A CRITICAL ETHNOGRAPHY OF HIV-POSITIVE WOMEN ATTENDING PUBLIC HEALTH CARE FACILITIES IN GAUTENG

by

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DECLARATION

I, Gretchen Erika du Plessis, hereby declare that the thesis, *A critical ethnography of HIV-positive women attending public health care facilities in Gauteng,* is my own work and that, to the best of my knowledge and belief, it does not contain material previously submitted for assessment to any other institute of higher learning for any other degree or diploma. I declare that all the sources that I have quoted have been indicated and acknowledged by means of complete references.

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This thesis is dedicated to all women living with HIV in South Africa. I also wish to dedicate it to the loving memories of my mother, Fransie and my brother, Hennie.

TABLE OF CONTENTS

Page number

TABLE OF CONTENTS (Continued)

Page number

TABLE OF CONTENTS (Continued)

Page number

TABLE OF CONTENTS (Continued)

Page number

TABLE OF CONTENTS (Continued)

Page number

TABLE OF CONTENTS (Continued)

Page number

LIST OF TABLES

Page number

LIST OF FIGURES

Page number

SUMMARY

Women living with HIV have a variety of reproductive health and psychosocial needs. The purpose of this critical ethnographic study was to examine how HIV, empowerment and reproduction are experienced by a volunteer sample of HIV-positive women attending public health care facilities in Gauteng. Feminist and critical approaches were used to guide the methodology of the research and the interpretation of the findings. Data were collected through in-depth interviews and observation.

An overview of literature pertaining to the social construction of HIV-AIDS, women’s empowerment and reproductive decision-making is presented. A discourse of “healthy lifestyle” as technologies of the self is considered. Women’s empowerment as an ideal is described and structural barriers to its achievement are discussed. Stigma and discrimination as products of hegemony are discussed as important issues in the disempowerment of women living with HIV. HIV-AIDS as illness experience is reviewed with reference to the social context and to the individual context. Reproductive decision-making models and theories are critically analysed for their applicability to women living with HIV. The need for a conceptual shift in the notion of empowerment in order to understand constrained decision-making for women living with HIV is propagated.

The stories of women living with HIV and dependent on public health care services are presented. Through the principles of a critical ethnography the lived experiences of these women are described by means of emerging themes. A historiography of family planning and HIV-AIDS services throws the narrations of the research participants into broader historic relief.

Findings revealed that biomedical hegemonic power contoured and marked the lived experiences of women following an HIV-positive diagnosis. Taken-for-granted views of passivity and of own responsibilities regarding reproductive health are challenged. The women in the study were dependent upon public health care personnel for treatment, testing, dietary advice/supplementation and recommendations for a social disability grant. ARV-treatment was regarded as a low point in the illness career. All of the participants reported that the overriding problems in their lives were having too few material resources and not having the means to change this. This made them vulnerable to compounded health problems and decreased their ability to voice their own opinions about treatment. They did not regard themselves as having been at risk for contracting HIV and some harboured resentment towards men who were seen as being absolved from testing and responsibilities towards female partners, born and unborn children. Women who were not tested as part of antenatal sentinel groups tended to suffer symptoms of ill health for some time prior to being tested for HIV.

Social support systems were either absent or consisted of trusted family members and friends. In many cases, women became the silent care-givers for those affected and infected by HIV. Anticipated stigma permeated the participants' narrations of living with HIV and disclosure of their statuses was difficult. The use of male condoms, stressed during counselling sessions, was narrated as a difficult burden for women to bear. Although the research participants expressed low fertility preferences, HIV-AIDS was seen as disrupting the link between heterosexual conjugal relations and the taken-for-grantedness of procreation. HIV-AIDS also disrupted norms in infant feeding practices and bottle-feeding was regarded as a sign of possible HIV-infection and hidden.

The research participants were not empowered with knowledge about how to deal with side-effects, condom failures and the reluctance of male partners to be tested for HIV. They enacted, resisted and lived with HIV in different ways, incorporating some of the biomedically prescribed posturing as women living positively and blending it with stigma-negating performances and gender-prescribed ways of dressing, walking and acting. Participation in a support group validated their experiences and promoted positive self-perception. The formation of a collective voice in the support group was hampered by irregular attendance, the interference of community leaders and horizontal violence. Power relations, yielded by biomedical hegemony, androcentric sociocultural practices, material deprivation, fear, discrimination and stigma potentially undermined the women's abilities to become empowered. Expansion of choices in various spheres or fields and collective action are proposed as dimensions to be added to an empowerment-of-women approach to the problems of reproductive health in the age of HIV-AIDS.

The contribution of the study as an emancipatory project is evaluated and implications for policy and practice are suggested. On a methodological level, this study is a demonstration of the contribution to be made by a micro-level, critical analysis to the body of knowledge about female reproductive health in the era of HIV-AIDS in South Africa. On a theoretical level, this study contributes to a wider conceptualisation of women's empowerment by recognising the interplay between micro-level elements of situated experience, knowledge and preferences and the macro-level elements of sociocultural, biomedical and material influences on health and reproductive behaviour.

Key words – biomedical hegemony, critical ethnography, empowerment, HIV-AIDS, South Africa, women.

LIST OF ACRONYMS AND ABBREVIATIONS

ABC	Abstain, be faithful and condomise
AIDS	Acquired Immunodeficiency Syndrome
ANC	African National Congress
ARV	Antiretroviral
CBO(s)	Community-based organisation(s)
CD4	“Helper” T-lymphocytes in human blood. A count of less than 200 CD4-cells per cubic millimeter of blood (or where the CD4-cells are less than 14 per cent of all lymphocytes) and the presence of HIV are diagnostic indicators for AIDS.
CDC	Centres for Disease Control and Prevention (USA)
CEO	Chief executive officer
CMV	Cytomegalovirus
CPS(s)	Contraceptive Prevalence Survey(s)
DHS(s)	Demographic and Health Survey(s)
DoH	Department of Health
EAP	Employee Assistance Programme
ELISA	Enzyme-linked-immunosorbent assay
GEAR	Growth, Employment and Redistribution Strategy
GRIP	Greater Nelspruit Rape Intervention Project
HIV	Human Immunodeficiency Virus, the etiologic agent for AIDS
HSRC	Human Sciences Research Council
HSV	Herpes simplex virus
ICPD	International Conference on Population and Development
IEC	Information, Education and Communication
KABP	Knowledge, attitudes, behaviour and practices
MAC	Mycobacterium avium complex
MDR TB	Multi-drug resistant tuberculosis
MRC	Medical Research Council
MTC	Mother-to-child-transmission (of HIV)
NACOSA	National AIDS Convention of South Africa

LIST OF ACRONYMS AND ABBREVIATIONS continued…

NAPWA	National Association of People Living with HIV-AIDS
NFPP	National Family Planning Programme
NGO(s)	Non-governmental organisation(s)
PDP	Population Development Programme
PEP	Post-exposure prophylaxis
PID	Pelvic inflammatory disease
PLWHA	People living with HIV and AIDS
PTCT	Parent-to-child-transmission (of HIV)
RTI	Reproductive tract infection
RDP	Reconstruction and Development Programme
SADHS	South African Demographic and Health Survey
STI(s)	Sexually transmitted infection(s)
TAC	Treatment Action Campaign
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VCT	Voluntary HIV Counselling and Testing
WFS	World Fertility Survey
WHO	World Health Organisation
XDR TB	Extensive drug resistant tuberculosis

CHAPTER 1

PERSPECTIVES ON THE RESEARCH ISSUE: HIV-AIDS AND REPRODUCTIVE HEALTH IN SOUTH AFRICA

PREAMBLE

As is often the case with social researchers, this study originated from personal history and experience. Whilst working at the Human Sciences Research Council (HSRC) in the late 1980s, I was involved in a large-scale demographic and health survey in which 22 000 randomly sampled women were interviewed. One of the themes explored in this survey was fertility preferences and I analysed this intensively. In 1998 the Department of Health (DoH) undertook the first official nationwide South African Demographic and Health Survey (SADHS) and, due to my involvement in the theme of fertility preferences, I was invited to assist the DoH in preliminary analysis of fertility preference and the unmet need for family planning from the SADHS. I again analysed the data for another round of the SADHS in 2003. At the same time, I became involved in volunteer work for people living with HIV, was trained as a lay counsellor, attended a university course on how to integrate HIV-AIDS into university curricula and started lecturing in postgraduate courses on the social and behavioural aspects of HIV-AIDS.

Exposure to these issues made it clear to me that fertility trends and patterns in South Africa are characterised by two related issues: The first is a sustained fertility transition that is unmatched in the rest of sub-Saharan Africa (Moultrie & Timaeus 2002: vii & 26; Potts & Marks 2001) and the second is the devastating and ineradicable presence of HIV-AIDS morbidity and mortality (Varga 1997:46).

At first glance, the two issues seem almost incongruous. A transition in fertility to a lower completed family norm is assumed to co-exist with high levels of female empowerment and with free, rational decision-making regarding family building (Mason & Smith 2001 & 2003; Riley 1997a). By contrast, a context fraught with a rampant HIV-AIDS epidemic seems to suggest reproductive lives burdened with risk.

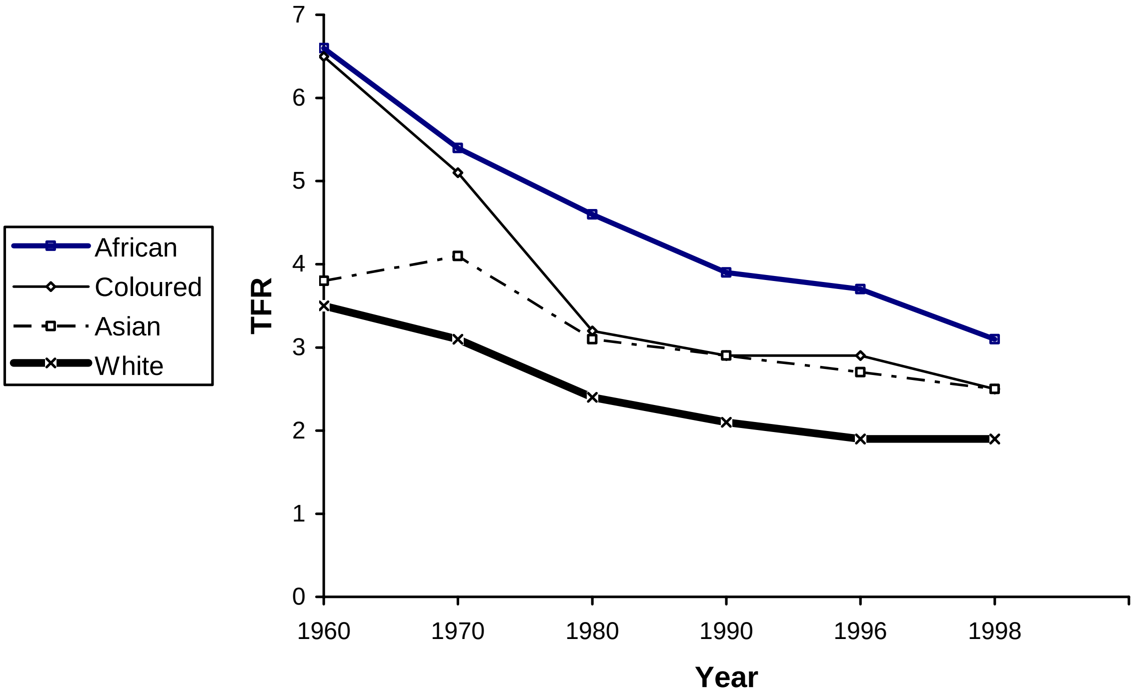
The quantitative analyses of fertility preferences are unable to offer answers to the question how an event that will forever change a woman's reproductive future (such as becoming HIV-positive) may influence her thinking about and representation of her own reproduction. This study is an attempt to develop a critical sociological understanding of reproductive episodes (pregnancies, births and actions to avoid, postpone or stop such events) amongst women who are faced with the reality of HIV-AIDS in their lives. This implies moving beyond the biological issues of HIV-AIDS and the polemic surrounding antiretroviral treatment[1] in South Africa. It is difficult to untangle the web of forces linking HIV-AIDS and reproductive life in South Africa, because the dynamics of sexual negotiation and decision-making and the role played by historical-political, sociocultural, economic and ideological factors in such dynamics are not well understood. In South Africa's third decade of a sustained fertility transition and second decade of AIDS and after much deliberation, conferencing and research, researchers are hardly closer to unravelling the complex interconnections between HIV-AIDS and fertility. It is my intention to show how the active disempowerment of women in South Africa has contributed to the context of risk in reproductive health (see Chapters 4 and 5). Furthermore, it has rendered HIV-positive women in their prime reproductive years with confusing and inadequate information to deal with HIV as a chronic condition. As Shiraz Ramji (1998:2) justly points out, although the democratic South Africa has a constitution[2] that unequivocally affords pregnant women protection against discrimination, and although women's participation in politics are much greater than ever before, public debates on reproductive rights are largely limited to women's organisations, television events or women's magazines.

1.1 A FERTILITY TRANSITION IN THE MIDST OF REPRODUCTIVE RISK – BUT IN

THE ABSENCE OF THE EMPOWERMENT OF WOMEN

South African fertility is currently stabilising at a level close to replacement (TFR at 2,43 for an estimate in 2001 by Moultrie and Timaeus or 2,9 as estimated from the SADHS in 1998) - the lowest in sub-Saharan Africa (see Figure 1.1). Despite three decades of fertility decline, however, South Africa still has a young fertility burden with one sixth of all births to women in the 15- to 19-year-old age group (Moultrie & Timaeus 2002:ix. Refer to Figure 1.2). African fertility declined from an estimated TFR of 7 in 1955 to 5 in 1970 and to 3,1 in 1998.

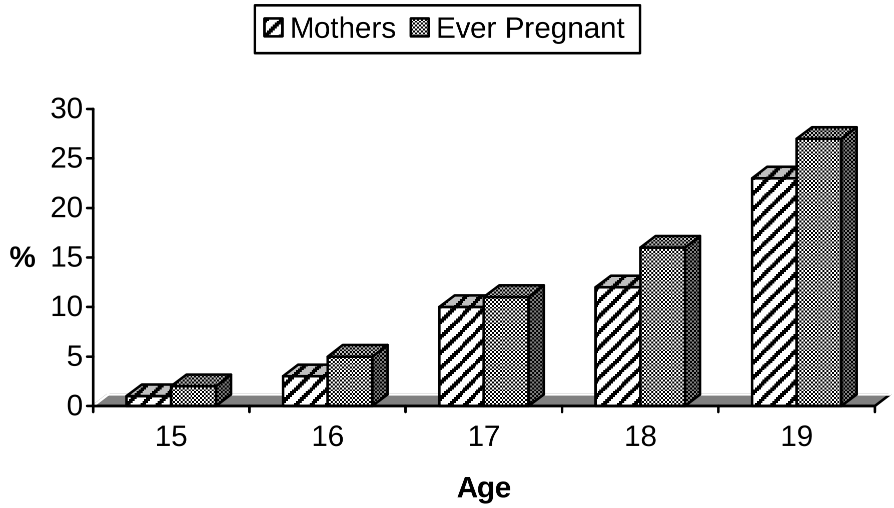
Figure 1.1: Estimates of total fertility rates by group[6], South Africa 1960-1998



(Source: South African Government, Dept of Social Development 2000:42)

Figure 1.2: Per cent women, 15-19 years who are mothers or who have ever been

pregnant, South Africa 2003[3]



(Source: South African Government, DoH 2004b:8[3])

The high rate of teenage childbearing in South Africa is a cause for concern for the educational achievement of young women, but it also raises the alarm for the trajectory of the AIDS epidemic in South Africa in the future (The Transitions to Adulthood Study Team 2004:7). The low contraceptive use and high rate of childbearing amongst sexually active teenagers in South Africa have many causes, such as:

- A lack of recreational facilities for previously disadvantaged youths that encourages sex as recreation
- A desire amongst adolescents to bear children in order to achieve the status of an adult woman
- A desire to prove love and fidelity or to gain a binding relationship with a boyfriend
- A desire to prove good health, fecundity[4] and the absence of infections
- Lack of adolescent-friendly family planning facilities, including the attitudes of health workers towards teenagers seeking contraception

- Poor perceived susceptibility to conception or infection with a sexually transmitted infection (STI)
- Power differentials between teenage girls and boys which means that sexual relationships are characterised by coercion or gifts or favours granted in exchange for sex (including the so-called sugar daddy phenomenon)[5]
- Logistic problems in attending family planning facilities (Kaufman, Clark, Manzini & May 2002; Kaufman, de Wet & Stadler 2000; Kaufman & Stavrou 2002; Preston-Whyte *et al* 1990; Rutenberg, Biddlecom & Koana 2000; Rutenberg *et al* 2002; The Transition to Adulthood Study Team 2004; Varga 1997; Varga & Makubalo 1996).

In addition, the fertility transition in South Africa is marked by a substantial increase in the birth intervals, from a mean interval of 30 months in 1970 to a mean interval of 50 months in 1996 (Moultrie & Timaeus 2002:viii & 42-44). Combined with the abovementioned trends in teenage childbearing, it seems likely that a young woman's first introduction to contraceptive use happens when she is pregnant and attending antenatal and postnatal visits to a primary health care facility. This increases opportunities of contraceptive acceptance on both the demand and the supply sides in that the young mother will be educated in the benefits of child spacing, be given a method of contraception in a setting that can be regarded by all concerned as "legitimate" (more so than contraceptive use amongst an unmarried teenager who has never been pregnant) and be enabled to attend a clinic. This will go some way in explaining the trends in large birth intervals amongst South African women.

