not apply to married women.

> ***'I didn't think it could happen to us because we were married.'***

Other women thought that HIV only applied to women they termed 'loose women', or sex workers.

> ***'I did not protect myself in any way because I thought AIDS belonged to the loose people, and especially those in Bulawayo city.'***

> ***'I thought it was for prostitutes only.'***

A married rural woman, described by the team as highly respected in her community, said:

> ***'I did not protect myself because I had confidence in myself and I knew I would not get HIV because I was faithful. HIV affects those who are not faithful so I never thought about getting it.'***

This woman's strong feeling of self-worth contrasts with the view that women put themselves at risk of HIV because they have low self-esteem (Sobo 1995).

Lack of knowledge is a consequence, rather than a cause, of the perception that HIV is an attribute of others. If HIV has nothing to do with you, why bother to find out more about it?

One or two women did not believe what they heard about HIV.

> ***'We used to hear about HIV and AIDS, but personally I never believed that it existed. The nurses, people in general and even in churches, there used to be daily talks about it, but we often thought that it was rubbish.'***

Risk and choice

Very few women realised at the time that they were taking any risk by engaging in unprotected sex.

> ***'I knew about HIV before, but I just did not want to follow the teachings and now I am regretting.'***

Those who recognised that they were taking a risk were also able to give a reason for doing so. The following is part of the account given by Elizabeth, one of the very few women who stated openly that she had knowingly put herself at risk. As we saw in Chapter 3, both Elizabeth's parents died leaving her with siblings to look after.

> ***'There was no other way to find money. I started to have sex with anyone who could give me money. It was not easy for me but I had to do it because I had to find food for my siblings. I knew all about AIDS because the nursing sister who used to come to see my mother at home was always giving me information about AIDS. People from the home care service used to come to our house and taught me about AIDS. Before I knew my HIV status I did not try to protect myself from getting AIDS. I had no choice. I had to feed the family and that time I was 18 years old.'***

Risk and marriage

Most of the married women had had children with only one partner and believed that they had acquired the virus from their husbands who were unfaithful. Some husbands spent little time with their wives as they worked in towns, and some women were aware that they were likely to have other sexual relationships there. However, they did not consider the health implications for them of men's multiple relationships until they found that they were HIV positive.

Whilst many women acknowledged that they knew their husband had been unfaithful, others were surprised and shocked to discover this.

> ***'It (the HIV diagnosis) really shocked me because I just thought my husband and I could by no means be HIV positive. I sincerely thought my husband was faithful.'***

In some cases, it was only after her husband was diagnosed with HIV that a woman would acknowledge her husband's infidelity.

> ***'My husband was very ill. They took him for counselling and he called me so that we could be together in the lessons. After we were counselled, I then remembered his ways and guessed that the disease could be from his unfaithful acts.'***

Women's perceptions of the HIV prevention strategies open to them in Zimbabwe have to be understood within the context of common expectations of marriage, which include having children and obeying your husband. Although women often express anger and resentment at the control exercised by their husbands, marriage is one of the few ways that women can ensure their social status and economic security.

> ***'If there is a gathering in the family and they want to discuss some important issue they will call those with husbands. An aunt without a husband, you're not called, they don't take you seriously, you are a nobody in that family'*** **(Review workshop).**

Using condoms in marriage

Whether as a means of contraception or as protection from STIs, condoms are strongly associated by men and women with extra-marital sex (Bassett and Mhloyi 1991; Meursing and Sibindi 1995).

> ***'My husband is not interested (in condoms). He never wanted to set eyes on those plastic things. If he ever found me with any he would allege that I was being promiscuous…'***

Most commonly, women said that it was their husbands who refused to use condoms. There is no doubt that men in Zimbabwe prefer not to use condoms (Civic and Wilson 1996). However, many women also felt that condoms were inappropriate within marriage

> ***'At that time (before HIV) my husband and I never used condoms. We thought they were only for use by prostitutes.'***

Many women felt that because a man had sex with his wife without a condom it meant that she was valued more than sex workers or other temporary partners.

> ***'We cannot have it that when one sleeps out he uses condoms on the extra-marital mates, and when one is sleeping with his marital mate he uses condoms as well. It does not make sense.'***

This may be why, in the rare cases where husbands proposed condom use, their wives were just as reluctant to use them as they claimed men were.

> ***'I knew nothing about HIV before my husband was infected. I never tried to protect myself from HIV but only from unwanted pregnancies. I remember that once he introduced a condom and I was so angry. I said, "but we are married" and he even said, "I know why" (i.e. I have my reasons).'***

Control of sex

Women felt that men generally controlled a couple's sexual encounters both in terms of if or when they had sex, and whether they used condoms. Over three quarters of women in the survey said that men usually initiated sex and over two thirds felt that they also controlled how sex was carried out.

> ***'Whenever my husband wanted to have sex we would do it just like that.'***

> ***'My husband never tolerated using condoms.'***

Both the women's stories and the community workshop discussions showed that men and women shared an acceptance of men's rights in marriage. Forced sex within marriage is very common in Zimbabwe and is widely regarded as 'normal', and even acceptable. Seventy-eight per cent of the women in our survey reported being forced to have sex by their regular partners, but only 43 per cent of those forced regarded the action as rape. Nearly 40 per cent of the women surveyed said they had been forced to have sex while the partner had STIs. At the time of the study, Zimbabwean law did not recognise marital rape. However, in 2001 the Zimbabwean government passed a new law, The Sexual Offences Act, that criminalizes the deliberate transmission of HIV, recognises rape in marriage and imposes heavy penalties for a host of sexual offences.

During the community workshop discussions, groups of male community leaders were asked for their views on forced sex. Women's reasons for refusing sex were seen mainly as signs of guilt or bad behaviour, such as having an extra-marital affair, possession by evil spirits, or having an STI. In such cases, sexual coercion by the male partner would be viewed as a punishment. But even if men felt that a woman was refusing sex for ‘genuine’ reasons, for example because she was angry or too tired, or had not been given money, these reasons were perceived as insufficient to challenge what the men perceived as their conjugal rights. This conferred an obligation on women to have sex whenever their husbands wanted them to because *lobola* had been paid—even when the husband felt the woman’s reasons to refuse were ‘genuine’ (Cf. Meursing and Sibindi 1995).

6.3 Contraception before being affected by HIV

In contrast to their limited knowledge of HIV prevention before they were affected by the virus, many women were familiar with modern contraception. In the course of discussions about safer sex, 25 (42 per cent) of women interviewed said they used modern contraceptives before they knew they were HIV positive.