As far as fertility preferences are concerned, analyses from the South African Demographic and Health Survey (SADHS) of 1998 revealed that South African women have fairly low fertility aspirations (see Table 1.1, 1.2 and 1.3). It was possible to calculate from the data the proportion of sexually active women of reproductive ages, not using contraception but

Table 1.1: Per cent women with an unmet need for family planning services,

South Africa, 1998*

Background characteristic	Unmet need for family planning			Number of women
	For spacing	For limiting	Total	
Age				
15-19	25,0	1,2	26,1	73
20-24	12,8	5,3	18,1	465
25-29	7,0	6,0	12,9	900
30-34	4,2	9,0	13,2	1 008
35-39	2,6	12,3	14,9	1 114
40-44	2,2	12,3	14,6	865
45-49	0,9	16,7	17,6	652
Residence				
Urban	2,8	8,1	10,9	3 038
Rural	7,5	13,5	21,0	2 039
Education				
No education	6,2	19,1	25,3	518
Grade 1 -5	7,3	12,6	19,9	739
Grade 6 -7	4,5	13,6	18,1	762
Grade 8 -11	4,8	8,7	13,5	1 876
Grade 12	3,0	6,7	9,7	748
Higher	1,1	3,3	4,3	434
Group[6]				
African	5,9	12,4	18,3	3 628
Coloured	2,4	6,0	8,4	553
White	0,7	4,0	4,6	615
Asian	0,7	4,9	5,7	250
Group[6]				
African urban	3,8	10,4	14,2	1 810
African rural	8,0	14,3	22,3	1 818
Total (currently married)	4,7	10,3	15,0	5 077
Not currently married	2,8	3,0	5,7	6 658
All women	3,6	6,1	9,7	11 735

(Source: SADHS 1998)

* Weighted, corrected and comparable data from the 2003 SADHS were not available to the author.

at the same time, expressing a desire to either avoid further or future childbearing or to better space their future births. This construct is commonly referred to as the proportion of women of reproductive ages who have an unmet need for family planning.

Fifteen per cent of currently married South African women have an unmet need for family planning. The corresponding proportions for all women are 10 per cent and for unmarried women 6 per cent.

Table 1.2: Planning status of births in the five years preceding the survey, according to birth order and mother's age at birth, South Africa 1998* (% of births)

Birth order and mother's age	Planning status of birth (includes current pregnancy)					Number of births
	Wanted then	Wanted later	Wanted no more	Missing	Total	
Birth order						
First	38,6	51,8	8,3	1,3	100,0	1 794
Second	53,6	31,7	13,5	1,2	100,0	1 336
Third	54,6	27,4	16,9	1,1	100,0	834
Fourth and higher	42,1	23,5	32,5	1,9	100,0	1 430
Age at birth						
< 19	20,2	65,8	12,5	1,6	100,0	900
20-24	42,9	44,2	11,7	1,2	100,0	1 410
25-29	57,4	28,4	12,9	1,3	100,0	1 279
30-34	57,2	21,5	20,2	1,1	100,0	988
35-39	49,4	14,1	35,2	1,3	100,0	612
40-44	38,9	20,4	35,4	5,3	100,0	187
45-49	37,7	19,3	43,0	0,0	100,0	28
Total	45,7	35,5	17,3	1,4	100,0	5 404

(Source: SADHS 1998)

* Weighted, corrected and comparable data from the 2003 SADHS were not available to the author.

Moreover, the SADHS results revealed that more than a third (36%) of recent births to South African women was reported as mistimed. Almost one in every five births (17%) was not wanted at all. These findings are profound indicators of the extent of fertility control failures in South Africa. The figures for unwanted and mistimed pregnancies are high for South Africa when compared with DHS-results for other African countries: for example Zimbabwe 34% mistimed and 10% unwanted, Namibia 21% mistimed and 12% unwanted (Du Plessis 1999).

Table 1.3: Comparative figures for total wanted fertility rates and total fertility rates, South Africa and selected sub-Saharan countries

Country/Group	Total wanted fertility rate	Total fertility rate
South Africa, 1998*	2,3	2,9
Cameroon, 1997	5,2	5,9
Ghana, 1997	4,2	5,2
Kenya, 1997	3,4	5,3
Nigeria, 1997	5,8	6,1
Rwanda, 1997	4,3	6,1
Senegal, 1997	5,0	6,0
South Africa, 1998* by group[6]		
African	2,4	3,1
Coloured	2,1	2,5
White	1,5	1,9
Asian	1,5	1,8
South Africa, 1998* by group[6]		
African urban	1,9	2,3
African rural	3,0	4,0

* Weighted, corrected and comparable data from the 2003 SADHS were not available to the author.
(Source: Demographic and Health Surveys 2002)

At the launch of the State of South Africa's Population Report (South African Government, Dept. of Social Development 2000) on the 15th of September 2000, Jacques van Zuydam, the head of the National Population Unit claimed that fertility transition in South Africa took place in the absence of significant empowerment of women. In the aforementioned Report it is stated that: *"There is general agreement that fertility began to decline among all major* *population groups in South Africa during the apartheid era. This occurred amidst the impoverishment of millions (especially African women), stark inequalities and the disempowerment of women"* (South African Government, Dept. of Social Development 2000:40).

The summation of an empowermentless fertility transition in South Africa bears witness to the success of the family-planning programmes under the apartheid regime to lower fertility, but the same cannot be said of the programme's successes in respect of the ICPD's (the International Conference on Population and Development, Cairo, 1994)[7] emphasis on empowerment of women. In fact, what does fertility transition within a context where actual female empowerment is lacking, mean? In this respect, the study by Mason and Smith (2001 & 2003) in Pakistan, India, Malaysia, Thailand and the Philippines is informative. They found the measurement of empowerment to be very difficult, and demonstrating the relationship between empowerment and fertility transition even more problematical. Mason and Smith (2001:3-4) conclude*: "Societies that promote greater equality between males and females may also tend to promote better reproductive health and family planning services.…The next leap for demography is therefore recognising gender equality as an issue worthy of investigation in its own right rather than strictly as a possible engine for demographic change."* In this study it is demonstrated that the reported lack of women's empowerment in South Africa, far from being an obstacle in fertility transition, actively creates a context conducive to poor reproductive health (see Chapters 4 and 5).

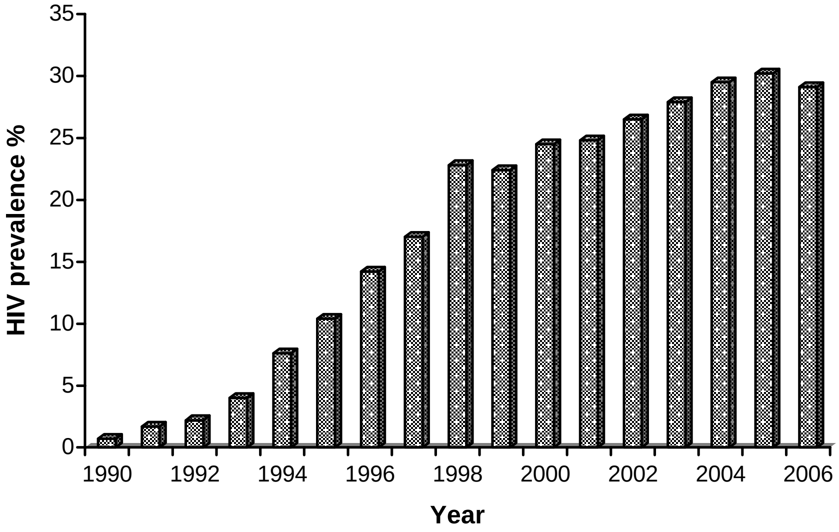
1.2 HIV-AIDS AND WOMEN IN SOUTH AFRICA

Since the late 1980s there has been a steady increase in HIV-infection amongst women and in sub-Saharan Africa, with women and girls accounting for 57% of all people infected with HIV (UNAIDS 2004:4). In addition, 82% of young South Africans (between the ages of 15 and 24 years) living with HIV is young women (Dorrington, Johnson, Bradshaw & Daniel 2006:19). Dorrington *et al* (2006: ii) also report that about 38 thousand South African babies are infected with HIV at birth and that a further 26 thousand infants are infected with

HIV through breastfeeding.

Findings of antenatal clinic HIV surveillance surveys conducted since 1990 (South African Government, DoH 1999a, 2000c, 2003, 2006b and 2007) reveal that infection rates amongst South African women of reproductive age are still increasing (with some modest stabilisation in the 2006 data). In 1990, less than one per cent (0,7%) of women attending public antenatal clinics was infected. By 1998 this figure had increased to 22,8% - then to 26,5% in 2002 and to 29,1% in 2006 (see Figure 1.3). Extrapolating from the 2006 data, it is estimated that 5,41 million South Africans of which the majority or 2,8 million are adult women are HIV-positive (South African Government, DoH 2007:15-16).

Figure 1.3: HIV-prevalence amongst antenatal clinic attendees, South Africa 1990-2006



(Sources: South African Government, DoH 2004b:6 & 2007:6)

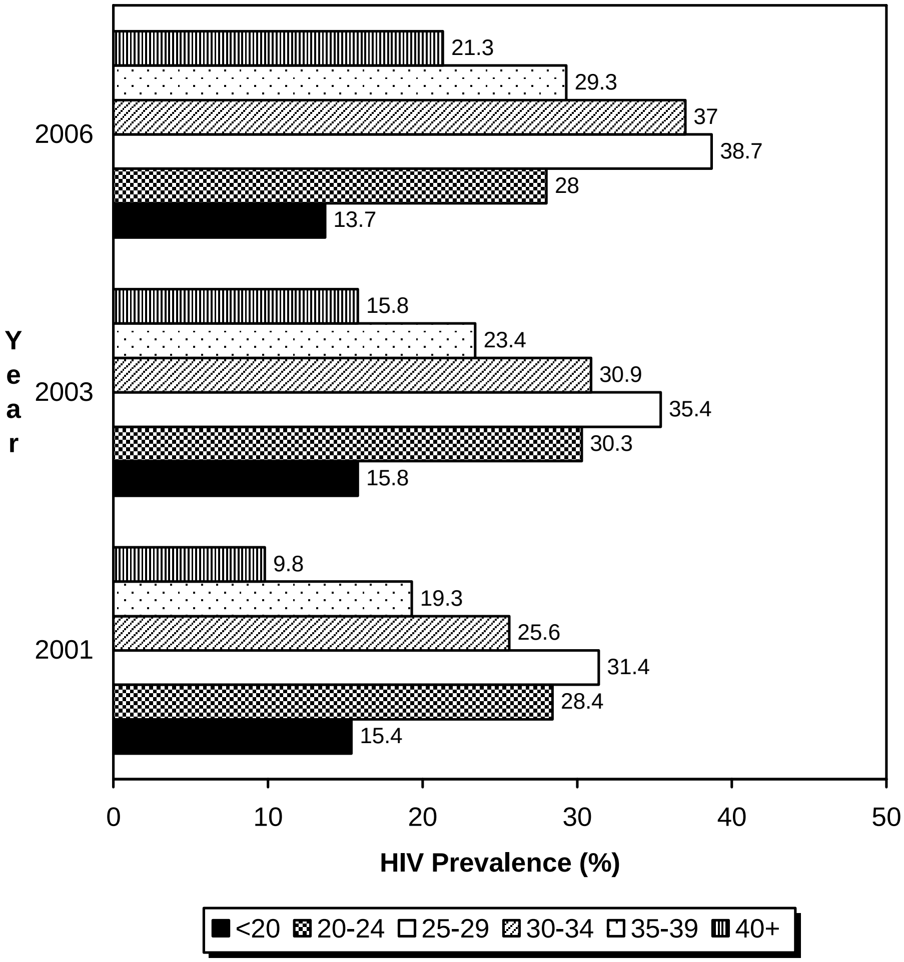
The growth curve in the number of infected women was virtually exponential over the past decade. The small decline between 2005 and 2006 should be observed with great circumspection as the confidence intervals for these two periods (29,1% to 31,2% for 2005 and 28,3 to 31,2% for 2006) suggest little change. Provincial infection rates vary greatly. Whereas more than a third of all women attending public antenatal services in KwaZulu-Natal are infected, about 15 in a hundred women in the Western Cape are HIV-positive (See Table 1.4).

Table 1.4: South African national and provincial HIV prevalence (antenatal clinic attendees) for 1998-2006

Province	**HIV-infection rate (%)**								
	1998	**1999**[8]	**2000**	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**
South Africa	22,8	22,4	24,5	24,8	26,5	27,9	29,5	30,2	29,1
KwaZulu-Natal	32,2	32,5	36,2	33,5	36,5	37,5	40,7	39,1	39,1
Mpumalanga	30,0	27,3	29,7	29,2	28,6	32,6	30,8	34,8	32,1
Free State	22,8	27,9	27,9	30,1	28,8	30,1	29,5	30,3	31,1
Gauteng	22,5	23,9	29,4	29,8	31,6	29,6	33,1	32,4	30,8
Northwest	21,3	23,0	22,9	25,2	26,2	29,9	26,7	31,8	29,0
Limpopo	11,5	11,4	13,2	14,5	15,6	17,5	19,3	21,5	20,6
Eastern Cape	15,9	18,0	20,2	21,7	23,6	27,1	28,0	29,5	28,6
Northern Cape	9,9	10,1	11,2	15,9	15,1	16,7	17,6	18,5	15,6
Western Cape	5,2	7,1	8,7	8,6	12,4	13,1	15,4	15,7	15,1

(Sources: South African Government, DoH 1999; 2000a; 2003 & 2007)

Figure 1.4: HIV prevalence among antenatal attendees by age group, South Africa 2001, 2003 and 2006



(Sources: South African Government, DoH 2003:8 & 2007:9)

Recent estimates suggest that other provinces are catching up to KwaZulu-Natal and that the prevalence rate in KwaZulu-Natal will peak at almost 40% before it will decline due to AIDS mortality (Bisseker 2001:34; Dorrington *et al* 2006). Between 90 and 103 thousand infants are infected (South African Government, DoH 2003) and there has been a steady increase in the percentage of antenatal clinic attendees that are HIV-positive in the 25- to 29-year age group – the prime childbearing years (see Figure 1.4).

The Transitions to Adulthood Study Team (2004:5) points out that the youth of South Africa is disproportionally affected by HIV as antenatal surveillance suggest a rise in HIV-prevalence in the 15- to 19-year age group from 7% in 1994 to 16% in 2004. Although the numbers in Figure 1.4 suggests a levelling off in the proportion antenatal attendees younger than 20-years of age group who test positive for HIV-infection at around 14%, it is unclear whether this might be distorted by reasons other than an actual decline in new infections in this age group. In this regard, UNAIDS (2004:23-24), Dorrington *et al* (2006) and Rehle *et al* (2007) report that new infections in the broader 15- to 24-age category in South Africa continue to rise. In the 2004 report by UNAIDS, reference is made to a population-based survey by the South African Medical Research Council that demonstrates that young people might postpone first sexual contact to their early twenties[9], but that HIV-infection rates sharply increases in the 20- to 24-year old age groups.

The AIDS epidemic commenced more recently in South Africa than in Botswana or Zimbabwe and due to this later start, the major demographic impact is both still to come and the subject of much speculation. The United Nations speculates that by 2015, South Africa's population will be 16 per cent smaller than what it would have been in the absence of HIV-AIDS (United Nations 1998b: 7). Even more speculative is assumptions about the fertility-reducing effect of HIV-AIDS. This interrelatedness of fertility and HIV-AIDS is examined in greater detail in the Chapter 4. The discussion here is intended to situate the research issue.

1.3 PURPOSE OF THE STUDY

The central aim of my study was to investigate women's perspectives and experiences of HIV-positive statuses and how that impacted on their decisions and actions regarding future pregnancies, reproductive health, autonomy and empowerment. Women accessing public health care facilities were selected as research participants, since being dependent on public clinics and hospitals for information and services to protect one's reproductive health was regarded as an important structural location and marginal position to be in. The biographical details of the research participants, the research design and details on data-gathering and data-analysis are discussed in Chapter 3.

The theoretical orientation utilised in this study was critical social theory as it relates to the empowerment of women. This orientation was used to conceptualise hegemonic views on HIV-AIDS and empowerment as well as to provide a context with which to analyse the diverse experiences of women living with HIV.

I investigated whether, and to what extend, HIV-positive women participated in reifying (or has internalised) hegemonic biomedical views of their own lives and have constructed understandings of their own ability (or inability) to cope with their reproductive health (see Chapter 5). In this respect Littlewood (1999:138) states*: "Understanding any illness as a biosocial pattern requires both an interpretation of how individuals choose or see themselves as constrained to engage in the illness for certain ends, explicit or otherwise, together with an explanation of its pre-conditions and influences"*. In adopting this vantage point, I was able to look at the social vulnerabilities of the research participants, at their socioeconomic characteristics, perceived gender roles, support systems and own perceptions of their abilities to become active, empowered agents. Existing literature on female empowerment, power in health-related decision-making, and hegemony guided the choice of the methodology and consequently critical ethnography was adopted to guide this investigation.

1.4 PROBLEM STATEMENT AND THESIS OF THE STUDY

In the current context of health care in South Africa, people are increasingly expected to be involved in their own health care by heeding health care messages and taking responsibility for their own health.[10,11] Examples are anti-smoking campaigns, arrive alive traffic safety and drinking-and-driving- campaigns, and the ABC-campaigns (abstinence, be faithful and condomise) for HIV and STI-prevention. The “own responsibility”-rhetoric can be seen as a counter hegemonic to biomedical hegemony in the area of health. Furthermore, the idea of self-directed, informed citizens accessing services and acting responsibly fits well with other mobilising metaphors that delineate a new democracy in South Africa. An entrenched overdependence on health care provided by professionals in public health care however is more conducive to the passive adoption of the values and norms of the dominant biomedical hegemony than to the full embodiment of an autonomous, informed and empowered decision-maker in one’s own health.

In addition, people living with HIV are expected to be vigilant about their own health, go for testing, eat healthily, live positively, prevent further infection, re-infection or superinfection and, when accessing ARV-treatments, adhere[12] to the treatment regime. HIV-positive women are expected to come to terms with their diagnosis, disclose their status to their partners, convince their partners to go for testing and use condoms, access health information and involve their doctors in any future planned pregnancies.

This discourse about self-directedness is backed up by a general rhetoric about human and patient rights to information, choice and fair treatment. Within the highly politicised arena of the rights of people living with HIV, semantic shifts often occur, for example ***mother-to-child-transmission*** became ***parent-to-child-transmission*** and ***AIDS orphans*** became ***orphans and vulnerable children affected by HIV-AIDS (ORVs)***. This denotes dynamic alertness in the fight for rights in the sphere of health and health care and a focus on the informed-of-her-rights-and-options health care consumer as opposed to a passive patient. But of concern to the researcher as a social demographer interested in the notion of empowered decision-making by women for their own reproductive health was the apparent disconnection between the notion of a rights-based responsible health care consumer and the impact of prohibitive sociohistorical and sociopolitical constraints to adopt such a role.

This research was carried out with the goal to move beyond description to uncover power relations that inhibit empowered decision-making by HIV-positive women in the area of reproductive health. Adopting a critical ethnography allowed the researcher to value such women, their experiences, roles and contribution to society and enabled the identification and confrontation of oppression based on gender. Fieldwork was central to this research and required immersion in participant's lives over time. This enabled the uncovering of taken-for-granted assumptions about accessing available public health care by people living with HIV.

In the light of the above, the thesis of this work was to critically examine the notion of female empowerment of women living with HIV as it is framed by social constraints and enablements.

1.5 SIGNIFICANCE OF THE STUDY

Exposing powerful discourses and hegemonic power relations opens up the possibility to examine the potential for emancipation. In this study, passivity, non-adherence and non-participation were seen as alternative ways of reacting to one's own health care needs and to the social constraints and enablements in one's social context. This, in turn, enabled the exploration of possibilities for developing strategies to empowered decision-making. This thesis is also an attempt to expand the notion of female empowerment within the discipline of social demography (see Chapter 6 for a response to this attempt).

1.6 DEFINITIONS OF KEY CONCEPTS

Some of the key concepts as used in this study are defined in this section. Other important concepts are defined in the text where they are discussed and the section here is therefore not a definitive list. In this study, the position was taken that concepts are inherently variable; that their meaning and significance vary according to settings, contexts and time periods. The definitions below act as sensitising explorations of the meanings of certain key notions. In this regard Maines (1989:173) states: *"Concepts in a sense must be turned over and over and looked at from different angles….The process requires what Blumer (1948:277-278) terms the 'intimate familiarity and broad imaginative grasp of the empirical arena to be conceptualised'."* The critical, reflexive and cautious approach that qualitative researchers hold regarding concepts is regarded as an important contribution to the conceptual tools and theory development in social demography. Qualitative approaches criticise the certainty or confidence that quantitative demographers have in their commonly used concepts and variables. Van der Geest (1998:40) refers to this as *"the false exactitude of such key terms in demographic parlance."*

1.6.1 HIV-AIDS

AIDS refers to acquired immune deficiency syndrome. This is caused by HIV, the human immunodeficiency virus. The HI-virus attacks the body's CD4 T-lymphocytes (further referred to as CD4-counts) and weakens the immune system. The Centres for Disease Control and Prevention (CDC 1986 & 1993) developed a surveillance case definition for HIV-infection in 1986 as based on clinical disease criteria and revised it in 1993 to emphasise CD4-cell counts as clinical markers for HIV-infection. The 1993-revision is the latest available clinical classification for HIV and AIDS. This definition, along with the recommendations by the World Health Organisation (WHO 2005) using the ELISA-test are used by the DoH in South Africa to diagnose people as HIV-positive (AIDS Guide 2007; South African Government, DoH 2004a & 2007:4; Southern African HIV Clinicians Society 2002). The definitions for the various clinical stages for HIV-AIDS are different for adults (defined as people 15 years and older) and children (South African Government, DoH 2004a; WHO 2005:5). As this study involved adult women, the clinical criteria for adults are discussed in this section.

The immunological staging of HIV-infection according to a blood test for CD4-cells in a person 15-years or older is as follows:

- CD4-counts larger than 500 per cubic millimeter of blood indicate that the person has no significant immune suppression
- CD4-counts between 350 and 499 per cubic millimeter of blood indicate that the person suffers from mild immune suppression and is vulnerable to opportunistic infections
- CD4-counts between 200 and 349 per cubic millimeter of blood indicate the person suffers from advanced immunosuppression and is likely to start exhibiting symptoms such as weight loss, diarrhoea and oral infections
- CD4-counts of less than 200 per cubic millimeter of blood indicate that the person suffers from severe immunosuppression (AIDS Guide 2007:62-63 & 72-73; Dorrington *et al* 2006:29; South African Government, DoH 2004a:4; Southern African HIV Clinicians Society 2002; WHO 2005:8).

HIV-positive means that the person has tested positive for HIV-infection, irrespective of the CD4-count levels. In South Africa there are no directly observed incidence[13] figures for HIV-infection, since the official data are based on when the person was tested and diagnosed as HIV-positive and the actual date and time of infection is unknown (Dorrington *et al* 2006; Rehle *et al* 2007; Whiteside *et al* 2006:70).

A person is classified clinically as having AIDS when she or he suffers from advanced stages of HIV infection. The 1993-revision of the CDC's definition of AIDS includes all HIV-infected people who have fewer than 200 CD4-cells per cubic millimeter of blood and/or HIV-infected people with any of 26 clinical conditions (CDC 1993; Dorrington *et al* 2006; South African Government, DoH 2004a; Southern African HIV Clinicians Society 2002; WHO 2005). The WHO’s African Region classification for the staging of HIV-AIDS in adults and the per cent distribution of the South African HIV-positive adult population according to these stages as estimated by Dorrington *et al* (2006) are given in Table 1.5. From the estimations by Dorrington *et al* (2006:29-30), it seems that almost a third of all South

African HIV-positive adults are asymptomatic whereas about one in twenty-five HIV-positive adults who are in need of ARV-treatments are not receiving any treatment.

Table 1.5: Revised clinical staging of HIV-AIDS for persons 15 years and older in the African Region as proposed by the World Health Organisation and estimated per cent distribution of HIV-infected persons per stage

Stage of HIV-infection	Symptoms	% of the HIV-positive adult SA population estimated to be at this stage in 2006
Clinical stage 1	Asymptomatic, persistent generalised lymphadenopathy, acute retroviral infection	29 %
Clinical stage 2	Moderate unexplained weight-loss, recurrent respiratory tract infections, herpes zoster. angular cheilitis, recurrent oral ulcerations, papular pruritic eruptions, seborrhoea dermatitis, fungal nail infections of fingers	21%
Clinical stage 3	Severe weight loss, unexplained chronic diarrhoea, unexplained persistent fever, oral candidiasis, vulvo-vaginal candidiasis, oral hairy leukoplakia, pulmonary tuberculosis#, severe persistent bacterial infections, acute necrotising ulcerative stomatitis, gingivitis or periodontitis, unexplained anaemia, neutropenia or thrombocytopenia	36%
Clinical stage 4	HIV wasting syndrome, pneumocrystis pneumonia, recurrent severe bacterial pneumonia#, chronic herpes simplex infection, oesophageal Candidiasis, extra pulmonary TB, Kaposi's sarcoma, central nervous system toxoplasmosis, HIV encephalopathy, extra pulmonary crytococcosis, disseminated non-TB mycobacterium infection, progressive multimodal leukoencephalopathy, candida of trachea, bronchi or lungs, isosporiasis, visceral herpes simplex, cytomegalovirus infection, disseminated mycosis, recurrent non-typhoid salmonella septicaemia, lymphoma, invasive cervical carcinoma#, visceral leishmaniasis	10% and using ARVs and a further 4% not using ARVs

These 3 clinical conditions were added in the 1993-revision for AIDS surveillance case definitions (Sources: CDC 1993; Dorrington *et al* 2006:30; South African Government, DoH 2004a:78-79; WHO 2005:5-6)

CD4-counts and the presence of certain clinical conditions are also used as indicators for when a person should start antiretroviral (ARV) therapy. According to the Southern African HIV Clinicians Society (2002:4) and the DoH (South African Government, DoH 2004a:2), the treatment guidelines for ARV-therapy for adult people are:

- Symptomatic HIV-positive persons with AIDS-defining conditions (such as those listed as stage four in Table 1.5) should start ARV-treatments immediately
- Asymptomatic HIV-positive persons with CD4-counts of less than 200 per cubic millimeter of blood should start ARV-treatments immediately
- Asymptomatic HIV-positive persons with CD4-counts of between 200 and 350 per cubic millimeter of blood should be monitored and ARV-treatments should commence when the CD4-counts approach 200
- Asymptomatic HIV-positive persons with CD4-counts of 350 or higher per cubic millimeter of blood should defer ARV-treatments.

Two important caveats exist for ARV-treatments, namely that the *“patients are prepared to commit themselves to long-term treatment and to maintain good adherence to the therapy”* (Southern African HIV Clinicians Society 2002:4) and that the presence of tuberculosis (TB) warrants a different treatment regime. The preparedness of the HIV-positive person is discussed further on, but for HIV-positive persons with TB the treatment options are as follows:

- If the HIV-positive person is already accessing an ARV-treatment regime and has TB, then the regime should be changed
- An HIV-positive person with a CD4-count of more than 200 per cubic millimeter of blood who has TB should only start ARV-treatment after completing TB therapy
- Finally, an HIV-positive person with a CD4-count of less than 200 per cubic millimeter of blood who has TB should delay ARV-treatment after completing the first two months of intensive TB therapy (Southern African HIV Clinicians Society 2002; South African Government DoH 2004a).

Whereas the first proviso for commencing ARV-treatment as mentioned earlier, namely commitment to treatment adherence, is ascertained by questioning the HIV-positive person during counselling, the presence of TB is clinically tested. Furthermore, a person’s readiness to commence with ARV-treatment is defined by the DoH (South African

Government, DoH 2004a:3) as encompassing six psycho-social considerations, namely that the HIV-positive person:

- Has *“demonstrated*” his or her *”reliability*”, defined as attendance of 3 or more scheduled visits to the public voluntary testing and counselling (VCT) and/or ARV-treatment site
- Does not abuse alcohol and illegal substances
- Does not have active depression for which no treatment was sought or received
- Has disclosed his or her HIV-positive status to at least one other person or to a support group
- Has accepted his or her HIV-positive status and has developed *“insight into the consequences of HIV infection and the role of ARV-treatment before commencing therapy”*
- Is able to attend the facility regularly and *“to maintain the treatment chain.”* In this respect, transport arrangements are suggested *“for patients in rural areas or for those far away from the treatment site.”* [14]

These psycho-social considerations are listed as *“not exclusion criteria”* and it is stated that *“the final decision to treat will be taken by the multi-disciplinary team”* at the public health care facility (South African Government, DoH 2004a:3). As is demonstrated in this study, this biomedical contouring of the psycho-social characteristics of the person living with HIV holds particular consequences for women living with HIV and accessing public health care facilities.

In addition to ARV-treatment for HIV-positive persons according to CD4-counts or clinical conditions, ARV-therapy is also offered to pregnant HIV-positive women, to persons following accidental exposure to HIV through occupational accidents and to persons exposed to HIV via sexual assault and rape (South African Government, DoH 2004).

Antenatal care, prevention of mother-to-child transmission (PMTCT) and Nevirapine (an ARV-medication) are given free of charge at public health care facilities. The national protocol states that Nevirapine for self-administration can be given to all HIV-positive women who are 28 weeks or more in their gestation periods when they go into labour. In addition, a baby born to an HIV-positive mother is given a single dose of Nevirapine within 72 hours of birth. In order to access PMTCT-services however, pregnant women should receive counselling and voluntarily undergo HIV-testing. The PMTCT-programme also offers free formula milk for a period up to six months to HIV-positive mothers who choose not to breastfeed their babies (South African Government, DoH 2004). As revealed in the narrations of the research participants, informed consent for antenatal testing and infant feeding practices are interpreted differently by the public health care recipients (see Chapter 5 of the thesis).

In this thesis a convention is followed in which HIV-AIDS is used when intending to indicate both the clinical condition and the social construction of the disease. The acronyms are used in hyphenated format as HIV-AIDS to denote HIV and AIDS. This practice (using HIV-AIDS) is being adopted by some activists and writers in the field, although many official documents still use the abbreviation HIV/AIDS.

Further incorporating the alternative discourse as used by activists and community-based organisations, the convention is applied to refer to ***living with HIV*** as opposed to ***living with HIV and AIDS***. The thinking behind this is that the focus should be on making an HIV-positive status into a chronic disease and directing efforts on strategies to live with the status, whereas AIDS denotes the end-stage of HIV-infection and few people are able to live for many years with AIDS.

1.6.2 Empowerment of women

In this study, empowerment of women refers to the development of women's abilities to alter or control the patterning of experiences that affect their sub-ordination. The notion of female empowerment was further broadened by the introduction of a gendered emancipatory discourse at the 1995 United Nations Beijing Conference on Women (Presser & Sen 2000).Empowerment is therefore not only material equity, but includes cultural resources such as knowledge and social respect. Mason and Smith (2003:3) suggest that empirical studies tend to measure women's empowerment via proxy variables such as level of education, employment status, age of entry into a sexual union, or age differences between spouses. Instead, they suggest that direct measures of the power and status of women such as decision-making power, freedom of movement and freedom from domestic violence should be considered. Casique (2001) attempts a similar broadening of the measurement of female autonomy in a study in Mexico.

At the International Conference on Population and Development (ICDP) in Cairo in 1994, the delegates agreed that the advancement of gender equality, the empowerment of women, the elimination of violence against women and enhancing women's autonomy in decision-making are important aspects of population and development efforts (Riley 1997a:1). In this study, the empowerment of women is regarded as a process (and not only a desired outcome) by which women gain power and control over decisions and resources that determine the quality of their lives. It recognises women not as victims or beneficiaries, but as key actors in their own lives and health. The notion of empowerment of women is considered in greater detail in Chapter 2.

1.6.3 Sex and gender: The focus on women and HIV-positive women

In this study, sex (male and female) refers to biological sex and gender (men and women) to socially constructed gender roles and expectations for men and women. As Nancy Riley (1997a:2) notes*: "we might talk of sex differences in life expectancies if we are referring to biological differences in survival rates, but refer to gender differences in life expectancies when we are talking about social influences on survival, such as the ways that girls are discriminated against in food allocation or the greater tendency for men to engage in high-risk behavior."*

Susan Greenhalgh (1995:23) comments on the reductionist treatment of gender in demographic theory and argues*: “Women’s social and economic characteristics appear increasingly often as variables in demographic models, suggesting the emergence of a demography of women. At the same time, however, the field seems almost prefeminist in the implicit assumptions and biases that inform its work (for example, that only women aged 15-49 are reproductively ‘dynamic’ and thus worth studying, that women and men occupy separate spheres, the former private, the latter public) and in the narrow range of women’s characteristics considered demographically important.”*

As Basu (1998:85) mentions, demographic interest in gender roles as it relates to power, opportunities, privileges and decision-making often focuses on the measurement of the status of women *“which rank women in respect to implications for fertility and mortality.”* In particular, demographic interest in gender often centres on autonomy in intra- and extra-household decision-making. Basu (1998:81) is critical of quantitative measures of the status of women that reduce it to two variables, namely the female levels of education and female employment *whereas “so much of what constitutes female status (and gender issues in general) is non-quantifiable and even intangible.”*

Commenting on the centrality of gender equity in current population policies, Basu (1998:85-89) warns demographers about the dangers of not critically reflecting on the local and contextual understanding of gender as a social construct. In particular, Basu cautions against:

- A generalising tendency that regards women’s interests or problems as a unitary body of concerns. assuming that gender as a social and cultural construct is the same across all cultures
- Becoming bogged down in reproductive determinism that link the “universal oppression of women” to their childbearing capacity or the costs and rewards of motherhood
- Seeing all “women’s problems” in terms of gender relations. That is, besides gender

> hierarchies as important factors in influencing demographic-relevant behaviour, the role of other power hierarchies such as age hierarchies or ritual positions should be considered. In addition, gender inequality may be shaped and sustained by structural factors such as the economy or the political system.

In this study, gender is regarded as created within power relations (Connell 1987; Kabeer 1994; Schoepf 1995) so that women's sociostructural positions as subordinate groups in terms of access to resources, capabilities, power and privilege can come to the fore. This study is furthermore a deliberate focus on women living with HIV. It grew out of a primary record (see Chapter 3 and 4) of women's struggle with public reproductive health care in South Africa. As such, gender is regarded as structuring principles of social life and not merely as biographical labels. Being an HIV-positive woman in South Africa is to own or contest a gendered status that is socially, historically, biomedically and culturally constructed. The study calls into question issues of power differentials, sex-related ideologies, material inequalities and conflict. It deliberately connoted agency, which implies that people are not just the passive victims of gender role or sick role prescriptions, but able to devise strategies to challenge dominant identities[15].

1.6.4 Reproductive health of women

The World Health Organisation (WHO 1998) defines reproductive health as *"a state of physical, mental, and social well-being in all matters relating to the reproductive system at all stages of life. Reproductive health implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when, and how often to do so."* This definition grew out of deliberations at the International Conference on Population and Development in Cairo in 1994 and was given greater impetus at the Fourth World Conference on Women in Beijing in 1995. As is often the case with definitions adopted at international gatherings, the definition itself is too broad and lofty to have more than symbolic value. On the other hand, the focus on healthy sex lives in the definition avoids the trap of restricting reproductive health to only childbearing and contraception. In fact, the International Women's Health Coalition (1994) emphasise both reproductive rights (encompassing choices in child number, spacing and timing, sexual and reproductive health and decision-making) and sexual rights (encompassing respect, well-being, confidentiality, non-discrimination, non-violence and freedom).