Mostly women interviewed had used oral contraceptives and injectables, but six women had used condoms before they were diagnosed HIV positive. One woman had participated in a Norplant trial. Another had used an intra-uterine device and continued to do so. Only one woman referred to traditional medicine as a means of contraception, but she had used this as well as oral contraceptives. One woman had used the ‘safe period’ as a means of controlling her fertility. This was the method advised by staff at the local Catholic mission hospital.

All the women interviewed knew something about contraception, though some said that they had not used family planning because they or their husbands wanted children. Very few women had discussed family planning with their husbands.

Box 6.1 Contraception in Zimbabwe

The Zimbabwe Demographic and Health Survey (DHS) reported that Zimbabwe had the highest level of contraceptive use of countries in East and Southern Africa where such surveys had been conducted. Forty-two per cent of married women and 53 per cent of sexually active unmarried women used modern contraceptive methods. Most contraceptive users (85 per cent) obtained their methods from public sector sources of which the main ones were rural and municipal clinics, community-based distributors and government hospitals and clinics (Central Statistical Office, Zimbabwe, 1995). Community-based distributors do not examine the women, but only distribute to people who have already been seen by a qualified health worker and have a suitable method prescribed.

Only six per cent of users obtained contraceptives from pharmacies or private clinics (Central Statistical Office, Zimbabwe, 1995 p54). Male condoms are available free from clinics and, although many Zimbabwean women prefer female condoms (Ray et al. 1995), neither these nor non-barrier contraceptives are available free. The negative behaviour of health staff is also a major barrier to provision of contraception to adolescents and teenagers who are not married or may be under the age of consent.

> ***‘We never talked about family planning. I just got pregnant.’***

One woman with six children said that her husband had advised her to take pills to prevent further pregnancies. Team leaders described strategies that some women used to avoid pregnancy without telling their husbands. One woman came to the team leader’s house every morning to take a contraceptive pill. Others hid pills in bags of mealie meal in their homes.

Information about contraception was much more readily available to women than information about safer sex. Many women mentioned that they had received no information about HIV at clinics where contraceptives were available.

> ***'There was no knowledge about it and our local clinics had little or no information about HIV.'***

One woman was taught about family planning by health workers who gave her free pills but she "never took them because when her husband was strong he seldom came home." It would seem that the health workers did not discuss the health implications of her husband's long absences with her. She only learned the difference between family planning and HIV prevention at the support group after she was already HIV positive.

HIV prevention campaigns have focussed on condom use as the main method for protecting against HIV infection. The women in this study were already HIV positive, but they recognised that the desire to have a baby means that even women who are able to negotiate condom use would put themselves at risk of infection by having unprotected sex in order to conceive. In chapter seven, women describe trying to get pregnant so did not use condoms with their partners, but worried about the risk of infecting their partners.

Table 6.1 Methods of contraception and secondary prevention since women knew they were HIV positive

Method	No.	%
Condom alone	22	37.3
Condom and other-non barrier method	12	20.3
Abstention*	17	28.8
No method	5	8.5
n.a.	3	5.1
Total	59	100

* Of the women who abstained, one had also been sterilised and the other kept an intrauterine device (IUD), which had been fitted before she knew she was HIV positive.

Sexual health since HIV

After their HIV diagnosis, women became much more aware of methods to prevent STIs and HIV re-infection[1] and were generally also very anxious to prevent conception. Thirty-five of the 59 women interviewed (nearly 60 per scent), used barrier methods alone or dual protection (barrier methods together with a non-barrier form of contraception). Although microbicides are currently undergoing clinical trials in Zimbabwe, they are not yet licensed for general use and were not referred to by any women interviewed. Eighty-seven per cent of women in the survey used contraceptives and 75 per cent used condoms to prevent STIs. Table 6.1 shows the methods of contraception and secondary prevention women interviewed used since they knew their HIV status. Since, as we have seen, very few women ever used condoms before they were diagnosed, this represents a marked shift.

Women found contraceptives easy to obtain, but some commented that pills were expensive. Two thirds of the women in the survey obtained condoms from the hospital or community-based distributor, while 13 per cent got them at beer halls. Project team leaders also referred to clinics as women's main source of contraceptives. Many women who had tried them preferred using female condoms, but often found them difficult to obtain.

Women did not question the safety or appropriateness of oral contraceptives and injectables for HIV positive women, and there was no discussion in the interviews of whether they disclosed their status in family planning clinics. However, team leaders suggested that this would be very unlikely since 80 per cent of women in the survey felt that society does not expect HIV positive women to be sexually active. This attitude may have contributed to much of the stigma and discrimination against HIV positive women who gave birth.

The women's stories suggest that they changed their contraceptive and prevention methods based on information from support groups or from counselling. This information helped them to be more assertive with their partners.

> ***'We discuss sexuality, how to plan it, and even the foreplay. We now have safer sex by using condoms. We got the advice from support groups and clinics.'***

Major relationship changes, and shifts in knowledge and attitude of their partners, also led to changes in how they looked after their sexual health. This process could take some time, and it was not always possible for women to use protection consistently and regularly.

Besides their concern with re-infection, many women were sure that they did not want to have any more children. Some women therefore used dual protection methods to prevent conception and re-infection.

> ***'I was pregnant when I discovered that I was HIV positive. I did not contemplate an abortion but I do not want to be pregnant again. I have used the Depo injection, and we use condoms.'***

> ***'I use family planning tablets and condoms. I use these tablets so that if by any chance the condom tears, I will still not fall pregnant.'***

Practising safer sex

Use of condoms varied greatly, according to age, relationship, number of surviving children and experiences of pregnancy. Five of the women interviewed, all in new relationships, used no protection because they wanted a child. A third woman, who had remarried her dead husband's brother to support herself and her children, felt forced to accept his wish to have another child and did not use condoms. Two other women who were sex workers used condoms with their clients but not with their non-paying partners, though both of them used oral contraceptives to prevent pregnancy with these partners. Two women described their husbands forcing them to have unprotected sex after they knew their HIV status.

For a woman to introduce condoms into a relationship successfully, the cooperation of her partner was crucial. Such cooperation often followed periods of great conflict and frequently involved the help of counsellors and the support groups. It also reflected increased assertiveness on the part of the women themselves.

Three women's husbands accepted the idea of using condoms after their wives began to talk about sexual health issues with them. All three accounts reflect mutual respect between the couples in the relationship and a practical perception of what needed to be done. The key issue for all of them was their recognition that they had to look after themselves in order to survive to look after their families. Two couples were helped by being diagnosed together.