Gary Dowsett (2003:24) makes the contentious statement that framing the HIV-AIDS epidemic within the notion of reproductive health reifies the notion of women's vulnerability versus men's culpability thereby bifurcating women into vectors of disease and innocent victims. His quest is to move beyond a discourse of a heterosexual epidemic in order to highlight the multiplicity of HIV-vulnerability. However, Dowsett's analysis offers little more than a reconsideration of the old epidemiologically created risk groups. The focus of this study was not narrowly on women as potential child bearers. Instead, it acknowledged that reproductive health encompasses the full ambit of human sexuality and sexual practices. At the same time, however, given the critical orientation, it located the source of women's oppression in the organisation of the social world (Lorber 2000).

1.6.5 Fertility and fertility preferences

Fertility refers to the actual (measured) reproductive performance of an individual, a couple, or an entire population. Fertility preferences are the reproductive intensions of women and include measures of their perceived ideal number of children, whether they would like to have another child soon (or any children in the case of childless women), what the ideal spacing of pregnancies and births are and whether they use contraceptive methods to achieve these intensions.

It should be noted that reproduction as used in the previous paragraph and at various junctures in this thesis refers to human (biological) reproduction. Within critical social theory, however, ***social reproduction*** refers to the patternedness of human activity whereby over time groups of people (especially social classes) reproduce their social structure and patterns (see Carspecken 1996:38). It is through the notion of empowerment that we can debate the relation between biological reproduction and social reproduction through the examination of systemic power. These ideas are revisited in Chapter 2.

1.6.6 Hegemony

Gramsci (1971) conceptualises hegemony as multifarious ideological control put into effect by dominant beliefs, attitudes and codified patterns of social action within interconnected political, cultural and social formations. In this sense hegemony delineates the contents of the taken-for-granted, common sense perceptions of people and this makes change difficult within the hegemonic relationship of dominant and sub-dominant groups. Hegemony thus is an instrument of domination and legitimation of the *status quo*. Due to a diversity of ideologies, critical moments for contesting, challenging and changing existing hegemonic ideologies and discourse exist. These critical moments arise in periods where structural inconsistencies challenge hegemonic discourses (Gitlin 2003:12; Strinati 1995: 165-169; Williams 1977).

Williams' less static (that is less static than in Gramsci's original conception) notion of hegemony is useful for the purposes of this study. Williams (1977:112) conceptualises lived hegemonies as complexes of experiences, relationships and activities. Hegemonies are continually renewed, recreated, defended, modified, contested and challenged. Hegemonies are seen as sources of constraints with counter-hegemonies offering critical moments for challenging hegemonic discourses. Hegemonic discourses, especially those prevalent in biomedicine, impede people living with HIV with regard to health care, treatment modalities, social support and stigma.

1.6.7 Power

The conceptualisation of power was influenced by Foucauldian and feminist interpretations of the concept (Cooper 1994; Joyce 2001; MacKinnon 1990; Sawicki 1991). In Foucault's view, power is multiple, inherently neither positive nor negative, fragmentary, diffuse, differentiated, indeterminate, historically and spatially specific, dispersed, infused throughout social practices and discourses, subjectless and productive in the construction of people's bodies, identities and unconscious self-surveillance (Foucault 1980a , 1980b & 1980c; De Lauretis 1987:16; Gavey 1996:53-56; Silverman 1985).

This means that power is seen in this study as relational and a process or phenomenon that is acted out by social actors as opposed to as a commodity to be owned. Power is not only regarded as repressive, but also as productive. Foucault's understanding of praxis (the liberating purpose of scientific research in addressing oppressive social arrangements) is one that requires both symbolic and material transformations, since knowledge is always shaped through power and power is always located in knowledge (Quantz 1992:466; 480).

Power is not regarded as vested in a single site, but as running *"through the capillaries of society"* (Cooper 1994:438). Power circulates through social relations and restricts and produces forms of behaviour. Moreover, the effectiveness of power lies in its ability to mask itself and hide its own mechanisms (Cooper 1994).

1.6.8 Discourse

Discourse is defined as ways of thinking, configurations of ideas, narrative accounts, explanations and systems of meaning created in social interaction and re-altered to the privilege and the preservation of particular power distributions in society (Turney 2000:162-

163). Discourses provide the threads from which ideologies are woven (Seidel 1993). Discourse is critical consciousness, based on traditions and beliefs that, for Bourdieu (1977b), are part of *doxa* – the unexamined, taken-for-granted, normalised assumptions and orthodoxies about social life.

As should be apparent from the discussion in Chapter 2, discourses are regarded in this study as symbolic in nature. Moreover, discourses are regarded as encompassing naming, classifying and framing experiences and as having material outcomes that impinge on people’s lives (Seidel & Vidal 1997:59).

1.7 ASSUMPTIONS AND LIMITATIONS OF THE STUDY

This study encapsulates one version of “truth” and I acknowledge that there are other perspectives. Van der Geest (1998:40) warns that *“some things are none of our* [the researchers’] *business, so we may not understand because we are never able to put ourselves completely in other people’s places and to feel what they feel.”* Visiting both the public and private spaces inhabited by women living with HIV or dealing with HIV-AIDS allowed the researcher to present this view. At the same time I must acknowledge that there are private spaces of decision-making, thought and action that was not accessible to me. I could not, for example, witness the actual negotiation between participants and their intimate partners regarding their reproductive health choices nor did I set out to do so. Some of this negotiation could be accessed indirectly through research participants’ own accounts.

1.8 BRIEF CHAPTER OVERVIEWS

The thesis is organised into the following chapters:

- In **Chapter 1**, the research issue is briefly outlined, the thesis for the study is stated and key concepts are defined
- **Chapter 2** is a review of the literature as it pertains to the empowerment of women, HIV-AIDS and related themes
- In **Chapter 3**, the characteristics of critical ethnography as employed in this study are discussed and the research design is considered
- **Chapter 4** is a primary record of the interrelatedness of fertility, HIV-AIDS and female disempowerment in South Africa
- In **Chapter 5** the data is analysed
- **Chapter 6** provides conclusions to the analysis and interpretation of the findings, evaluates the emancipatory success of the research encounter and makes suggestions for a new conception of women's empowerment.

1.9 CONCLUSION

The thesis of this study was to critically examine the notion of female empowerment of women living with HIV as it is framed by social constraints and enablements. With this as a goal, critical ethnography was used to gather and analyse data and uncover critical moments for transformative action. In the next chapter, the issues raised in this one are examined in further detail drawing upon the literature.

ENDNOTES FOR CHAPTER 1

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[1] Even with the change in policies about the provision of antiretroviral drugs to HIV-positive pregnant women, antiretroviral drugs (ARVs) only block transmission of the HI-virus from the mother to the baby and the HIV-positive mother's status remains unchanged. Even those women, who are given antiretroviral drugs during pregnancy, will always face the sad fact of HIV in all their reproductive choices and actions over their entire reproductive and healthy lifespan.

Endnotes

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[2] The second chapter of the South African Constitution (108 of 1996) states the right of every person to make decisions regarding procreation (Article 12) and to have access to health care services (including reproductive health services – Article 27). Reproductive rights, however, go beyond knowledge in order to make informed decisions about procreation and access to services to turn those decisions into actions. The constitution claims these rights for citizens, but social actors should turn these rights into empowering actions.

[3] The 2003 data from the South African Demographic and Health Survey should be viewed with circumspection, as there were methodological and other issues that influenced the data. These are preliminary results and the final weighted data were not available for use by the author at the time of writing.

[4] Some studies suggest that adolescent girls might fear that using contraception prior to having a child would harm their fecundity (Rutenberg *et al* 2002:8). The extent to which this misconception is related to side-effects (such as delayed menstruation) experienced by some women using hormonal contraceptive methods or perhaps encouraged by the attitudes of family planning health workers who attempt to discourage teenagers from having sex by withholding contraceptive protection, is however the subject of speculation.

[5] Shisana *et al* (2005: xxix) found that one third of males in their survey had had sexual partners who were more than five years younger than them.

[6] The use of the old racial categories should be contextualised here. Although, in legal terms, South Africa became deracialised in the 1990s, the rigid system of racial discrimination that were in place since 1948 meant that demographic regimes and transitions (as is the case with socioeconomic indices, poverty and access to health services) tended to differ for the different groups. South Africa remains one of the most unequal societies in the world, despite a rapid growth of a black middle class (Schneider & Fassin 2002). The convergence (in the tables in which this is mentioned) between the "urban African"-subgroup and the rest of South African women and the difference with the "rural African"-subgroup should be noted. It seems that certain categories of the South African population remain vulnerable to social exclusion, especially those in rural areas.

[7] Deliberations at the ICPD of Cairo in 1994 gave impetus to a shift in focus on fertility reduction to a focus on reproductive health – a sentiment also reflected in the South African Reconstruction and Development Programme (Finkle 2002; South African Dept of Social Development 2000).

[8] Dorrington *et al* (2000) point out that the 1999 decline to 22,4% was incorrect and due to a decline in Mpumalanga (which accounts for only 7% of the South African population). They suggest that a population-weighted method should be followed in reporting the prevalence rates.

[9] Gregson (1994) hypothesises that HIV-AIDS may lead to rejuvenation in the age at entry into sexual unions. Two reasons are mentioned for this assumption. First, men might choose younger female partners with the assumption that they are more likely to be virgins or to have had fewer sexual partners and thus be HIV-negative. Second, teenage girls may increasingly be forced into sexual unions due to adult mortality and the resultant AIDS orphanhood and survival needs. Studies in Uganda, however, point that such assumptions are unfounded as fear of HIV-AIDS exerts

downward pressure on the age at first union and to a delaying of marriage (Asiimwe-Okiror *et al* 1997; Mukiza-Gapere & Ntozi 1995). At this stage there are not enough data available to conclude whether South African youth will postpone sexual unions due to a fear of HIV-infection – although the quoted Medical Research Council study and the study by Rutenberg *et al* (2002) suggest that such behavioural changes might be taking place. This needs a deeper qualitative exploration. South African youth have over the past few years been bombarded with Information Education and Communication- (IEC-) awareness creation programmes and Knowledge Attitudes Behavior and Practices (KABP-) –surveys. Both of these things might influence respondents to closed survey questions to provide social desirability answers. In addition, the analysis by Rutenberg *et al* (2002) relies heavily on proxy measures and modelled effects to link knowledge of HIV-AIDS to fertility preferences.

[10] In a speech on 24 March 2007 at the provincial TB-day event, the premier of the Northern Cape stated: *"…you must not put our children at risk. You have no place sending them to the bottle store to buy drinks and cigarettes, and you also have no right to send them on errands once the sun has set, for we have a very high incidence of rape in the Northern Cape and this is further fuelling the incidence of HIV infections. We must thus do everything in our power to protect our children. As responsible citizens of this country, you should also take it upon yourself to have an HIV test, as I myself have done*"(Peters 2007).

[11] President Thabo Mbeki (2002) stated; *"This is one of the central objectives of the Letsema Volunteer Campaign - to mobilize the masses of our people to become their own liberators from poverty and underdevelopment. It aims to end any sense of disempowerment among the people and any feeling of complete dependence that destroys the striving towards self-reliance, personal initiative and personal responsibility. This is important in many respects. For instance, we are waging the ABC campaign with regard to AIDS. It can only succeed if the people themselves take responsibility for their lives and do the things raised by this campaign. This also extends to the other diseases of poverty that claim many lives. In this regard, in addition to the things that government must do, questions of hygiene are critically important. The people must be educated to understand that they too have a responsibility for their own health and must therefore do everything they can to take care of their personal hygiene."*

[12] In this study, adherence (also called compliance) means taking medications or undergoing treatment as prescribed. Biomedical wisdom holds that nearly-perfect adherence to anti-HIV regimens (that is, 90-95 % of prescribed doses taken as directed) is required to avoid the development of drug resistance (Broyles, Colbert & Erlen 2006:184-5). As explained by Broyles *et al* (2006: 186): *"With incomplete or erratic dosing, viral suppression is diminished, allowing HIV to become resistant not only to the specific medication(s), but also often the entire class, resulting in poorer clinical outcomes for the individual and the potential public health crisis of resistant strains being spread throughout the community."*

[13] Incidence refers to new cases in the epidemiology of an infectious disease, whereas prevalence refers to all people exhibiting the disease at a particular time in a population (Whiteside *et al* 2006:70). Dorrington *et al* (2006:29) estimate the incidence rates for HIV-infection based on a mathematical model at 1,2 % for the total population in 2006 and at 2,4% for women aged 15- to

49-years of age in 2006. Rehle *et al* (2007) use survey-type estimation for HIV-incidence and report similar figures.

[14] The terms “rural” or “far away” are not defined in the document.

[15] It should be noted that by working through volunteers who contacted the researcher personally and with women at public health care facilities, the majority of the research participants were black African. This is not to indicate that black women are more “at risk” of HIV-infection. People with access to private health care services are often better able to “hide” their seropositive statuses (see Benatar 2006:102; Whiteside *et al* 2006:76). The focus of this study is on women dependent on public health care service delivery. Notions of racial “otherness” and insatiable, exotic sexuality that put certain racial or ethnic groups at greater risk of infection are strongly rejected in this study (see Bibeau & Pedersen 2002).

CHAPTER 2

HIV-AIDS AND REPRODUCTIVE HEALTH

2.1 INTRODUCTION

In this chapter a nexus of themes related to the research topic is discussed, namely fertility, female identity, HIV-AIDS and motherhood. This discussion is intended to show how hegemonic discourses and structural factors shaped the experiences of women living with HIV. To make this argument, the chapter is divided into four sections:

- First, the social construction of HIV-AIDS is discussed with reference to the hegemony of biomedical and androcentric discourses. A discourse of "healthy lifestyle" as technologies of the self is examined
- Second, women's empowerment as an ideal and some structural barriers to its achievement are considered. Stigma and discrimination as products of hegemony and symbolic violence are discussed as important issues in the disempowerment of women and women living with HIV
- Third, HIV-AIDS as illness experience is reviewed with reference to the social context and to the individual context in terms of biographical reconstruction
- Fourth, reproductive decision-making models and theories are critically analysed for their applicability to women living with HIV.

The different viewpoints on fertility decision-making examined in this chapter speak of private decisions with public consequences from a variety of different historical and theoretical vantage points. Each represents a discursive site on the long trajectory of social scientific engagement with population and public health concerns. The views they offer are multiple and contradictory, revealing ruptures as well as continuities in the way sexual and fertility decision-making are perceived. In this chapter, these views are critically discussed by focusing on the social construction of HIV-AIDS and of responses to it and by examining a wide range of issues pertinent to the reproductive health of HIV-positive women.

2.2 THE SOCIAL CONSTRUCTION OF HIV-AIDS

The AIDS epidemic became publicly known in 1981 when a condition termed "Acquired Immune Deficiency Syndrome" (AIDS) was described. In 1983 researchers managed to identify the "human immunodeficiency virus" (HIV). Prior to the identification of the virus, however, it had already started spreading among populations. In the initial AIDS strain that was identified, approximately 10 to 12 years elapsed between infection with the HI virus and death as a result of AIDS. Since then, a number of strains have been identified. These strains develop as a result of mutations of the virus (AIDS Guide 2007; Root-Bernstein 1994).

Once the disease was identified, it was realised that HIV-AIDS posed a major threat to the human population, since no cure was known. This threat has been borne out. Since the inception of the epidemic, approximately 20 million people are estimated to have died of AIDS-related complications. By the end of 2005 an estimated 40 million people are living with the HI virus. Based on surveillance data, an estimated 6 million South Africans were living with HIV by the end of 2005 (AIDS Guide 2007).

Sociological investigations into HIV-AIDS tend to focus on behavioural aspects or on knowledge, attitudes, beliefs and practices regarding HIV-AIDS (the so-called KABP-studies). Alternatively such sociological studies focus on the social impact of AIDS and the social construction of the meaning of AIDS (Aggleton, Davies and Hart 1990; Aggleton, Hart & Davies 1989; Aggleton & Homans 1988; Feldman & Johnson 1986; Fineberg 1988; Mann & Carbalo 1988; Weeks 1989). The social construction of HIV-AIDS implies a critical look at the way in which human actors experience HIV-AIDS through discourse. As

Treichler (1992:66) explains, the social construction of HIV-AIDS refers to the way in which the disease affects social life and the symbolic expressions and *vice versa*.

The social construction of HIV-AIDS has a particular history and course of deployment that has profound and complex intended and unintended consequences for:

- The spread of the epidemic
- The ability of persons to adopt precautionary practices
- The ability of persons to seek treatment when exposed, infected, affected or ill (Wilton 1997:54).

Paicheler (1992:12) sketches the social construction of HIV-AIDS in terms of interrelated elements such as:

- Naming and framing the pandemic
- Comparing it to other epidemics in human history
- Popularising biomedical knowledge as the main authority on HIV-AIDS
- Creating a climate of competition in biomedical research for cures, diagnostic tests and patents
- Giving rise to discourses about the other.

The first component (naming and framing) seems to be crucial in the subsequent unfolding narrative of AIDS as a disease. Gagnon (1992:27 and 39) even refers to AIDS epidemic**s** to emphasise the unique characteristics of the disease's epidemiological routes and to highlight the different sociomedical histories and contextual spheres of HIV-AIDS. Two issues are of special importance in this regard: the domination of biomedical discourse and the domination of androcentric Western biomedical research in setting the wheels of the construction of HIV-AIDS into motion. Each of these is discussed below.

2.2.1 The domination of biomedical discourse in the social construction of HIV-AIDS

The naming and framing of AIDS took place in a context in which biomedical model[1] dominated. In this context the scientific means to identify and classify persons as HIV-positive or -negative or as having AIDS-related illnesses created the concepts, classification criteria and terms by which HIV-AIDS became "knowable." Treichler (1987 & 1988) refers to AIDS as the epidemic of signification by which she implies that the very label "AIDS" partly constructs the disease and helps make it intelligible. Moreover, as will be discussed further on in this chapter, the naming and framing of HIV-AIDS almost sealed the fate of the objectification of the human physiological condition (Sherr 1996:18; Turner 1996:124).

Objectification of disease and illness, or progressive medicalisation[2] of social life, are of course, older than the history of HIV-AIDS itself. With historical roots extending back to the 19th century, objectification rests on two interrelated processes. First, the development of biomedical science removed disease as lived, individual experience and relocated it in anatomical pathology as the object of medical discourse. Second, the medical profession developed as a bounded, organised profession that marginalised other forms of medical care. Taken in conjunction, these dual processes placed the patient as a docile body or passive agent under the clinical gaze and surveillance (and thus control) of a powerful expert (Bury 1998:5-9). Symptoms and health conditions that stem from structural origins are redefined as weaknesses of individuals and therefore as subject to biomedical intervention (Levinson 1998:75). Objectification and medicalisation contributed to a belief in medical interventions as the only appropriate vehicle for the control of disease. In this sense, public health concerns are medicalised and one-sided biomedical approaches to "control" morbidity and mortality come to the fore. Technical knowledge is championed and used for instrumental action. Thus the "solution" to interpersonal violence is to teach people conflict negotiation skills; the "solution" to malnutrition is to hand out food parcels and the "solution" to HIV-AIDS is to hand out free condoms and to embark on public health education programmes (Levinson 1998:75).

For Foucault, contemporary politics are biopolitics (Turner 1992:46) and sexuality was the strategic site for intervention into the lives of individuals and populations. Treichler in this respect reminds us of Hilary Putnam's (quoted in Treichler 1999:324) notion of a "division of linguistic labour" whereby we surrender certain spheres of life (such as disease) to acknowledged experts. This is reminiscent of Habermas' colonisation of the life-world by system elements. In the era of HIV-AIDS this surrendering to experts is not complete, but widely challenged.

Biomedical hegemony legitimises its political influence to discourage competitors in health service provision and subordinate other role players, thereby reifying existing sociocultural constructions of health issues and health care. Biomedicine thus becomes an instrument of social control reproducing the dominant ideology of health care in a hegemonic relationship with the state. This hegemonic control provides the contours for legitimate sick roles and of the matching medical intervention and professional management thereof. Furthermore, the hegemonic hierarchical ordering of ownership claims to legitimate knowledge about treatment options for people with a given condition (such as being HIV-positive) supports biomedical control over such treatment.

Biomedical hegemony also supports a process of increasing rationalisation of experience (Bury 1998). Rationalisation is defined by Lyon (1994:24) in Weberian terms as *"the gradual adoption of a calculating attitude towards more and more aspects of life."* As far as this concerns the medicalisation of social life, rationalisation provides a feedback loop so that as soon as the institutional elaboration of modern biomedicine is well established in centres of biomedical expertise such as the clinic or hospital or pathology laboratory, its practices and perceptions imbue everyday life in innumerable ways. In relation to HIV-AIDS, surveillance studies and routine antenatal screening for HIV-infection are prime examples of this spread - populations are constantly investigated for signs of abnormality and infection. Echoes of this can be seen in the South African government's reticent stance on the deployment of antiretroviral treatment and a frantic fight to "control" the disease via the establishment of state-run surveillance facilities. The question then arises whether, in the minds of the academics providing policy recommendations based on their population projections and in the minds of the policy makers and policy implementers, populations still refer to actual living people with real histories, real stories and real diversities?

As far as HIV-AIDS is concerned, epidemiology provided the narrative and the conceptual frameworks for the social categorisation used in HIV-AIDS (Berridge 1992:49-50). Epidemiology set pregnant women up as the key sentinel groups for blood-testing in order to track the incidence of new infections – a practice so pervasive that it has become the main way of quantitatively describing the progression of the epidemic in South Africa. By epidemiologically connecting the incidence of HIV to a status discoverable in a pregnant woman's blood, woman's physicality was again subjugated by a powerful hegemonic discourse. Furthermore, epidemiology readily provided a language for susceptibility to HIV-AIDS that promoted the notion of risk groups[3] (Watney 1989:67).The ***othering*** in the social construction of HIV-AIDS was fuelled by the fallacy that HIV infects ***others*** - that is, people who are other than white, heterosexual or non-drug-users. This coincided with an attempt to blame these "others" for the spread of the disease (Bury 1994; Herdt 1992).

Although the dangers of the notion of "risk", is discussed below, it seems that what unifies the women in this study was that they presented an "at risk"-group. They were at risk of dying of AIDS-related illnesses. They were at risk of losing a young child to the toll of HIV-AIDS. They were at risk of losing their HIV-positive partners. They were at risk of infecting HIV-negative partners. They were at risk of being socially isolated. They were at risk of conceiving another HIV-positive baby. These risks reside in the fabric of sociohistorical constraints that placed these women in positions of disempowerment and NOT in their biographical personhood.

When unpacking the notion of risk, the prominence of the material dimensions of risk, embedded in the social realities of unequal opportunities in the educational, occupational and economic spheres and largely structured by race, gender[4] and class[5] becomes clear.

“Unmet need[6]” and “at risk” are labels that carry the danger inherent to the use of any label, namely that labelling (1) diverts attention away from the social circumstances that place these women at risk and (2) locates the risk within these women themselves. Following such a shift in focus, the burden of transformation is placed on the shoulders of the affected group, whilst the larger society is absolved from any responsibility to address the inequalities of race, class and gender that create the conditions of risk. Furthermore, the notion of risk silences the voices of the women themselves and obscures the differences between those in the labelled group (Carspecken 1996:7; Paicheler 1992:18;
Taylor, Gilligan & Sullivan 1996:237; Wilton 1997: xiii, 67-70, 126-124).

2.2.2 The domination of androcentric western biomedical discourse in the social construction of HIV-AIDS

In this regard Foucault’s suggestion of mechanisms of knowledge and power that evolve to form the competing discourses on sexuality, are informative. In particular his ideas on the hysterisation of female bodies and on the socialisation of reproductive behaviour seem relevant in this regard. Hysterisation refers to processes in which women’s bodies became sexualised, but in which issues related to female sexuality, such as reproductive health, pregnancy, childbirth, contraception and abortion were medicalised. Socialisation of reproductive behaviour refers to processes through which family planning became a domain controlled by the state and studied through the surveillance of population growth (De Lauretis 1987:16; Gavey 1996:53-56; Silverman 1985).

The Foucauldian view of the body is that of a site of resistance against control, regulation and standardisation. It is a resistance against the docile, disciplined and productive body created by capitalism. Foucault (1980a:139) declares*: “The disciplines of the body and the regulations of the population constitute the two poles around which the organization of power over life was deployed.”* Singer (1992:60) takes up this idea and suggests that the

AIDS epidemic provides justification for the state's intervention into the bodies of certain categories of individuals - gay men, military recruits, pregnant women, prisoners or intravenous drug users. This, according to Singer, is part of a wider trend in the normalisation and rationalisation of routine surveillance and screening of individuals and populations.

The power relations at work in this situation shape and form the consciousness of the "woman-living-with-HIV" - a consciousness that can be regarded as open to contestation, acquiescence or active reshaping. Even so, the phallocentric discourse of patriarchies[7] implies that women are made dependent on the medical profession to define their health statuses and to provide expertise in reproduction, health care and childbirth (see Bordo 1993; Casper 1999).

Moreover, concerns about mother-to-child-transmission of HIV rehash old assumptions about male invulnerability and female responsibility in respect of foetal health or risk. Consequently maternally mediated risk is granted overdetermined causality whereas father-foetal associations are dismissed. Clearly, given the prevalence of heterosexual transmission of HIV[8], for every HIV-positive mother that is at risk of infecting her current and possible future foetuses with HIV there is (potentially) a male partner out there who contributed to the infection. In the parlance of HIV-AIDS, official reports still shift between using the terms mother-to-child-transmission (MTCT) and parent-to-child-transmission (PTCT) to address this issue. However, individual responsibility for reproductive health can only make sense in a context of reproductive autonomy and self-determination which cannot be assumed in patriarchal societies (Wilton 1994:85). Ward (1993:426) makes the important observation that many women's reproductive illnesses are in fact vertically transmitted if viewed in terms of power in sexual relationships. The emphasis on vertical transmission should therefore be seen against the wider backdrop of the social construction of HIV-AIDS and the feminisation of STIs.

The feminisation of STIs takes medical surveillance of women a step further and introduces a discourse in which the foetus as the primary obstetric patient needs protection from uninformed and irresponsible mothers (Lay *et al* 2000:19). Sally Dowling (1994:116) found in her studies that in counselling[9] HIV-positive mothers on the risks of vertical transmissions and on the risks of pregnancies and childbirth to their health, the focus remains on a concern for the health of the baby as opposed to the mothers. Wilton (1997:70) deconstructs the preoccupation with the safety of the offspring (as opposed to the health of the mother) and sees a link between the ideologies of femininity and national and familial ideologies. Sherr (1996:18 & 29) also laments the lack of research foci on the experience of contraception, conception, pregnancy, childbirth and sexuality in HIV-positive women.

Weeks (1989) makes the point that through the social construction of HIV-AIDS, it has become a symbolic bearer of social composition, of racial boundaries, of social marginalisation and of sexual othering. These polarisations are stressed in various discourses around AIDS in a post-permissive society. The most dominant theme in AIDS discourse is the notion of lifestyles characterised by sexual overindulgence and carelessness in the face of prevention. Reasonable conduct is now defined in terms of self-control and risk management (Watney 1989:64). Megan Vaughan (1991) demonstrates how the introduction of biomedicine in colonial settings were embedded in the colonisers' anxieties about maintaining order over the "colonised other" for the benefit and safety of the colonisers and how this is at odds with self-reflexive subjects entrusted with taking responsibility for their own health.

The assumptions of rationality, individual choice and personal responsibility that underlie many public health care education campaigns ignore the dynamics of relative power in sexual relations. This has the further discursive effect of turning women's problems in converting knowledge about sexual risks into practice into paltry excuses (Richardson 1994:51; Ward 1993:422-3). Sherr (1996:35) suggests that abandoning powerful/powerless dichotomies in discussing sexual relationships between men and women may counteract this. She lists scenarios portraying women's reactions to HIV-AIDS in heterosexual relationships that (so she argues) can be seen as something other than lack of power - for example:

- Women's tendency to stay with their partners after disclosure of these male partners' HIV-positive status is not powerlessness but *commitment*
- Women's tendency to reveal their HIV-positive status to their male partner versus men's reported tendency not to disclose such details is not powerlessness but *honesty*
- Women's reported greater exposure to unprotected sex from their HIV-positive male partners rather than the other way around is not powerlessness but *male disregard*, *selfishness* and *lack of responsibility*
- Women's reported greater tendency to be tested and to be tested without informed consent for HIV is not powerlessness but *discrimination*
- Women's reported later attendance (in other words at more advanced stages of HIV-infection) for treatment and their tendency to rather bring their children for treatment than themselves is not powerlessness but *self-sacrifice.*

Upon closer inspection, it seems that what Sherr (1996:35) lists as something other than female disempowerment are in fact dimensions of their disempowerment. By trying to move beyond a lack-of-empowerment-stalemate argument, Sherr is reifying the very issue she is intending to attack. Lack of commitment, deceit, inattentiveness, egocentrism, disrespect, discrimination and self-deprivation reign supreme in heterosexual relationships precisely because women occupy a subordinate role.

Attending to the theme of women's roles in heterosexual relationships, Duncombe and Marsden (1998), Freund (1998), Hochschild (1997; 1983), Reay *et al* (1998) and Shilling (1993) refer to the emotion work women do. Women are more often called upon to do emotion work in support of their close relationships[10]. To refer back to Sherr's work commented on in the previous paragraph, it can then be said that women do the emotion work in sexual relationships in the presence of HIV-AIDS by becoming the caring, attentive, self-sacrificing partner. The consequence of one person in the dyad always undertaking the emotion work is that that person suffers the strain and develops a false consciousness[11], denial and a loss of authenticity.

Freund's (1990:452 & 1998:276) understanding of the consequences of an overload of emotion work is that it will disturb the bodily balance of forces and the actor's ability to interpret embodied feelings, resulting in emotional false consciousness. The latter involve a rupture between bodily expressions and an awareness of internal sensations. This analysis is a hook on which to hang an understanding of how individuals can conspire as their own agents of social control or in reproducing adversarial arrangements. The chronic experience of emotional false consciousness thus has the consequence of reifying inequitable relationships and blaming the victim. A docile body that, through a commitment to emotion work in close relationships, submits herself to surveillance, drug trails and dangerous sexual liaisons will undervalue her own ability to act. It is my contention that an understanding of this inequitable division of emotion labour and the social feeling rules that underpin these is crucial for making close couple heterosexual relationships for women safer in the time of HIV-AIDS.

2.2.3 Summary ideas on the social construction of HIV-AIDS

In the above section, the naming and framing of HIV-AIDS has been discussed. The contours of discourses that framed HIV-AIDS and its related health-seeking behaviours were outlined.

As mentioned in Chapter 1, HIV-positive women are expected to come to terms with their statuses, disclose their statuses to their partners, convince their partners to go for testing and use condoms, access health information and involve their doctors in any future planned pregnancies. It seems that the biomedical and androcentric discourses conspired to make women bear the burden of the epidemic. The following statement in a biomedical study of HIV-positive women in Burkina Faso illustrates the discourse of HIV-AIDS as women's troubles : *"Counselling recommends the adoption of a responsible sexuality and the choice for a combined approach (condom and hormonal contraception) to avert the transmission of the infection to others, most particularly to the husband and, above all, to limit the possibility of occurrence of a new pregnancy that would expose the new child to the risk of HIV infection and to the risk of becoming an orphan"* (Yacouba *et al* 2001:367).

Alternative discourses have the potential to bring to the fore different ways of knowing, naming, doing and being, thereby revealing taken-for-granted, normalised aspects of the social order. In the section below, two possible counter hegemonic discourses, namely self-directed healthy lifestyle choices and the empowerment of women are discussed. The first is evaluated as not a counter hegemonic discourse, but a masked extension of the biomedical hegemonic discourse. The latter, the empowerment of women discourse, is evaluated for its emancipatory potential.

2.2.4 A discourse of technologies of the self: Adopting a healthy lifestyle

It has been mentioned in Chapter 1 that the "own responsibility"-rhetoric can be seen as a possible counter hegemonic discourse to biomedical hegemony in the area of health. Counter hegemonic discourses can fracture hegemonic ones. However, introducing notions of self-care in an environment characterised by poverty and deprivation dilutes its liberating capabilities so that this counter discourse becomes usurped by the hegemony of biomedical control. The ideology that underlies the rhetoric of free, conscious, self-activating agents merges uncomfortably with disempowered recipients of the products of biomedical interventions. Self-regulation, self-control or own responsibility in reproductive health as technologies of the self[12] then becomes extensions of the social regulation and control functions of biomedicine. The reason why such an extension is possible is that hegemonic discourse already constructed reproductive health as belonging to the realm of the public. Biomedical hegemony furthermore enables the construction of human identities by the so-called helping professions (medical, psychological, psychiatric, social welfare, educational) not for reasons of rationality, but for strategic objectives relating to power and control (Fox 1995; Singer 1992:58; Turner 1992;Turner 1996:3).

Connell (1995:391) makes the interesting observation that by having sexual relations with another person you are already making decisions about that person's life. It is the extent to which that encounter is negotiated, communicated and full disclosures are made that we may speak of shared decision-making. This notion of self-regulated responsibility in reproductive health is usurped in a punitive biomedical discourse. Bury (1998:11-16) describes this tendency of biomedicine to infuse lay discourse to this extent as further phases in the objectification of disease. He describes a normalising process in which the emphasis shifts from the monopolistic professional expert to that of active consumerism and lifestyle. The consequence of this is an almost obsessive preoccupation with own vigilance and risk calculation (Bury 1998:11-12). Dilger (2001) points out that the "healthy lifestyle"-discourse extends into prescriptions[13] for "living positively" with HIV that imposes practices such as following a given diet, adhering to treatment regimes, going for regular check-ups and maintaining social activities which include a free exchange of ideas with advisors and fellow HIV-positive people on how to live with the disease[14].

Despite the rhetoric of a healthy lifestyle, this discourse on technologies of the self (Foucault 1988) allows for little reflexive consciousness and strategic decision-making. Instead the subject is seduced and disciplined in a game of chance and risk calculation. This constant personal vigilance almost imprisons the individual as he or she constantly weighs up risks, manages his or her health and considers his or her diet and environment. Wilton (1997: 10) makes a scathing attack against the rhetoric of individual responsibility to health and points out how ridiculous such and individuated mode of thinking would be if applied to military defence in which each individual is made responsible for defending themselves against attack or invasion. Aronowitz (1995:375) emphasises:" *Faced with the AIDS epidemic, to focus on self-help as some have done is to foreclose hope, except for the relatively small number of its victims who can be made more comfortable in their cline."*

South African academics and activists tend to partake in continual reform mongering as far as the Information, Education and Communication (IEC) campaigns regarding HIV and safer sex are concerned. Constantly improving messages, however, misses the mark completely as far as the sociopolitical contours of ill health are concerned. Instead, the constant bickering about the cultural acceptability of anti-AIDS campaigns amount to the clinical construction of culture as opposed to the cultural construction of clinical reality.