> ***'Whenever my husband wanted to have sex, we would do it just like that. We only started using condoms when we already knew our HIV status.'***

Two women managed to introduce condoms into their relationships, without telling their partners their status, by stressing the value of HIV prevention. Both of them found it difficult. One of them said that she did not tell her boyfriend because she was afraid he would reject her. She stressed the encouragement and support she received from the support group she had joined.

> ***'We started using condoms but I had to be diplomatic for him to accept it because he did not know that I was HIV positive.'***

Changes in sexual feelings

HIV affected women's sexual relationships, including their sexual feelings and their sexual enjoyment.

Of the 59 women interviewed, 11 felt that there had been no change to the sexual side of their relationships and that sex was still good, except that they now used condoms. One woman suggested that sex for her was now better because it was safer.

Many widows did not enter into another sexual relationship after they were diagnosed HIV positive and their partner died. Some women could not contemplate sex with another partner and one woman said that she had little desire because her 'real lover' had died.

> ***'Since my husband died I have never been sexually active. I am afraid of using a condom. I don't think I will have sex again.'***

One woman described how the loss of a child, after she was abandoned by the child's father, affected her.

> ***'I spent about four years without a boyfriend. I was thinking that my sexual feelings had died with my child's death.'***

Abstinence within an ongoing relationship was not common. When it did occur, it had to do with loss of desire, and to protect their health. One woman said that she felt that her husband did not have sex with her because he no longer cared for her.

Two women discussed masturbating as a way of dealing with unsatisfied sexual desire. One of them also advocated good non-sexual friendships.

> ***'Associating with good friends who are not interested in sexual issues is good. I go for good friends who teach me self-control and abstinence as did the old folks who could go for years and years knowing no man.'***

Several women said that sex was less frequent or irregular or that it was painful because of STIs. Some women commented specifically that their own or their partner's sexual health problems interfered with their sex lives.

> ***'No man would like to have sex with someone who is always bleeding, even if I use condoms. I am still young and I want to have sex.'***

6.4 Conclusion and summary

Most of the women had little or no knowledge of HIV transmission or risk before they acquired the virus, even though they had access to and used family planning services. Even when they had knowledge of HIV transmission they did not consider themselves to be at risk, especially if they were married and faithful to their partner. They also perceived themselves as having little control of sex within their relationships. Yet, following their HIV diagnosis and assisted by peer education and support, many women changed this perception and increased their sexual control within their relationships. The part men play in HIV positive women's sexual health is crucial, and the women's stories show that, with appropriate support, men can change as well. The women's accounts show that they continue to have sexual feelings after diagnosis and that many of them continue to have, and to enjoy, sexual relationships.

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[1] Re-infection refers to the risk of becoming infected with a different strain of the HIV virus. It is thought that re-infection may accelerate progression to AIDS by increasing viral load, but medical opinion is divided on this. Many of the women interviewed were aware and concerned about re-infection—so much so that they avoided sex in order to avoid re-infection.

7 Choices in childbearing

7.1 Introduction

This chapter explores HIV positive women's choices about whether or not to have children, and some of the issues that affected these choices. It looks at how women in the study were treated by ante-natal and maternity services. It also looks at the women's views on infant feeding and the alternatives to breastfeeding available to them.

7.2 HIV and pregnancy

Childbirth is an integral part of the lives of nearly all Zimbabwean women but has new implications if you know (or fear) you are HIV positive. The study explored women's views and experiences of pregnancy and childbirth.

Box 7.1 Parent-to-child HIV transmission

HIV can pass from a mother to her baby in pregnancy, childbirth and through breastfeeding. Most children born to women living with HIV are not infected with HIV themselves. Current estimates of the risk of HIV transmission from HIV positive mothers to their babies suggest that approximately two thirds of babies born to mothers with HIV will not be infected with HIV. Of the remaining one third of babies who do have HIV, it is believed that approximately half become infected during pregnancy or at birth and half during breastfeeding. (UNAIDS, 2000:81). Short-course anti-retroviral therapy, such as zidovudine (AZT) and nevirapine, lowers the mother's viral load (the amount of HIV in the blood) and can reduce the risk of HIV transmission in labour and during delivery by as much as half (Healthlink Worldwide 2000: 10, UNAIDS 2000: 82).

There is a greater risk of HIV transmission if the mother has a high viral load, or if her immune status is poor (UNAIDS/WHO 1999). Her viral load will be higher if she has just become HIV positive or shows signs of developing AIDS. In general, good nutritional status, and general health in women (including absence of other STIs such as gonorrhoea, chlamydia or syphilis) is associated with a lower risk of HIV transmission.

All babies are born with their mother's antibodies and it can take up to 15 months to know if the baby is HIV positive or negative by performing an HIV antibody test.

Views about having children

Out of the 209 women who took part in the survey, 64 per cent thought that their community and relatives did not expect HIV positive women to bear children and 89% of this group of women themselves thought that HIV positive women should not have children.

Almost all the women expressing these views were over 25 and had already had at least one child. The feelings of the women in this study around pregnancy and childbearing were influenced by the following concerns (Review workshop):

- Women who already had some children wanted to give priority to these children. They were worried about the economic impact of another child on their household, and the extra burden on their time and energy. They were also concerned that pregnancy and childbirth would affect their health and that their children would be left orphans.
- The personal experience of these women was that the health of women living with HIV deteriorated in pregnancy and that HIV infection had a negative effect on pregnancy outcomes. Twenty-eight women were pregnant when diagnosed with HIV or gave birth after diagnosis, totalling 41 pregnancies in all. Some women had been pregnant more than once since diagnosis. Of these 41 pregnancies, 27 resulted in live births while six ended in miscarriage, eight as stillbirths or neonatal death. Over half of these women reported health problems during pregnancy. Team leaders commented that they had noticed members in support groups who had been well for some time becoming sick either during pregnancy or after delivery, and that babies often died within six months of birth.

There has been limited research on the effect of pregnancy on the health of women with HIV. One review of such research suggests that there is “limited but growing evidence from developing countries that: (1) complications of pregnancy, delivery and induced abortion are more frequent and more severe in HIV positive than HIV negative women, especially those who are symptomatic, (2) pregnancy may contribute to HIV disease progression, immune deficiency and AIDS, in pregnant as compared to non-pregnant women . . .” (Berer 1999: 198; see also Verkuyl 1995). A review of HIV and pregnancy concluded that while pregnancy appears to have little effect on the progression of infection in asymptomatic HIV positive women or those with early infection, there may be more rapid progression in women with late stage HIV. The higher rate of poor health seen in pregnant HIV positive women may be due to women with advanced HIV becoming pregnant with higher rates of complications. Because of their higher viral loads, these women are also more likely to transmit infection to their infants, with poor pregnancy outcomes. Research in Africa has shown higher rates of miscarriage and stillbirth even after controlling for the effect of other infections such as syphilis. [UNAIDS/WHO 1999] Access to good quality antenatal care during pregnancy is important to prevent other causes of poor outcome such as infections, anaemia and high blood pressure.