Fox (1998:35) suggests that part of the promise of postmodernism is to enable *the sick* and *the other* to embrace their right to otherness and to refuse and resist an objectified discourse. Part of the social construction of HIV-AIDS is collective reaction to the disease. Involvement in volunteer AIDS work may help resocialise HIV-positive persons and provide a vanguard against the ravages of a dominant discourse. In Goffman's terms (1963:121), this banding together of stigmatised persons in self-help groups can, however, also be seen as trying to achieve "phantom normalcy." In this way the "normals" (the unstigmatised) protect themselves from intimate contact with the stigmatised (Lock 2001a).

It should be apparent that forcing women living with HIV into support groups (or restricting their social expression to such groups) can be seen as an extension of othering and disempowerment. In the next section, the discussion therefore shifts from discourses to the notion of female empowerment and barriers to empowerment.

2.3 EMPOWERMENT OF WOMEN

Sen and Batliwala (2000:18) define empowerment as *"the process by which the powerless gain greater control over the circumstances of their lives."* Two important aspects are encompassed in this definition. First, it emphasises that empowerment is procedural and relational. As an outcome of a process of empowerment, it can also be the intended goal of emancipatory processes (Gage 2000). Second, it places power (versus powerlessness) at the centre of the definition. Foucauldian ideas assist in elucidating that there are different ways in which power imbues sexuality for women and men. Due to the power stemming from social practices and discourse, women may be moved to have sex with men irrespective of their own sexual desires and sensibilities about the dangers of unprotected sex in the era of HIV-AIDS.

These insights enable the understanding that there are dominant discourses on heterosexuality[15] that create subject positions for women that may prescribe passivity, compliance and submission (Espin 1996:90; Gavey 1996:53). The discourse on female empowerment is a powerful anti-hegemonic one, but as Gavey (1996:54) points out: "*although a woman may be theoretically free to resist the operations of power that persuade and oblige her to submit to unwanted acts, she does not always see or feel this freedom*."

Again, this brings the problematic of fertility change in the absence of female empowerment[16] in South Africa into sharp focus. Indeed it is the disempowerment of the research participants in this study ***as women*** that underlies the making of their sexuality. The discursive practice of conceptualising women as passive, submissive sexual subjects renders them vulnerable to heterosexual coercion (Fine 1988:36-7; Gavey 1996:53). This implies that women face threats of castigation of various forms (including physical violence) for asserting sexual agency in heterosexual relationships.

If the rhetoric of female empowerment in the post-Cairo population policy narratives is to be taken seriously, research in the area of reproduction needs to promote alternative understandings of women's sexual agency and autonomy that would disrupt and challenge the androcentric discourse of male dominance. Moreover, Sen and Batliwala (2000:18) notes that the empowerment of women includes control over physical, intellectual, emotional and financial resources as well as over beliefs, values and attitudes. This conceptualisation of empowerment points to intrinsic and extrinsic control over one's life.

Ward (1993:426) defines disempowerment as dependency in terms of a loss or abrogation of control. For her, the notion "dependency" is linked to "addiction" or being "subordinate" and she points out that whereas addiction is regarded as socially unacceptable, subordination is an organising principle in the lives of disempowered women. If wider empowerment of women is the project, then the challenge is to identify the particulars of the oppression of women without contributing to the discursive disposition of femininity as fragile, weak, powerless, and vulnerable and intrinsically a victim. Sen (1985:208) makes an important contribution to this debate by distinguishing between negative and positive freedom. With negative freedom, people are freed from the negative consequences of others having power over them. Positive freedom takes empowerment further from mere emancipation and encompasses a power to achieve chosen outcomes in one's life.

Kabeer's (1999) analysis of empowerment links it to resources (as constraints or enablements), agency (as the procedural part of empowerment) and achievement (as the outcome of empowerment). In terms of resources, extreme deprivation and dispossession are disempowering in all aspects of life, whereas agency links empowerment with choice or decision-making. Kabeer (1999:3) makes the important observation that not all decisions in life are equally important and that in respect of the empowerment of women, strategic life choices are the foci. For Lorber (2000:86) empowerment encompasses both gender equality and gender-marked equity. Under gender equality she sees the roles of men and women becoming fully interchangeable. Under gender-marked equity she sees the acknowledgement that there are physiological and procreational sexual differences between people and the quest to make these differences socially equivalent.

Many observers connect the empowerment of women to the extrinsic factors such as education and access to financial resources. Such analyses often point to the equally important role played by intrinsic and interpersonal factors. Cleland and Kaufmann (1998) in their study in Bangladesh on the link between female education and autonomy for example found that as far as reproductive decision-making and control over household resources are concerned, uneducated and educated women are equally disempowered. The empowering potential of education fades in the face of structural powerlessness. Also commenting on the link between female education, the empowerment of women and demographic change, Bradley (1995) suggests that the status of women can change in many directions under the influence of education and can have unforeseen consequences. More importantly, Bradley (1995:171) observes that empowerment of women through education relies in great measure on the availability of job and other economic opportunities in which to apply newly acquired skills.

Kabeer (1999:3) links resources not only to the above mentioned extrinsic factors, but also to structural elements linked to the actual allocation of resources (distributive resources). Also added to this equation are authoritative resources that enable social agents to delineate priorities and impose claims to resources. By drawing on authoritative resources, for example, chiefs, relatives, heads of households and so on can exercise decision-making power that exceeds that of the individual woman or couple. England (2000) also refers to these aspects in her discussion of frameworks and norms (see below).

Paula England (2000:52) offers a framework to examine female disempowerment by taking cognisance of both intrinsic and extrinsic factors. She identifies:

1) ***Economic resources***. In this study, poverty (as a form of structural powerlessness) is regarded as an important cross-cutting structural barrier to empowerment.
2) ***Legal and institutional frameworks***[17]. For England (2000:47) this also includes a contemplation of policies that influence the cost of bearing and caring for children. She makes the important observation that women who raise their children alone "*directly provide more of both the labour and the money that goes into raising children.*"
3) ***Informal norms.*** England (2000) differentiates between unequal treatment norms and norms that result in unequal impacts. Under disparate treatment norms,

England (2000:52) includes norms that give men more rights, greater control over resources and more power; regard women as nurturers and as destined to do all the housework and give men power over their wives and sisters. Under norms that result in disparate impact by gender, England (2000:53) includes norms that value toughness and competition as desirable male dominant behaviour and discourage women's social networks[18].

4) ***Internal subjective states***. With internal subjective states, England (2000:55) refers to a sense of self-efficacy and entitlement. For England self-efficacy is the belief that one's considered actions will have the desired, intended effects. She observes that even in a context with equitable access to material resources, women may fail to act in their own best interest if they have an insufficient sense of self-efficacy and believe that their endeavours to become more empowered are ultimately doomed to fail. For England a sense of entitlement entails thinking about what one deserves with reference to other social actors. A disempowered woman may believe that she deserves little and consequently not act in accordance with resources available to her. Kabeer (1999:7) also observes that disempowerment may be the product of choices made by women themselves and that this should be seen as the result of some women internalising suppression.

These intrinsic characteristics are shaped by the other factors and, in the area of HIV-AIDS, have bearing for women's abilities to negotiate their own protection from disease or to persuade an infected partner to seek treatment. The choices available to women living with HIV, and the consequences of such choices can become transformatory and destabilise social inequalities or can reproduce such inequalities. As Kabeer (1999:10) mentions: *"Choices that express the fundamental inequalities of a society, infringing the basic rights of others or systematically devaluing the self, are not compatible with the notion of 'empowerment'".* Therefore the final component in gender relations in England's (2000:55-56) framework is important. This component is the actual exercise of power which stems from the external (i.e. laws, norms, values, resources, rules) and internal power factors (i.e. self-efficacy and entitlement or the lack thereof).

Stigma related to HIV-AIDS cuts across all the components mentioned by England, as stigma:

- Follows the fault-lines created by social disadvantage
- Prevails in the face of non-discriminatory legal frameworks
- Are located in informal norms and influence subjective states.

2.3.1 HIV-AIDS stigma

The stigma of HIV-AIDS is a central concern in the sociological study of the disease. In this sense it is important for the purposes of this study to define stigmatisation as a social construction and not as an individual attribute. Many commentators link HIV-AIDS stigma to the way that the disease has been named and framed by the biomedical discourse. In other words, HIV-AIDS is stigmatised as signifying moral decay (Gilman 1988; McGrath 1990; Turner 1992; Weeks 1989).

Stigmatisation inevitably leads to discrimination and a vicious cycle starts in which people are afraid to talk about the disease and to disclose their statuses. HIV-AIDS-related stigma and discrimination build on pre-existing forms of stigma and discrimination associated with sexuality, gender, race, and poverty. It deepens pre-existing fears about contagion and disease. The discourse about AIDS as punishment, guilt, shame, and otherness has intensified these fears, reinforcing and legitimising stigmatisation and discrimination (Herek 2002; Parker *et al* 2002).

Part of HIV-AIDS-discourse was racist assumptions about "African sexuality" on the one hand and by perceptions of Western “immoral behaviour” on the other. Racial and ethnic stigmatisation contributes to the marginalisation of minority population groups, increasing their vulnerability to HIV-AIDS, which in turn exacerbates stigmatisation and discrimination (Parker *et al* 2002). The HIV-AIDS epidemic coincided with a growing polarisation between rich and poor and this also reinforced pre-existing social inequalities and stigmatisation of the poor, the homeless, the landless, and the jobless. Accordingly, poverty increases vulnerability to HIV-AIDS, and HIV-AIDS exacerbates poverty (Parker, Easton & Klein 2000). Martha Ward (1993:413) explains that for poor women in New Orleans, HIV-AIDS is yet another life-threatening condition added to a whole bunch of serious diseases.

It is clear that pre-existing sources of stigma, such as those related to sexuality, race and class overlap and reinforces one another. This interaction leads to a two-step deepening of HIV-AIDS-related stigma. First, because HIV-AIDS is associated with marginalised behaviours and groups, all individuals with HIV-AIDS are assumed to belong to marginalised groups. Second, HIV-AIDS exacerbates the stigmatisation of individuals and groups who are already oppressed and marginalised. This in turn increases their vulnerability to HIV-AIDS (Malcolm *et al* 1998; Parker *et al* 2002; UNAIDS 2000).

Bourdieu's concepts of habitus, capitals and symbolic violence are useful in this regard. Bourdieu (1986) differentiates between economic, social and cultural capital and when any or all of these capital forms are recognised as legitimate by others, it transforms into symbolic capital. Bourdieu sees cultural capital as referring to embodied capital in terms of the knowledge, skills, dispositions, linguistic practices and representational resources of the bodily habitus (Carrington & Luke 1997:102). A person's accrual, control over and use of capital take place in what Bourdieu conceptualises as a "field". Fields are "*semi-autonomous, structured social spaces characterised by discourse and social activity"* (Carrington & Luke 1997:100). Living with HIV and accessing public health care can therefore be seen a field in which care providers and recipients/clients/patients differ in their convertibility of the various types of capital available in that field. Bourdieu' notion of symbolic violence as *"violence which is exercised upon a social agent with his or her complicity"* (Bourdieu & Wacquant 1992:167) is pertinent to our understanding of stigma and women living with HIV.

Symbolic violence and hegemonic discourses combine in HIV-AIDS to establish social order and control in a struggle for power. Symbolic violence and hegemonic discourses furthermore convince the dominant to accept existing hierarchies and to limit the ability of the oppressed to resist the forces that discriminate against them. Leclerc-Madlala (2001:533) illustrates this convergence of symbolic violence and hegemony poignantly in terms of women and HIV when she says that the growing popularity of virginity testing in, for example KwaZulu-Natal, should be seen as *"a gendered meaning-making process consistent with commonly held beliefs that the epidemic is the result of women being sexually out of control"* and as *"an attempt to manage the epidemic by exerting greater control over women and their sexuality."*

Lovell (2004:51) suggests that symbolic violence is inflicted on women because of their sexed identities – combined with an HIV-status the force of symbolic violence is amplified. This brings up the notion of reflected appraisals whereby individuals form self-perceptions on the basis of how they perceive others to see them. It also extends to situational identity negotiation whereby people strive for congruence between their self-perception (own identity standard) and reflected appraisals (Kaufman & Johnson 2004:808-811). This "working" on the self - or in Goffman's (1963:63-40) words the moral career of the stigmatised (in order to pass as normal) is further examined in the next section on HIV, embodiment and social contexts.

2.4 HIV-AIDS, CHRONIC ILLNESS, EMBODIMENT AND SOCIAL CONTEXTS

In keeping with Foucauldian notions of power as constraining but also potentially liberating, sociological studies of chronic illness narrative were examined to discover how the experience of illness can offer moments for contestation and emancipation. The questions that presented themselves were:

- Can claiming a woman-living-with-HIV-identity empower individuals to become active decision-makers who live positively, exercise choice in their own interest and experience greater freedom and better health through self-management?
- Can people dependent on public health service delivery and already overburdened by poverty embrace this?
- Can women experience HIV-illness as gaining agency? Can they accrue corporeal symbolic capital in a disclosed living-positively status?

Studies that have investigated the personal experiences of people with AIDS have drawn on related works dealing with chronic illness and dying such as the seminal works by Elizabeth Kubler-Ross and Bernard Lapointe (quoted in Pierret 1992). Other investigators emphasised transitions in identity upon learning about one's HIV-positive status, using a concept coined by Michael Bury (1982:169-70) namely *biographical disruption.* According to Bury (1982) such a disruption involves a disruption in personal assumptions and behaviour; explanatory systems and self-concept and mobilisation of resources.

While these works are all-important contributions, it should be kept in mind that AIDS is different from other terminal illnesses in the following important respects[19]:

- There is a varying, but often long, protracted and unpredictable latency period between HIV-infection and the appearance of symptoms of AIDS
- There is a varying, protracted and unpredictable period between the first appearance of opportunistic infections and more severe manifestations of the illness
- The risk of illness remains a constant threat and it requires the HIV-positive person to be constantly vigilant. In addition, the most competent contemporary treatment strategy involves costly multiple drug therapies that at best anticipates the transformation of HIV into a chronic fatal disease whose sufferers survive for

several decades (Morris 1998:59)

- Although the diagnosis of HIV-infection is certain, the prognosis for the development of full-blown AIDS is uncertain. In other words, the threat of serious illness is ever present, but neither the form nor the timing of that threat is known.

These uncertainties surrounding HIV-AIDS lead Morris (1998:59) to conclude that:*” AIDS is in many ways a mirror of postmodern uncertainties..... And its association with changing sexual behaviour and gender roles give it a prime claim as the master illness of our time.”* At the same time, however, death is the inevitable outcome of this terminal disease.

The notions biographical disruption[20] and biographical reconstruction are useful heuristic concepts to describe the identity work that needs to be undertaken by the HIV-positive individual. Following a critical orientation in this study, notions of power as constraining and enabling were mapped onto sociological notions of the autobiographical and reflexive self. In other words, the study assumed the possibility of social actors to become self-reflexive persons *“understood by the person in terms of his or her biography”* (Giddens 1991:54).

The uncertainty of the illness trajectory of HIV-AIDS and the often protracted nature of the asymptomatic HIV-infection status necessitate the individual to undertake biographical reconstruction in order to cope. The HIV-positive person needs to reconstruct and gradually reaffirm his or her identity and sense of self. In analogy to the sociological understanding of chronic illness, part of the biographical disruption that occurs in a person upon learning about his or her HIV-positive status, is that his or her taken-for-granted understandings of his or her own body is disrupted and the person feels alienated from his or her own body (Williams & Bendelow 1998:135). In this respect, Hankins (1996:2) reports on a few studies that have found a loss of libido in HIV-infected women. In the majority of such cases, fear and confusion about options for sexual activities were cited as the main reasons for this.

Biographical disruption deepens when HIV-infection becomes symptomatic of AIDS. The work done by Kathy Charmaz (1991 & 1995) on the sociology of chronic illness suggests phases in such a reconstruction process that involve:

- Developing coping strategies[21] (for the HIV-positive person this includes dealing with uncertainty and stigma[22], self-reflection and temporary isolation)
- Developing an illness career or illness trajectory (for the HIV-positive person this includes the search for information to deal with a compromised immune system as well as a range of psycho-social factors related to the disease)
- Adjusting one's social context (for the HIV-positive person this involves issues relating to family life, reproduction, marriage, intimate relationships, workplace and future plans and association with volunteer organisations). Some of these ideas are explored in the next section on HIV-AIDS illness careers.

2.4.1 HIV-AIDS illness careers

The development of illness careers is an idea found in many sociological studies on chronic illness. Coyle (1999), Davis (1996), Riemann and Schütze (1991) and Strauss and Glaser (1975) use the notion illness trajectory to describe a process that involves:

- The realisation that there is something seriously wrong with one's body
- Regarding one's body as different, flawed, uprooted[23]
- Upon perceiving that there are no solutions to these physical failings, developing feelings of hopelessness, despair and eventually resignation.

The contours and parameters of a sick role are located in discourses that shape the acceptability of that role. As envisaged by Parsons (1951), the sick role carries with it the prescripts of ideal patient behaviour and implies certain responsibilities in return for being let off from work and family commitments. According to Parsons sick people were expected to get healthy by seeking help and by observing medical regimes. Being healthy therefore becomes a moral duty and illness is a failure of that duty. Popular conceptions of illness are imbued with moral judgements about personal integrity and competence (Coyle 1999). The different nature of HIV as a chronic disease makes the contouring of such a sick role all the more difficult. Coupled with the stigmatisation of HIV and AIDS, the task of reconstructing a moral identity by demonstrating competence, knowledge and rationality becomes an arduous one indeed.

In a comparable vein, Carspecken and Apple (1992:519-523) refer to the notion “normative realms” in their analysis of presentations of the self. Normative realms are separate from the subjective states of the actors so that people can, and often do, deceive others about their actual subjective states. They assert: *“It is because one’s own identity is not the same as one’s subjective states that one must constantly claim to be a certain kind of person in social interactions and look towards the reactions of others to gain a degree of certainty about it”* (Carspecken & Apple 1992:526).