The negative attitudes displayed by this group of women to childbearing by HIV positive women are striking and could be due to:

- Women in the study were very aware of the risk of HIV transmission to their infants and did not want their child to have HIV.
- The women knew that they had no or limited access to appropriate information, treatment and antenatal care that would protect their own and their babies' health. This includes in particular, access to short-course antiretroviral therapy to reduce the risk of HIV transmission during labour and childbirth, and advice on safer infant feeding.
- Women reported being scolded and shouted at by some health workers for getting pregnant. However, they also reported that nurses were more sympathetic if they had been through counselling training and referred them for family planning and to support groups.

As many women in Zimbabwe are not tested for HIV in pregnancy unless they or their baby shows signs of illness, it is possible that people are only aware of pregnancies and births to HIV positive women whose immune systems have already been weakened by HIV. Women in the support groups had usually been HIV positive for some time. They were more likely to become more ill during pregnancy and to have babies born HIV positive than women in the early stages of HIV whom other people do not realise are HIV positive because they have not been tested and do not show symptoms of HIV/AIDS. Almost all the women who participated in the study were members of support groups and all had known their HIV status for at least a year.

Women's experiences

Fifty-nine women were interviewed in depth. Sixteen of these women (27 per cent) were diagnosed during or following the birth of a sick child. Eighteen women (including six of the 16 above) became pregnant after their diagnosis (see table 7.1). Their decisions about, and experiences of, pregnancy since they knew they were HIV positive are discussed here. Some of these women badly wanted to have a child while others became pregnant reluctantly or by accident. The interviews showed how the women's different feelings about having children reflected their different personal circumstances. We have examined these women's accounts of their pregnancies and classified them into 'wanted' and 'unplanned' pregnancies.[1]

Table 7.1 Wanted versus unplanned pregnancies commenced after knowledge of HIV positive status, by numbers of living children

Living children	Attitude to pregnancy		
	Wanted	Unplanned	Total
0	5	0	5
1	1	0	1
2	1	2	3
3+	0	9	9
Total	7	11	18

Wanted pregnancies

Table 7.1 shows that seven women interviewed had wanted to have a child after they knew they were HIV positive. Of the five women with no living children, four were in new relationships. Two women had a child, but no living children from their current relationship. One woman had two children, but these were from a previous relationship. As the following quote shows, some women really wanted a child for themselves.

> ***'This is my first pregnancy. I would really love to have a child. I have been well informed about the potential problems as an HIV patient but I am prepared to try my luck. I never tried any family planning methods because I wanted a child. I have deliberately not chosen to have an abortion because this could be my only child ever.'***

Other women wanted a child because they were in a new relationship, or because their husband paid *lobola* or just to please their partner. These feelings are not mutually exclusive as Elizabeth's story (see also Chapter 3) illustrates.

Elizabeth became pregnant while she was a teenager. She was very ill during the pregnancy and miscarried. After a slow recovery, she decided to go for an HIV test and was diagnosed HIV positive. Later she married and became pregnant. During this pregnancy she became very ill again and gave birth to a baby who died at nine months. At the time of the interview Elizabeth still had no child and was pregnant for a third time.

> ***'At the moment I am six months pregnant. I had to have a child to please my husband. It is not my choice, my husband paid*** **lobola** ***and he must have a child. I know that if I did not get pregnant he will look for another wife. I also want another child despite the fact that I lost another child to AIDS. I still want to be a mother.'***

Their pregnancy histories show that some of these women were prepared to seriously risk their health to bring a pregnancy to term successfully and have a child who survived. Five women with wanted pregnancies had already lost babies to AIDS, two after multiple stillbirths and neonatal death, yet all of them got pregnant again. Christine's story is an example of such difficulties.

> ***'At first I did not know that I was infected. I was a teenager when I met a man who infected me. He made me pregnant when I was still at school. My first pregnancy ended with a stillbirth. I was very sick during that pregnancy. I had STIs. I got treated, but when I was about six months pregnant, I fell ill again and was admitted to the hospital for two days. I was at the Maternity department and they were monitoring my disease. I gave birth to a dead baby. That was my first pregnancy.***
>
> ***Then I met and married another man who made me pregnant again and I gave birth to a premature baby girl. She was underweight. She nearly died but fortunately, she is still alive. After that I had two stillborn babies and now I'm pregnant again hoping to give birth to a live baby. This time I am taking the AZT[2] tablet.'***

At the time of the study, two of the women were still childless after failed pregnancies or child deaths. One of them who was in her first pregnancy during the study, lost her baby at six weeks old (reported in Review Workshop). The other was Elizabeth (see above) but we did not have information about the outcome of her pregnancy. The other five women now have living children from pregnancies since they were HIV positive but at least one of the children is sick. One woman had been enrolled on an AZT programme; two women described being very sick during their pregnancies; one contracted an STI during pregnancy but was successfully treated for it. Only one woman had a pregnancy with no problems.

Women who chose to have children recognised the risks involved, but these were outweighed by their own desire for a child as the following example shows.

Juliet had lost her first child to AIDS and became pregnant again partly to please her new partner but also because 'the need to have my own child was so great that I decided to take the risk'. Juliet's child is healthy.

> ***'She is a very cheerful child. Sometimes I forget that that I had this child when I knew that I was HIV positive. I hope my child will grow up when I am still alive.'***

The women's stories reveal the strength of feeling behind some HIV positive women's desire to have children. None of them wanted many children, but simply to give birth to and, if possible, raise one healthy child.

Box 7.2 World Health Organization Strategy

The World Health Organisation has recently launched a three-pronged strategy to reduce parent-to-child-transmission of HIV

1. Primary prevention of HIV especially for young women
2. Prevention of unintended pregnancy in HIV positive women
3. Prevention of transmission of HIV from mother to infant during pregnancy, childbirth and infant feeding.

Unplanned or unintended pregnancies

It is a double tragedy for an HIV positive woman to get pregnant when she did not intend to, but also to find that child may be infected with HIV. Women with unplanned pregnancies were in very different situations from those who wanted children. Although their HIV diagnosis affected their wish not to have more children, it was also influenced by the fact that most of them already had several children. The desire to stop having children among married women increases sharply the more children a woman has, regardless of her HIV status (Zimbabwe Central Statistical Office 1995: 89-90). All but two out of the eleven women who had unplanned pregnancies had three or more children, some of whom were already grown up. Three women were in new relationships but had children from previous partners, including one woman who had married her husband's brother.