In addition Carspecken and Apple (1992:529-530) suggest that certain groups of people are systematically undervalued because they lack control over the normative realms that enable the construction of identity repertoires. Such people are allowed truncated, impoverished selves restricted by the forced use of identity repertoires dominated by others. Human actors in these settings display coping behaviour in the form of:

- Repressing impulses
- Developing low self-esteem by believing that the impoverished identities are the only means to gaining some kind of recognition
- Developing different identities suitable to different social environments (Carspecken & Apple 1992:546).

Dana Jack (in Anderson & Jack 1998:164) used a similar frame of reference in her oral history interviewing with women suffering from depression. She came to realise that*:” a person’s self-reflection is not just a private, subjective act. The categories and concepts we use for reflecting upon and evaluating ourselves come from a cultural context, one that historically demeaned and controlled women’s activities.”* She notes how the depressed women in her study at first glance exhibited “typical” characteristics associated with depressive females, namely that they were passive, dependent and compliant (Jack in

Anderson & Jack 1998:165). Through immersion in the oral histories of these women, Jack (in Anderson & Jack 1998:165) uncovered that her research participants' sense of despair derived from their inability to be authentic selves whilst at the same time meeting moral obligations of the "good woman" (Jack in Anderson & Jack 1998:166). Jack (in Anderson & Jack 1998:169) suggests three ways of listening that would alert the researcher to the mismatch between subjective states and normative realms, namely, to listen to:

- The narrator's moral language – or clues to moral codes or norms
- Meta-statements in the narrative (that is statements that demonstrates a tension between what is expected and what is said)
- Changes in the logic of the narrative (contradictions may be clues to the tension between subjective states and normative realms).

The social context, and in particular, family life can act as a buffer against despair and assist in biographical reconstruction. In most developing countries, "family" is the main source of care and support for HIV-infected persons or persons living with AIDS (Aggleton & Warwick 1999; Parker *et al* 2002; Warwick *et al* 1998; World Bank 1997). These issues are further examined in the next section.

2.4.2 HIV-AIDS and the social context

An issue that touches both on coping strategies and on changes in the social and familial context is the topic of this study, namely reproductive decision-making in persons who are HIV-positive. Worldwide the largest proportion of HIV-infected women are at an age when they are under strong social and cultural pressure to bear children and many of these young women only learn about their HIV-status once they have fallen pregnant and attend antenatal clinics (Dowling 1994:115).

Sunderland (1990) in her study of the reproductive choices of HIV-positive women found that 50 per cent continued their pregnancies to term. Two other notable studies in this regard are those by John Arras (1990) and Carole Levine and Nancy Neveloff Dubler

(1990). Both these studies investigated reproductive decision-making in HIV-positive Western women and both suggest counselling for such women to *“lead full lives independently of reproduction”* (Levine & Neveloff Dubler 1990:345) or to make different choices based on *moral education* (Arras 1990:374). Transplanting these ideas to contexts in which reproduction is part of female identity somehow rings false. In the context of female disempowerment, the individual woman’s reproductive health is not a purely individual affair. Moreover, an individual’s rights rhetoric is foreign to such a context where reproduction and production are both integral to social relations. In addition, these prescriptive approaches come across as silencing the voice of women as a typical form of othering that aims at telling HIV-positive persons how to be and how to behave and how to be more responsible. In other words, the recommendations with which these researchers chose to conclude their research on HIV-positive women resulted in making their research participants appendages of a dominant discourse. In this respect, Laurie Hauer[24] (quoted in Panos Institute 1990b:47) makes a more insightful comment: *“For many women, childbearing is seen as life-affirming in the face of poverty, drug use, racism, and perhaps the loss of other children to foster care or AIDS.”* It should also be noted that women often have to campaign for a cluster of primary health concerns (such as food, shelter, safe water, sanitation, primary care services, environmental pollution) besides HIV-AIDS. In this regard Wilton (1994:87) laments the absence of collaborative work amongst women to protect their own sexual health.

In terms of HIV-AIDS, safe sex is equated with marital sex, yet practices such as incest and intramarital rape is preserved (Singer 1992:42-43). Russell’s (1982) research on marital rape for example, reveals that sexual violence by husbands occur along a continuum of coercion, intimidation, claims to ownership, rights and needs, economic pressure, persuasion and traditional interpretations of marriage. Keeping in mind that according to the World Health Organisation (WHO), unprotected heterosexual sex accounts for 70 to 75 per cent of all HIV-infections worldwide (Wilton 1994:2), unless male fidelity can be assured, conception cannot be combined with sex that is safe for women and their unborn children (Doyal 1994:20).

Richardson (1994:51) and Singer (1992:67; 81) observe that the very notion “safe sex” is part of a male-dominant, phallocentric, classist and exclusivary discourse. It assumes that sex was safe prior to the problem of HIV-AIDS. In terms of the risk of HIV-transmission, phone-sex and certain forms of pornography can also be construed as safe sex, yet these practices carry physical and psychological threats for women. In addition, history reveals the violent appropriation of female bodies during colonial occupation and military invasion and the continued practice in the postcolonial global market via sex tourism.

Whilst underemphasising the structural basis of women’s subordination, Jean Baker-Miller’s (1986) notion of the self in relation theory holds that women are oriented towards others and towards building and maintaining meaningful relationships[25]. According to Baker-Miller (1986) this happens because women’s unequal ascribed roles and statuses make giving to others a central part of their identities. Working from this premise, it then seems that negotiating safer sex in a situation in which the discontinuation of the relationship holds greater danger for women, renders personal risk reductions problematic for women.

2.4.3 The power to become empowered: Biographical reconstruction for the HIV-positive woman

Every step in the biographical reconstruction process for the HIV-positive woman, who has learnt about her condition, is fraught with contradiction[26]. Every positive step towards dealing with the illness holds the danger of surrendering more personal control. The HIV-positive woman has to depend on medical professionals to watch out for signs of illness, thereby intensifying the objectification of the disease. Making the decision to start taking ARV-drugs is another step in the biographical reconstruction that necessitates further surrender to biomedical monitoring and surveillance. Somewhere in this process controlled by medical experts, issues of sexual activity and reproduction will also have to be, in a sense, surrendered to the scrutiny and sanction of medical professionals. In further exploring these issues, the notion of “being a woman” is dealt with and then “being a woman with HIV” is discussed.

2.4.3.1 Being a woman

The heteropolarity[27] of sex and gender rests on the assumption that biological sex predates gender. In addition, it assumes that biology is somehow universal whereas culture, race, or class are not (Riley 1997b). Against this type of biological reductionism or foundationalism, Judith Butler (1990), maintains that gender is performative. In other words gender is discursively reproduced and a relational concept instead of the label for some essence. Gender performativity fits into a postmodern understanding of identities as fragmented and multiple and with an understanding of the self as having no fixed essence. Instead, gender performativity refers to acts that, through repetition, constitute gender identities.

In this sense the label ***woman*** is not a fixed, synchronous and monolithic term, but a provisional term to describe a self-identity built around sex/gender. Along the same line, women as a group with a common identity across cultures and contexts or as a commonly oppressed, already constituted, coherent group is equally misguided. When reproduction is heedlessly linked to women in demographic studies so that reproduction becomes the most salient way to think about gender, we have the discursive enforcement of a norm.

Young (1995:192), however, argues that this kind of reasoning is problematic for the project of feminist research and that the reason for conceptualising women as a collective is first to provide feminism with a subject by pointing out that women occupy a structural collective social position of oppression and second to sustain a viewpoint counter to liberal individualism (which tend to obscure oppression and locate problems within the individual). The dilemma it seems is as follows: Feminist and empowerment-oriented approaches are compelled to describe women as a social collective, but they must at the same time guard against falling into a trap of false essentialism. For Caraway (1991), Fuss (1989:36) and Russo (1991) the solution to this dilemma is to draw on identity or coalition politics, thereby using the identity *woman* to invoke a fluid construct for political action or to forge unity, solidarity and a common commitment to fight oppression.

Obviously, the biological components cannot be ignored in analyses of health, though that does not make it easier to delineating the biology/culture interface. The complexity increases if we heed the warning by Haraway (1996:323) *that "Biology is not the body itself, but a discourse on the body."* Lock (2001b:483-484), Mohanty (1995) and Nicholson (1995) stress that embodied experiences such as well-being, health or illness are partially informed by the body. At the same time physical bodies are contingent on evolutionary, environmental, and individual variables. In this way the biological and the social are co-produced and dialectically reproduced.

2.4.3.2 Being a woman with HIV

Strange as it may seem, the tragic reality of HIV-AIDS forces us to deal with the biological underpinnings of sex, to look at women as a group and to come to terms with vulnerability and susceptibility to disease along the contours of sex, gender, class, race and age. In terms of biological sex, studies suggest that women are at a greater risk[28] than men of contracting HIV from an individual act of sexual intercourse on the one hand and from each sexual partnership on the other hand (Doyal 1994:13). Moreover, HIV-AIDS emphasises the complex link between biology and the sociocultural contexts that shape it.

The social construction of gender provides limited ways in which women can recognise and legitimate their bodily experiences and practices. Of course women can resist these constructions, but in order to do so, they must be adequately empowered, become critically conscious of disembodied femininity and have effective strategies to acquire and secure their empowerment. Holland *et al* (1994:71-75) suggest that for women who are in situations where sexual encounters are defined by men, the subordination of women's desires to the needs of men and the disciplining of their bodies feeds the disembodiment that distances them from their own sexuality and from caring for their own bodily safety.

HIV-positive mothers are defined almost exclusively as mothers who should be watched, objectified in surveillance studies, educated and monitored. Since femininity is construed as nurturing and protective, a mother who fails to protect her babies against a killer disease is seen as pathological (Travers & Bennett 1996:67).

Of interest is to note the trend in Western medical discourse that attempts to draw both partners into a consideration of reproductive issues in a mutually supportive relationship. This is almost nonexistent in South Africa where contraceptive issues and the risks of reproduction are shouldered almost exclusively by women.

Having the financial resources to protect oneself against reproductive and other health risks (such as access to emergency HIV preventive drugs after a rape) causes a stratification of risk. In a related field in reproductive health, namely antenatal and genetic screening for foetal abnormalities, Condit (2000:138) clearly points out that parents who make use of high-tech antenatal screening tests have the financial resources, are able to use the test result information, possess values that favour control over reproduction and embrace rational and statistical assessment to guide their decision-making. Such parents are in a much more favourable position to act on their reproductive choices, yet counsellors, doctors and geneticists are still powerful gatekeepers preventing access to the available technology. This means that the structuring or pre-structuring of biomedical information remains an important factor superimposed on issues of wealth and class to shape and influence preferred reproductive outcomes and acceptable risks in that regard.

By placing social class and stratification at the level of macro-analysis, it is not difficult to see the interrelatedness of the health status of a population, world markets and labour. Migrant labour systems in many previously colonised areas, impoverishment of rural areas, the creation of urban slums and poor women entering into sex work or sexual barter arrangements to support themselves and their children all created contexts conducive to the spread of STIs[29] including HIV (Hankins 1996:3; Levinson 1998:72). Wilton (1997:6) observes*: "It has long been recognized that social factors such as socio-economic class, geographical location and occupation exert a significant influence on who becomes ill, why, how and at what age, and on their chances of recovery…It would indeed be surprising if the human immunodeficiency virus were an exception to this, and clearly it is not. AIDS is rapidly becoming a disease of poverty both globally, in its observable impact on countries impoverished by colonialist exploitation, and locally, in its tendency to affect disproportionate numbers of the poorest people even in the rich nations of the industrialized West."* Wilton (1997:118) also opines that the spread of HIV coincides and moves along socially constructed vectors of power so that poverty, stigma and oppression are found to be factors associated with high rates of morbidity and mortality, irrespective of the disease under investigation.

Moreover, poverty and disempowerment exacerbate HIV-infection. In terms of vertical transmission of HIV, so-called biological co-factors that elevate the risk to both the mother and the baby are often discussed in ambivalent terms. So, for example, caesarean section, hypothesised to reduce the risk of vertical transmission by lowering the baby's exposure to blood and vaginal secretions, is termed a compromised benefit (see Campbell 1999:42) due to the increased risk of maternal morbidity. In actual fact, poor women, without medical aid benefits and not near well-equipped medical centres, are more likely to have vaginal births or be denied caesarean sections even if they wanted it. Advice to birth attendants and midwives in South Africa regarding delivery care for HIV-positive mothers is not to rapture membranes, to administer Nevirapine when the membranes are ruptured, to refrain from performing episiotomies and to clean the birth canal at regular intervals[30]. This management of births to disempowered HIV-positive pregnant women focus primary on the prevention of MTCT and not on the woman's wishes or comfort.

2.5 RATIONAL-CHOICE FRAMEWORKS IN THE ANALYSIS OF FERTILITY: WHAT HAPPENS TO AGENCY?

Microeconomic and rational choice approaches (or rational actor theories) regard social actors as motivated to maximise their benefits and as rational (calculating, informed, thinking, agency-overloaded) creatures. Whereas the macro-level demographic transition theory and diffusionist approaches regard people as the passive victims of culture, the microeconomic perspectives and the rational actor theories tend towards a less cultural deterministic view of demographic actions. However, their view of culture is one that disregards particular contexts of actions and culture is regarded as the "thing out there" that creates opportunities and preferences (Carter 1998:246).

Central to the rational choice perspectives on fertility decision-making is a view of demographic actors as rationally weighing up preferences (or benefits, or consumer tastes) against opportunities (or costs). Decision-making is thus regarded as analogous to consumer choices. According to Susan Greenhalgh (1995:8) these approaches *"still focus on the economic calculus of fertility decision-making, neglecting contextual and historical forces impinging on those cost-benefit deliberations."*

Rational choice theory champions the agent as envisaged by classical economics as an idealised person whom can calculate, is extremely knowledgeable (and can access available information readily), is consistent, selfishly organises her own desires and makes informed choices (Archer 1998:78; Skeggs 2004:82). Supply-and-demand frameworks of fertility are not able to explain the specific local circumstances and its historical antecedents that facilitate high fertility, or high infant mortality (Bongaarts 1993). Fertility decision-making is regarded as essentially rational, individual-level and family-level choices and this assumes a context that allows for free, rational choice at the level of the individual (Carter 1998:250). It also does not seem to provide an explanation for persistent high fertility despite the high opportunity costs of children and the fact that few parents in developing societies are able to pay all their children's costs (Bledsoe 1994). The rational-choice model furthermore builds on the assumption that the cost of child rearing is carried by couples or the mother alone. In fact, Bledsoe (1994:112) argues that the spacing of children is seen in some African societies as a means of ensuring that older siblings contribute to the economic burden of raising their younger siblings. Child fostering is yet another means of dispersing the opportunity costs of child rearing in some African communities to the benefit of the child (Bledsoe 1994; Bledsoe, Banja & Hill 1998; Bledsoe & Brandon 1992). A further objection to the classical cost-benefit analysis of fertility decision making is that the commodification of such a fundamental human act such as producing offspring seems awkwardly at odds when considered against the female empowerment approach mentioned before.

Studies (such as Kabeer 1999; Kofman 1999; Randall & Le Grand 2003) suggest the reality of constrained decision-making contexts for demographic actors as far as gender roles, marriage, reproduction, health and migration are concerned. Bledsoe (1994:124-5) for example, refers to the *retention of reproductive options*. This refers to the tendency amongst poor people to not opt for permanent methods of family planning because fecundity and fertility are social investments in the face of uncertain circumstances. Faced with uncertain socioeconomic circumstances, holding on to the possibility to reproduce for as long a period as possible is a rational survival strategy offering the hope of forming beneficial personal ties to spouses and their networks.

It would therefore seem that the current stock of theories available to explain fertility decision-making is inadequate to help observers understand reproductive decision-making in the era of HIV-AIDS. Surely a diagnosis of a serious incurable chronic condition such as HIV presents any free, rational actor with a dilemma about future childbearing and sexual practices. In defending an empowerment-of-women-approach for demographic research in general, Dixon-Mueller and Germaine (2000:73) suggests that, just like decisions about the division of family labour, income and resources, decisions about reproduction are also part of general social struggles for survival, security and social advancement. The strategies developed for such struggles play out differently for men and women.

2.5.1 Theory that can accommodate problematic choices

What is needed for contemplating the reproductive health options and choices of women living with HIV is a theory that can accommodate constrained choices. Hewitt and Valverde (2000:271) suggest*: "Women's experience of illness and women's dealings with medical and other health service providers – experiences that have been so formative for women's movements around the world – can best be addressed and understood through innovative interdisciplinary work undertaken by activists and scholars with broad intellectual interests and a spark of creativity."*

Theory on reproductive decision-making amongst HIV-positive women therefore needs to incorporate these women's dealings with their seropositive statuses as well. Excursions into sociological thought on rationality in constrained situations bring up theories by Boudon and Bourdieu. Raymond Boudon advocates reason (a cognitive model of agency) as opposed to utility-maximising rational choice. Reason in this sense is tempered by norms, values and structural constraints (Hamlin 2002). In addition, the kind of rationality that is used depends on the structure of the situation in which the action occurs.

Bourdieu's notions of field, habitus, capital and symbolic violence have relevance for theory on constrained decision-making in the era of HIV-AIDS as an epidemic of signification. Bourdieu (Bourdieu & Wacquant 1992) offers the concept of field as *"a network, or a configuration, of objective relations between positions"* to accommodate the relational character of social structure. Fields are sites of struggles over the (economic, symbolic, social and cultural) capital that confers access to specific goods at issue in a particular field. The spread of capital charts the structure of a field and actual and potential access to capital delineates power positions relative to the production and reproduction of capital in the field. Although Bourdieu (2001) envisages women as holders of a feminine habitus denoting subjection, feminists such as Lois McNay (2000; 2004) and Bridget Fowler (2004) argue that gender is neither a field nor a habitus, but rather a form of symbolic violence in a cultural field so that different forms of femininity emerge. As discussed earlier on in this chapter, Bourdieu offers the notion of symbolic violence as the device whereby the socially subjugated naturalise the *status quo* and blame themselves for their structural subordination in society's hierarchies and injustices.