However, these women were also concerned by other HIV-related issues including the risk of mother-to-child transmission, their lack of access to short-course antiretroviral therapy and the few or no alternatives to breastfeeding available to them. Women who had several living children said that they did not want more children because they were afraid of leaving orphans and wanted to give priority to their existing children. They were also worried about the economic impact of another child on their household. Two women's husbands died while their wives were pregnant.

> ***'We were always careful to use condoms to avoid another pregnancy. We wanted to look after the kids we already have.'***

The women also wanted to protect their own health and did not feel they had the energy to cope with another baby (Interviews and community workshops).

For all these reasons, many of this group of women wanted to prevent further pregnancies or births. This was often very difficult because of lack of access to appropriate contraceptives, lack of control over contraception, and lack of access to safe abortion (see section on abortion below).

Women who were married with several children, particularly in rural areas, often had not used contraceptives before they were diagnosed HIV positive. Three women started using protection only some time after they became aware of their HIV status and conceived before they did so. Only two women were using condoms regularly when they conceived. They described their pregnancies as accidents.

One woman said the condom tore and the other woman said she only once had sex without condoms since she knew her HIV status. ‘It was like foreplay and it resulted in me getting pregnant, but otherwise we always used condoms.’

The remaining seven women were not using condoms at all. Maria (see Chapter 3) used condoms with all her paying partners but not with her regular boyfriend. The other four women said that their husbands refused to use condoms. Two of them seemed to accept this but the others described their husbands as forcing them to have unprotected sex.

Box 7.3 Abortion in Zimbabwe

In Zimbabwe, abortion is only legal if there is a serious threat to the mother’s life or physical health or if the child is likely to be born with a serious handicap, or the pregnancy is the result of rape or incest. While the law does not specifically provide for abortion on the grounds of HIV because it predated the advent of HIV, provision for HIV could fall within the terms of the Act. The Act states that abortions should take place in the first three months of pregnancy but the complicated procedures involved in getting medical permission for legal abortion make it almost impossible.

As a result of the lack of access to safe, legal abortion in Zimbabwe, women who wish to terminate their pregnancies will often have illegal abortions, which may have serious health consequences. In a study of maternal mortality in a rural and urban setting, researchers found that haemorrhage and abortion sepsis were the leading direct causes of maternal death in the rural setting, while abortion was one of three major causes of death in the urban setting (Mbizvo et al. 1993).

Attempts to change abortion legislation in the past have met with fierce resistance from religious institutions, often with funding from fundamentalist American churches. Attempts to clarify the law with regard to HIV as a medical reason for legal abortion have also been resisted and left to the discretion of the medical profession. Within the medical profession, 75 per cent of doctors felt that the present abortion law in Zimbabwe was restrictive and 56 per cent supported change. The main factor determining attitudes to abortion was found to be knowledge of the dreadful consequences of unsafe abortion (Kasule et al., 1999).

Abigail, now a widow, who became pregnant with her sixth child three years after her HIV diagnosis, said,

> ***‘I had problems with my husband who never wanted to use condoms. When I told him (my diagnosis) he just said, “Even if you are like that I cannot use your condoms”. Many times he would force me to have sex. I no longer had much desire for it. I feared re-infection and worsening my health. When I was pregnant, I rarely thought about sex. He would often go mad about it.’***

Since the conclusion of their pregnancies, all but one of these women said that they used condoms regularly, or used dual protection with condoms and oral contraceptives. Only Maria continued to have unprotected sex with her regular boyfriend, but she now also took contraceptive pills to avoid conception and still used condoms with her paying partners.

Many of this group of women also experienced difficult pregnancies. Most became more ill during the pregnancy or afterwards, and four of them gave birth to babies who were sick or died. Four had healthy babies and one woman was still pregnant at the time of the interview. Two women terminated their pregnancies.

Abortion

Nearly two thirds of women in the survey said they would have an abortion for an unwanted pregnancy if it was available, but practical and legal restrictions make this almost impossible.

Five of the women interviewed, whose pregnancies were unplanned, considered having an abortion, but did not do so because it was illegal or not available in

Catholic hospitals. One woman said she would have had to disclose her HIV status to get a legal abortion and, determined to keep her status secret, she preferred to continue the pregnancy.

The only other option was to use traditional medicine, but some women were worried about the risks to their health. Two women who had terminations used traditional medicine and both experienced serious complications.

Juliana became pregnant after her husband raped her.

> ***'When I found that I was pregnant I tried to terminate it but it was not easy. The doctors refused to terminate my pregnancy even though I told them about my HIV status. Another doctor told me to give her Z$3,000, which I did not have at the time. I tried to look for it to no avail. Seeing that I had failed to have an abortion from the specialist, I looked for traditional medicine. I used it and I had an incomplete abortion. I was very sick and was taken to the hospital.'***

The women's experiences reveal that restrictions on abortion in Zimbabwe do not stop women seeking terminations and may lead to dangerous and even life-threatening consequences for mothers, while many other women who do not seek terminations are bearing extra children unwillingly at a risk to their own and the children's health.

Box 7.4 Maternity services in Zimbabwe

Public health services are widely used for ante-natal and maternity care in Zimbabwe, although the quality and availability of facilities varies between urban and rural areas, and between regions, with rural areas in Matabeleland least well served. Over two thirds of women in Zimbabwe give birth in health facilities. Seventy per cent of women giving birth received assistance from medically trained personnel. For 93 per cent of births, women received ante-natal care from a doctor, trained nurse or midwife, though the number of visits to ante-natal services varied. Two thirds of women made their first ante-natal visit at less than six months of pregnancy, and a quarter between six and seven months (Central Statistical Office, Zimbabwe, 1995).

Ante-natal care involves routine examinations to monitor the foetus and the health of the mother. Treatments are offered if abnormalities are detected during any of the investigations. Women are also routinely given iron tablets and folic acid. However, there are charges for ante-natal services, which vary from area to area. Although Zimbabwe has a high coverage of ante-natal clinics, some women may not have access to trained midwives and obstetricians because of the current shortages in health staff. Such women may then be taken care of by traditional midwives—of whom only some have received training in how to conduct safe deliveries. The number of women using traditional midwives is rising because of the current economic problems.

Ante-natal and maternity care

Most women who had been pregnant at the time of diagnosis or since, felt that they had been well treated during their ante-natal and maternity care. However, only three reported being given advice about how to look after their general or sexual health during pregnancy. About a quarter felt that they were not given proper care because of their HIV status. This was also true of women who were diagnosed during pregnancy.

Four women did not disclose their HIV status to health workers in order to avoid exposure and discrimination. One woman said that she did not receive proper care when she gave birth because the health workers were all afraid of being infected with HIV. Another complained that she was criticised by health workers for having a child, despite the fact that her child was conceived deliberately and was much wanted by both herself and her husband.

> ***'The nurses advised me not to have any child again. I gave birth to another child two years later but my husband became ill and died of HIV/AIDS in the same year. The nurses shouted at me why I did not listen to their advice. My child is six years old now. I had her because I wanted a child in my life. If I had died in the process I did not care. The child is healthy and I don't think she is infected.'***

7.3 Infant feeding

Preventing parent-to-child HIV transmission was a paramount concern of all the women who participated in the study but they had little if any information on ways to reduce HIV transmission through safer breastfeeding and lacked access to infant feeding alternatives. Current research in Africa has shown that either exclusive breastfeeding or exclusive artificial feeding has less risk of HIV transmission than mixed breast and artificial feeding. Unfortunately very few women in this context are able to exclusively feed with formula because of the cost of these feeds and also because of the stigma associated with being seen to bottle-feed since this is like "advertising" their HIV positive status. [Nicoll 2000]

Knowledge of HIV transmission through breastfeeding

There has been a good deal of research on the relative risks of HIV transmission to infants from different methods of infant feeding (See Coutsoudis et al. 1999; Nduati et al. 2000; WHO Collaborative Study Team on the Role of Breastfeeding on the Prevention of Infant Mortality 2000; for an overview of issues relating to exclusive breastfeeding see White 1999, Nicoll 2000). There is currently a debate on the merits of exclusive breastfeeding (feeding with breastmilk only, with no other liquids or solids) for the first six months and then weaning abruptly to a breastmilk substitute. As the study was carried out before findings about exclusive breastfeeding became available, women were not asked whether they practised exclusive breastfeeding, or would be able to do so.

Eighty five per cent of women in the survey knew that breastfeeding could transmit HIV to babies and over two thirds thought that HIV positive women should not breastfeed. In focus groups, it was clear that women wanted more information about breastfeeding and breastfeeding alternatives. In principle, many would have liked to avoid breastfeeding because they believed this would be a safer option, though they did not distinguish clearly between breastfeeding substitutes and supplements. However, substitutes were not perceived as a realistic alternative, mainly because of their cost.

In discussions, women reported that all newborn babies used to be routinely breastfed in hospitals but that now HIV positive women were being given advice by antenatal and maternity staff on alternatives to breastmilk and how to prepare them hygienically. Information on locally produced nutritious foods to supplement breastfeeding and for weaning was shared by women in support groups, and one woman in Harare informed herself about baby foods from a book about food for people with HIV/AIDS.

Breastfeeding and the cost of substitutes and supplements

Most women interviewed breastfed their babies for between nine months and two years. Only two women did not breastfeed at all. In one case the mother had a fever and the child refused to suckle, and in the other case the mother was able to afford milk powder and Cerelac (a brand name porridge). A few women said that they breastfed for only a short time, but did not specify how long this was.

The interviews showed that even locally produced substitutes, such as cow's or goat's milk, were unavailable to most women because of lack of money. Many of the women interviewed who breastfed said they did so for reasons of cost. Team leaders felt that breastfeeding alternatives were easier to obtain in rural areas where it might be possible to get free cows milk from people who kept cattle, but some rural women interviewed said that as they had no more cattle they had no alternative but to breastfeed. Straight animal milk is not appropriate as a substitute feed in early infancy but needs boiling, diluting and mixing with sugar to approximate it to the consistency of breastmilk and to make it digestible for the immature bowel of an infant.

Duration of breastfeeding was also affected by the cost of weaning foods. One woman was diagnosed when her baby was eight months old and advised to substitute with foods such as *sadza* (maize porridge), peanut butter, one egg per week and other 'readily available foods'. However, she did not have enough money for this and could not even afford sugar for porridge. Women who had some financial support also breastfed, but could do so for a shorter period because they were better able to afford substitute foods.

Stigma and not breastfeeding

The fear of stigma from not breastfeeding was discussed in the community workshops but was not mentioned by any of the interviewees. Women in focus group discussions made the point that there have always been women who did not breastfeed for a variety of reasons, such as women having sores on their breasts, their milk drying up, or babies refusing to suckle. However, traditional explanations of such problems were almost always negative, including women being mentally ill, being possessed by an evil spirit, having breast cancer, having lied about their baby's paternity, or being unfaithful. All such explanations reflected badly on the woman concerned and stigmatised women who did not breastfeed. HIV could be one more stigmatising explanation.

The women in the focus group discussions said that nowadays there were new reasons for women not to breastfeed, particularly if they were employed or were advised not to breastfeed by a doctor. Not breastfeeding was less likely to involve 'involuntary disclosure' for a working mother, as people might think she had chosen not to breastfeed or that she could afford formula, but poorer women who did not breastfeed were more likely to be stigmatised.

In practice, cost as well as stigma limited HIV positive women's infant feeding choices. They had very little choice at all, since most of them could not afford formula milk and even fresh cow's milk or other baby foods were not options for most of them. As a result they were forced to continue breastfeeding, often for longer than they would have wished or were advised. They also did not have access to advice on how to practice 'safer' breastfeeding, such as by exclusive breastfeeding, getting early treatment for breast problems such as inflammation or infections, and treatment of mouth sores in babies. [for more on 'safer breastfeeding' see Humphreys and Iliff 2002]

7.4 Conclusion and summary

Many women in the study had wanted or had unplanned pregnancies after their HIV diagnosis. The study showed that, whatever their childbearing preferences, the women in the study did not have access to the information or services they needed in order to exercise them. Some women, usually women who had been married for a long time and already had several children, did not want to have more children. However, it was often difficult for them to control their fertility because of lack of access to and control over contraceptives, and lack of access to safe abortion. Other women, mostly young women or women within new relationships, who had only one or no children, had a strong desire to have a child. Whether a woman wanted a child after she was diagnosed depended far more on whether she already had children or was in a new relationship, than on her HIV status. None of the women in the study had easy access to the information they needed to make an informed choice about childbearing or access to information or appropriate services to safeguard their own or their babies' health.

The women who participated in this study were deeply concerned about the role of breastfeeding in transmission of HIV to infants and the focus group discussions suggested that, especially with peer support, they would be able to confront stigma attached to not breastfeeding. However, the cost of alternative infant feeding alternatives remained a major barrier to exclusive and consistent use.

Nyaradzo, Anatolia and Joyce M during the advocacy workshop

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[1] Because of the complex conceptual difficulties involved in the notions of both 'planned' and 'unwanted' pregnancies, we have categorised pregnancies as either 'wanted' or 'unplanned' since unplanned pregnancies are not necessarily unwanted (Trussell, Vaughan and Stanford 1999, Fisher et al. 1999).

[2] Christine was enrolled in a pilot programme that offered short-course antiretroviral therapy in pregnancy. Her baby was born after the end of the study and is well.

8 Conclusions and recommendations

This chapter presents conclusions and recommendations that emerge from the research findings. Many of these recommendations are linked and some deal with issues that are being addressed by women's advocacy groups.

8.1 Reproductive and sexual health

Most of the women who participated in the study had little or no knowledge of HIV transmission or risk before they acquired HIV, even though they had access to and used family planning services. They had heard of HIV and AIDS but they had not thought that they were at risk of infection. Many of the women associated HIV with particular social groups such as sex workers, rather than with sexual behaviour. Many appeared not to have questioned whether their own or their partner's current or previous sexual behaviour could put them at risk. In particular, married women and women in long-term relationships, who only had one partner, did not perceive themselves to be at risk of infection.

There was also a high prevalence of STIs in the study population. The presence of an STI significantly increases the risk of HIV transmission as well as having negative effects on women's health and pregnancy outcomes.

Once women knew that they were HIV positive, it was difficult for them to access reproductive and sexual health services because of the widely held perception that HIV positive women should not engage in sexual activity. However, the women's accounts show that they continue to have sexual feelings after diagnosis and that many of them continue to have and to enjoy sexual relationships, adding to the quality of their lives.

Some women in the study, particularly younger women who did not have any children, had a strong desire to become mothers and chose to become pregnant. These women were often confronted by negative and scolding attitudes towards them from health care workers, their community and other women. Women in the study balanced their feelings about their current relationship and their desire for children against the potential risk to themselves and their babies. They did this balancing act without adequate support or information to make rational decisions for themselves or their children, and often bore the consequences in isolation.

Most women in the study with several children stressed that they wanted to avoid pregnancy, but that they were often unable to do so because of poor access to effective contraception including emergency contraception and female condoms, because of poorly supplied family planning services and prejudicial attitudes on the part of health workers related to their HIV status and sexuality. They were also denied access to abortion facilities through ignorance and prejudice from health staff. Several women in the study were unable to terminate pregnancies despite a wish to do so, and two women suffered complications from self-administered abortive herbal preparations. Under current legislation in Zimbabwe, abortion could be deemed legal for HIV positive women on health grounds. In practice the study showed that HIV positive women are unable to access abortions in most health facilities because of their own ignorance of the law and that of health workers. Women's fear of disclosure of their HIV status, which would make them eligible for legal termination, further constrains their application for abortion services.

The women who participated in this study were deeply concerned about the contribution of breastfeeding to HIV transmission to infants. Intensive public education on prevention of HIV transmission from parents to infants only started in Zimbabwe after the study was completed. The policy in Zimbabwe, as with many high HIV prevalence developing countries, was to promote breastfeeding regardless of HIV status. The women knew this contradicted the advice given to HIV positive mothers in rich countries and their anxieties were often based in not knowing what to do for the best for their babies. The study findings suggested that with support, they would be able to overcome the stigma attached to openly giving artificial feeds. However, cost of substitute feeding remained an important constraint. Research has now shown that exclusive breastfeeding and exclusive artificial feeding carry similar levels of risk of HIV transmission, that mixed breast and artificial feeding carries the highest risk. The advice is to do one or the other but not both [WHO 2001].

These findings suggest the need for:

- ➢ More intensive public campaigns to remove the stigma and discrimination faced by HIV positive people particularly in relation to their sexuality which should be seen as a fundamental human right.
- ➢ More intensive education and training for health workers in the public and private sectors to provide advice and services in confidential, non-discriminatory and respectful ways for HIV positive women and men, from a client centred perspective rather than imposing personal prejudice and ignorance.
- ➢ More effective public and personal communication on HIV and safer sex that associates HIV with risk behaviour and not with particular social groups, and helps people to have a better understanding of personal risk
- ➢ Reproductive health services to provide support and information specifically targeted at HIV positive women to support them whether they want to get pregnant or if they want to avoid pregnancy. For this, health workers have to better informed themselves, requiring

advocacy at all levels of the health service. Advice is needed on the impact of pregnancy and breastfeeding on HIV positive women's own health, treatment of STIs, safer conception for discordant couples, the risks of HIV transmission to infants during pregnancy, childbirth and infant feeding. The various ways to reduce these risks have to be discussed, from condom use during pregnancy to prevent reinfection with HIV or other STIs, short course antiretrovirals, adapted obstetric practices during labour including vaginal swabbing and elective caesarean sections, as well as intensive support to women to either exclusively breastfeed or exclusively artificially feed their infants.

- Improved advice and access to free, legal, safe and confidential abortion services for HIV positive women.

- STI-related services (including HIV-related services and education) to be more closely linked to family planning services and more accessible to all sexually active Zimbabweans.

- Increased advice and access to male and female condoms, and other forms of contraception and protection including emergency contraception. HIV positive women could work with community-based distributors and clinics to include HIV education in contraception advice and distribution.

- Greater provision of services for men within these integrated sexual and reproductive health services.

8.2 Counselling and testing, care and support

The women described feelings of shock, fear and hopelessness after receiving their HIV diagnosis. Most women in the study were offered little information about HIV before they were diagnosed and the decision to test was taken more often by a health care worker than by the women themselves.

More women in the study received some form of post-test counselling and this was reported as having a positive impact on the women interviewed. A few women received counselling with their partners and this was perceived as beneficial and possibly helped couples to cope with their HIV diagnosis.

Women in the study were clearly distressed by the discriminatory attitudes and behaviour of health care workers. A few women avoided such discrimination by not disclosing their HIV status to health workers in ante-natal clinics and maternity services, although this was not possible if they were seeking treatment for opportunistic infections. It also meant that they could not get care appropriate to their reproductive health needs. In the community workshops, health staff responded sympathetically to complaints by HIV positive women and offered to deal with cases of discrimination that were drawn to their attention. The study also revealed widespread use of traditional healers because of their more sympathetic approach.

The study demonstrated that HIV diagnosis had a dramatic impact on women's relationships. Disclosing one's HIV status to partners or close relatives was extremely daunting and difficult for most of the women in the study. There was great fear of rejection by partners and families in-law. Many women were treated unfairly by their partner's family, particularly after the partner's death. Married couples, more than people in informal relationships, usually stayed together but it was not easy for relationships to survive a diagnosis. Some couples were helped by counsellors and HIV support groups. Support groups were also a vital source of emotional and practical support for most of the women involved in the study. HIV positive women need ongoing support, especially from other positive women, to help cope with relationship change and other problems stemming from an HIV diagnosis. Support groups are an important advocacy resource at local and national level since they are most directly in touch with the needs of their participants.

These findings highlight the need for:

- Improved access to good pre-test counselling to ensure that women understand the test and can make informed decisions whether to go for testing.
- Improved access to good post-test counselling to ensure that women who are diagnosed as HIV positive have support to help them cope with their diagnosis, and that women who are diagnosed as HIV negative are encouraged to practice safer sex.
- Voluntary counselling and testing [VCT] sites to proactively discuss contraception, pregnancy and prevention of parent to child transmission with all young people attending for VCT.
- Approaches to counselling and testing that reduce stigma and discrimination; this includes research into couple counselling and group education, and increased training and resources to expand counselling services.
- Further education and training about HIV among health care workers, including sessions to address their own HIV-related fears and values.
- A more inclusive approach to HIV care and support that would recognise the different support needs of those reluctant to join support groups, such as professional men and women, health care workers and community leaders.
- Comprehensive HIV-related training for traditional healers and inclusion of traditional healers into HIV programmes where possible.
- Further research into traditional treatments for reproductive and sexual health, including HIV and AIDS.
- Further research on ways to assist HIV support groups and their members so that they can meet the huge emotional and practical demands made of them.
- Negotiation and public education with community leaders, women's groups and religious leaders to explore ways to reduce the stigma and discrimination towards HIV positive women from their in-laws.

8.3 Livelihoods

Poor women were further impoverished by the impact of HIV as illness and death reduced household income and increased expenditure. Gender inequality, including women's lack of rights to land and property, had a significant impact on women in the study. The study did not specifically investigate the relationship between poverty and women's health, yet it is clear that the reproductive and sexual health of the women who participated in the study was compromised by poverty. For many women, sexual relationships were an important means of achieving better economic security, whether selling sex for money or goods in kind, or through long-term relationships with men.

These findings suggest the need for:

- Partnering with women's organisations already campaigning for better access to land and property rights, review of inheritance laws and advocacy at the community level to particularly take note of the impact these have on HIV positive women.
- Strategies designed to increase women's financial independence—such as micro-credit schemes, financial support for carers unable to work—and to keep children, particularly young girls, in education.

8.4 Impact on participants

The Voices and Choices project has shown that HIV positive women deal actively with the consequences of their diagnosis, often in very difficult situations. The growth of HIV support groups has provided a framework for women to learn about HIV and related health issues, and in many cases to become more assertive of their rights. The project also shows that the solidarity and knowledge women get from sharing their common experiences can enable them to become valuable peer facilitators, not just with other HIV positive women, but also with adolescents, older people, traditional community leaders and local health workers.

The project was especially valuable as a process of peer-facilitation and in raising the profile of HIV positive women in their communities. It has had a great impact on the team leaders and they will need ongoing support to carry out their new roles successfully. The project has also been educational for members of support groups and other individuals who have been involved with it.

However, the project planning underestimated the amount of support and counselling that the team leaders would need in order to deal with the highly emotional nature of the interviews and the death of HIV positive women involved in the study. Future projects should identify the practical and emotional needs of project participants related to the projects, so that these can be addressed.

8.5 Limitations of the project methodology and lessons learnt

The project achieved its goals in enabling HIV positive women to carry out their own research on their reproductive health needs, following this up with feedback to their groups and developing advocacy plans. Very valuable insights have accumulated as a result of this process that will inform future advocacy campaigns, benefiting many women living with HIV and AIDS. However, by virtue of the participants coming from support groups who are self-selected groups of women, there were groups of women with specific reproductive health needs related to HIV that were excluded. The main limitations of the study were therefore the lack of representation in the study of young women (under 25) and women living with HIV who were not in support groups. Recognising these limitations gives indications of what further research questions remain particularly concerning young women, probably requiring alternative methods of enquiry. As the advocacy campaigns from this piece of research develop, there will be ways of accumulating experience of other HIV positive women on an ongoing basis through personal testimonies, extending peer facilitation to other groups of women such as university students and professional women, networking with other women's organisations. As the project chose to target women, the experiences and attitudes of men were not explored, although the women commented on men's behaviour. It is also important to understand how men feel about their own diagnosis and the impact this makes on their relationships and their feelings about parenthood.

In the original protocol, research and advocacy were practically and conceptually separate. In practice, participatory research creates a sense of increased control over the issues raised, and fuels a desire for change. The *process* of research is therefore part of the advocacy process, whether it is advocacy to individuals in terms of informing them of their rights and assisting them in challenging various forms of oppression, or advocacy to groups as took place in community workshops. A critical achievement of the process in this study was to increase the team leaders' sense of pride and self-efficacy both in their own eyes and in the eyes of their communities. Moreover, the review workshop showed that as issues are better understood, further research may be necessary for more effective advocacy.

These findings suggest the need for:

➢ Further research into the reproductive and sexual health needs of women under 25 years old.

➢ Similar participatory research into men's HIV-related reproductive and sexual health needs.

➢ More studies of this kind, which encourage the active participation of communities affected by HIV and link research to promoting change.

Positive women rarely have the opportunity to express their opinions and feelings but without them, any response to the HIV pandemic is incomplete. The shared experiences of women in this project have increased understanding of the impact of HIV at a personal level and highlighted the need to develop a gendered response to the needs and dreams of women with HIV.

Birchenough Bridge support group women learn participatory methods during community feedback sessions

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This book is the result of a project documenting the reproductive and sexual health experiences of HIV positive women.

The book is intended to provide information that HIV positive women and AIDS Service Organisations can use in advocating for changes in policies and practices so as to improve the reproductive and sexual health choices available to women living with HIV and AIDS. It presents the findings of a study of Zimbabwe.

This book:

- Examines the sexual and reproductive health of women living with HIV and AIDS
- Explores issues of testing and counselling
- Surveys the economic and social problems of women living with HIV and AIDS.

The book links the findings and recommendations from the research project to advocacy strategies for increasing the reproductive and sexual health choices available to women living with HIV in Zimbabwe.

Chapters include:

- Dealing with an HIV diagnosis: women's experience of testing and diagnosis
- Changing relationships and livelihoods
- Women's experiences of health services
- Exploring sexual and reproductive health
- Choices in childbearing.

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