In the habitus, Bourdieu offers a system of prereflexive dispositions that departs from the model of agency that is wilful and rationally utilitarian. In addition, the habitus has a past, present and future: *"this system of dispositions - a present past that tends to perpetuate itself into the future by reactivation in similarly structured practices, an internal law through which the law of external necessities, irreducible to immediate constraints, is constantly exerted"* (Bourdieu quoted in Jenkins 1992:6).

These notions (cognitive agency within a given situation, a habitus that produces practices, symbolic violence and capital) opens up the possibility to look at constrained decision-making with antecedents in past forms of behaviour regarding sexual and reproductive health. In addition, these notions can be grafted onto an extended version of England's model of the disempowerment of women as discussed earlier on in this chapter. Moreover, these notions can be used to energise a critical sociological understanding of living with HIV as a woman dependent on public health care in South Africa.

2.6 CONCLUSION

In this chapter the social construction of HIV-AIDS with reference to the hegemony of biomedical and androcentric discourses was explored. This was juxtaposed with an exposition of a discourse of healthy lifestyles as technologies of the self. Women's empowerment was considered with reference to stigma and discrimination as products of hegemony and symbolic violence. This was followed by a review of HIV-AIDS as illness experience. Finally reproductive decision-making models and theories were critically analysed for their applicability to women living with HIV. It was posited that theory that can accommodate constrained decision-making can offer up rich concepts to examine the experiences of women living with HIV.

A review of the literature revealed that women's empowerment is multilayered and complex. Whereas policies prescribe an empowered, informed health consumer as the foundation of public health care services and responsible citizenship, critical political, economic and sociocultural factors impact on the achievement of this ideal. As discussed in Chapter 1, the aims of this study were to critically examine empowerment of women living with HIV as it is framed by social constraints and enablements and to expose experiences of women living with HIV within the context of hegemonic discourses. In an effort to achieve these goals, fruitful and interesting intellectual debates occurring in the nexus of themes relating to women, empowerment, reproductive health, HIV-AIDS and constrained decision-making were explored in this chapter, which in conjunction with the critical research approach as discussed in the next chapter provides a frame of orientation for the study.

ENDNOTES FOR CHAPTER 2

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[1] This argument does not claim to negate or refute the centrality of biomedical science in producing the form of knowledge that enables us to identify the nature and threat of AIDS. Rather the intention here is to point to biomedical science's privileged position as an expert discourse.

[2] Turner (1992:21) defines medicalisation as "*the rational application of medical knowledge and practice to the production of healthy, reliable, effective and efficient bodies."*

[3] The point is however, that risk remains socioculturally defined and social scientists grappling with these issues came up with alternative notions such as risk milieus (Voeller, Reinisch & Gottlieb 1990; Zenilman 1988).

[4] If the conception of risk is extended to include the notion of blame - i.e. the person at risk or posing the risk is to be blamed for the infectious threat they pose to those not-at-risk, then cognisance should be taken of the fact that many theorists posit that women are social scapegoats who are often blamed for the health and moral risks they pose (Miles 1991; Shanner 2000; Turner 1996:11-12 & 132-133; Wilton 1994).

[5] Although it has become almost cliché to declare that class is less important in post-industrial society, and to use such terms as "class dealignment" or even "the death of class" (Pakulski &

Waters 1996), many studies still reveal differences in human condition and experience in terms of what sociologists call social class (Lee & Turner 1996).

[6] Need in terms of fertility careers carries the connotation of a necessity and a failure to satisfy some pre-set ideal with deleterious consequences.

[7] The word patriarchies are used here to indicate the multiple, heterogeneous and context-specific nature of patriarchal hegemonies in different cultures, societies and historical moments.

[8] This is not to dismiss the fact that, the case of HIV-infection via shared needles in intravenous drug use, possible male partners who are also drug users contribute in equal part to the creation of a social context that is harmful to the health of the mother and the baby.

[9] Moreover, as regards antenatal HIV testing, it is always the mother and never the father who is considered for testing and data on the HIV status of the father is rarely considered, measured or referred to (Sherr 1996:19).

[10] Reay (2004) remarks on the development of the notion of *emotional capital* – seen as on par with Bourdieu's notion of social capital - to conceptualise the role that women play in relationships and family life in terms of affection, attention, care and nurturing.

[11] Kabeer (1999:8) discards the notion of a false consciousness in the contemplation of women's empowerment on the basis that whomever judges the "consciousness" to be false as opposed to authentic might be in the position to talk *for women* instead of letting women talk for themselves.

[12] Foucault (1988:16) defines technologies of the self as permitting "*individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality".*

[13] Here we are reminded of Paolo Freire's (1993) admonition that all prescriptions represent the imposition of the oppressor's choice upon the oppressed.

[14] Similar prescriptions appear in the AIDS Guide (2007:108 emphases added), for example: *"Trust that things will get better. The first months after learning that you are HIV-positive will be the most emotionally difficult. Over time, the intensity of these initial feelings will probably lessen and you will begin to feel like your* ***old self*** *again."* The implicit instruction to return to a former self is apparent. It should also be noted that Dilger (2001) refers the "healthy lifestyle" – discourses as the empowerment approach, but that in this study empowerment is seen as much more than the handing out of information or prescriptions on how to live and emote.

[15] Spivak (1987:151) regards heterosexuality as an assemblage of material-ideological facts that frame women as objects of exchange and appropriation by men.

[16] For the purpose of this discussion, empowerment of women is defined as improving women's ability to alter or control the patterning of experiences that affect their sub-ordination. Empowerment

is not only material equity, but also encompasses cultural resources such as knowledge and social respect.

[17] For the purposes of this study, the policy framework for reproductive health had to be considered and this is discussed in Chapter 4 as part of the primary record.

[18] This part of the empowerment framework by England can be construed to imply that the empowerment of women is a zero-sum game in which women gain power and men lose power. As Batliwala (1994:131) suggests, men can gain from the empowerment of women, by losing traditional burdens and becoming liberated psychologically (see also Rao Gupta 2000).

[19] In addition, many illness narrative stories tend to present what Nancy Hewitt and Mariana Valverde (2000:267) refer to as *“mythical identities…the heroine who courageously battles illness, the noble victim who silently suffers, the family who find salvation through the mother’s impending death”.* These kinds of illness narrative genres present the stories as linear steps in a kind of reconstructed logic in which the narrators bravely move from denial, fear, negotiation, acceptance and finally to heroic, jaunty coping (see Douglas Ezzy 2000 for a departure on illness narratives by people living with HIV).

[20] It should be mentioned that Williams and Bendelow (1998:130) regard biographical disruption and the search for meaning as modernist ideas as it encourages the fabrication of a subject trapped within a body. They make equally compelling arguments for why this embodiment is a necessary theme in contemporary sociology of health.

[21] David Silverman (1989) identified four coping styles amongst HIV-positive men, namely cool, anxious, objective and theatrical. Of interest is the different ways in which medical professionals reacted to such coping styles.

[22] The Panos Institute (1990a:9) in London uses the phrase the “Third Epidemic” to refer to the social ills that accompany HIV-AIDS, namely denial, blame, stigmatisation, prejudice and discrimination.

[23] Lesko (1988:123) regards the body as an important site of identity construction and notes that physical appearance and style signify consciousness in relation to social contexts, institutions and peer groups. This is even more significant for women, because female bodies are idealised, commodified and controlled. Part of this control is space-related, because in many societies women are controlled via their allocated tasks to be contained in a given space, usually the home. Goldstein (1990) regards AIDS as emblematic of stigmatised others.

[24] A similar sentiment is expressed by Kurth (1993), Selwyn and Antoniello (1993) and Temmerman *et al* (1990). In fact, Temmerman *et al* (1990) found that some of the HIV-positive women in their study expressed the desire to increase their number of pregnancies so that they might have a child before their CD4-cell counts diminish any further or so that at least some of their children might beat the odds and survive. In this respect, some HIV-positive women might therefore have higher levels of fertility preferences.

[25] This is almost diametrically opposed to Wilton's (1997) above-mentioned structural assessment of women's subordination via discursive practices.

[26] It is perhaps poignant to note that AIDS itself seem to be an intensely contradictory disease as many observers report on the strange aesthetic beauty of the three-dimensional model of the HIV (see for example Treichler 1992).

[27] This refers to the discursive constructions of a binary opposition between masculine and feminine.

[28] The reasons for the increased susceptibility of women are biological and related to exposure to amounts of potentially infectious fluids, HIV-concentrations in semen versus in vaginal fluids, the greater permeability of the mucous membranes of the vagina versus that of the penis, etc. (Doyal 1994:13).

[29] Within the broader definition of reproductive health, the notion RTIs is also used. This refers to reproductive tract infections and includes more than sexually transmitted infections. It also includes genital mutilation and poorly executed invasive procedures such as abortions, sterilisations, IUD insertions that result in reproductive tract infections (Dixon-Mueller & Germain 2000:84-85).

[30] The advice (AIDS Guide 2007:88) is stated as follows*: "The South African recommendations for the best practice for women who are found to be HIV-positive at the time of labour, and who have had no prior treatment with ART, is as follows:*

- *Single-dose Nevirapine (NVP 200mg orally) at onset of labour and a single dose of NVP (2mg/kg orally) to the baby at 48 to 72 hours;*
- *Or oral AZT/3TC during labour and then one week of therapy with AZT/3TC for the baby;*
- *Or AZT injected intravenously or administered orally during delivery, followed by AZT orally to the infant for six weeks.*

Nevirapine is usually given at the time of the rupture of the membranes. It should be noted that the Nevirapine dose should not be repeated. If the woman took Nevirapine and it turns out that she was in false labour, she should not receive Nevirapine again when she goes into labour at a later stage. The reason for this is to prevent drug resistance. Women should be warned to be on the look-out for possible side-effects of Nevirapine, such as fever, rash, and sore throat that may indicate Stevens-Johnson syndrome." An emphasis on a fear for drug resistance, for infection to the baby and making women responsible for monitoring possible side-effects are apparent from these guidelines.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

The purpose of this chapter is to list the methodological considerations for this study. The aims of this study were to:

- Critically examine the notion of female empowerment of women living with HIV as it is framed by social constraints and enablements
- Uncover experiences of women living with HIV within the context of hegemonic discourses.

In attempting to understand the lives and experiences of women in their reproductive ages living with HIV in Gauteng, South Africa, a critical approach to female empowerment/disempowerment in reproductive health was used. In Chapter 6, the contribution of this study in expanding the literature on female empowerment in reproductive decision-making in the era of HIV-AIDS is discussed.

The reason why a qualitative approach was chosen is explained in this chapter by describing the limitations of quantitative measures of fertility preferences and by expounding the characteristics of critical ethnography. In addition, issues of access to women living with HIV, data sources, data-gathering, recruitment of participants, the profiles of the participants, coding of the data, data reduction and ethics are discussed.

3.2 THE LIMITATIONS OF QUANTITATIVE MEASURES OF REPRODUCTIVE PREFERENCES

Quantitative data on fertility preferences have been criticised for potential problems in reliability and validity (Bongaarts 1990, 1991, 1992 & 1997; Bongaarts & Bruce 1995a:60-61; Demeny 1988; Hauser 1967; McClelland 1983; Westoff 1991). Closed questions (in a survey) on preferences may elicit response error such as social desirability reactions on the part of the respondents and answers may have little bearing on actual desires and convictions. Individual responses may not be representative of general trends regarding reproductive choice, which are often influenced by social forces wider than the individual woman or couple. In addition, actual fertility performance in terms of number of children ever born may influence the respondent to rationalise about her so-called “ideal” family-size (this is commonly referred to as *ex-post facto* rationalisation).

Furthermore, preference information is said to emphasise voluntary, free, rational choice in reproductive matters whilst ignoring the influence of social pressures and power issues in fertility decision-making at the level of households, families and communities. A problem generic to the measurement of fertility preferences in surveys directed exclusively at female respondents is that the role of her family members, spouses or male partners in reproductive decision-making is not measured. In the absence of information on the fertility preferences of significant others in a woman’s life, data on fertility preferences should be viewed with some circumspection and seen as indicative of general female attitudes regarding fertility and the adoption of contraceptive methods for spacing and limiting births.

Bledsoe, Banja and Hill (1998:47) draw attention to yet another methodological shortcoming in the measurement of fertility preferences - namely that researchers tend to treat preferences and intentions as fairly static, predictable forces tied to parity and chronological maternal age. Instead, Bledsoe *et al* (1998) argue that preferences and their correlates are *“highly relative”* and tend to fluctuate over the life course of the woman or the couple *“in response to the vagaries of personal circumstances.”*

Many of the criticisms levelled against the stark quantification of reproductive preferences as discussed in this chapter note that these quantitative approaches are based on assumptions drawn from theories in which the epistemological task is to find, verify and “know” the “truth” within circumscribed frames of reference. In many instances such theories were the so-called “evolution” or “diffusion” theories of fertility transition and the tasks of verification of the knowledge-claims cantered on issues of accuracy, systematicity and replicability. Phillips (1992:19) argues that hermeneutical and critical claims in the social sciences have forced the empiricists to broaden their views of the nature of human beings and *“to regard persons as actors located within social and historical webs of meaning.”* In the next section, the characteristics of critical ethnography are reviewed.

3.3 CRITICAL ETHNOGRAPHY AS A CHOSEN APPROACH FOR THE STUDY: RATIONALE AND STEPS

According to Schwandt (2006), critical ethnography is a theorised study of social practices and institutions that are critical of the taken-for-granted social, economic, cultural and political assumptions about social life. As with other qualitative methodologies, critical ethnography uses data gleaned through deep familiarity, participation and immersion in the life worlds of the research participants, but it goes beyond description to uncovering hidden interests and power inequalities to reveal forms of domination. As a methodology based in critical social science, critical ethnography endeavours to uncover political inequality, false ideology and distorted self-understanding. Madison (2005:6) refers to this as unsettling layers of complicity. As discussed in Chapter 2, notions of power as constraining and enabling were mapped onto sociological notions of the autobiographical and reflexive self in this study by assuming the possibility that social actors can become self-reflexive persons.

In the preceding chapters it has been argued that decisions, intentions and practices regarding reproductive health are socially and politically constituted. As Jim Thomas (1993:61) explains, critical ethnography requires researchers to stretch their sociological imaginations and shift focus from discrete instances of phenomena to their broader social contexts. Furthermore Susan Greenhalgh's (1996:48) critique of quantitative demography's contribution to the study of reproduction is illustrative of the need for an infusion of a critical stance into social demography. She opines: *"As a field strongly oriented towards generating numbers under the notion that 'if you can't measure it, it isn't important', demography resists theoretical constructs that are inherently difficult to operationalize, measure, and analyze as variables. Such concepts as reproduction as a social construction or gender as a political relationship - both central to the anthropological and historical understanding of fertility - simply do not lend themselves well to being treated in this manner."*

Critical ethnographers assume that the relationship between social structures and social agents involves a two-way, mutually constituting process. The enablement and constraints imposed by structural elements influence social and individual action. Such actions, in turn, can serve to maintain or transform social structures (Carspecken 1996; Kincheloe & McLaren 1994; Madison 2005; Thomas 1993).

Research as a social enterprise is also part of the two-way process. The crisis of representation in critical ethnography thus requires a reflexive contemplation of truth claims. Atkinson (1990:106), for example, warns that efforts to construct authentic-sounding research stories can amount to obscuring or reifying the social production-status of research writing. Critical ethnographic research-stories are constructions and thus partial, tentative truths that are produced within particular historic, political, cultural and economic contexts and related sets of power relations (Kincheloe & McLaren 1994; Lock 2001b; Madison, 2005).

From the previous discussion it follows that when restricting "knowledge" of the intricacies of fertility decision-making to analysing constructs such as unmet need, or preferred family size, such knowledge is rendered as largely correlational rather than theoretical. Demographic inquiry into the complex human and social drama of fertility and human reproduction is irreducible to the collection of indices which have demonstrated their workability. Furthermore, given the survey-constructed history of unmet need, it can be argued that it is in fact a residual category for those women who do not fit into the expected boxes or categories of responsible action. Two issues played a mayor role in propping up the value of a quantifiable measure "unmet need." First, a large proportions of women who were not easily categorisable were uncovered in the World Fertility Surveys (WFSs), Contraceptive Prevalence Surveys (CPSs) and Demographic and Health Surveys. (DHSs) conducted in various countries. Second, these women were construed as the "problem children" of family-planning (or the problem cases in an ideal world of perfectly contracepting couples).

The critical stance taken required the analysis to move beyond description of "unmet need" or "deviant/problematic pregnancies" in order to uncover social practices and power relations that limit choices, constrain meaning, denigrate people and inhibit women's access to better reproductive health. A critical ethnographic approach to the study of reproductive decision-making seeks to uncover hegemonic legitimacy-claims of "knowing" and "framing" reproductive behaviour. This demands a focus on situational/structural issues as meaningful, constraining and/or enabling in terms of the reproductive behaviour. Basu and Aaby (1998:16) emphasise that *"attention to the larger context of people's lives, as an important determinant of their behaviour, by no means implies that individuals are passive victims of their circumstances, whether cultural, socioeconomic, political, or legal. Not only are the constraints imposed by structural or cultural circumstances often actively resisted, but often such resistance is not even necessary: instead, these constraints can be peacefully negotiated, reinterpreted, and even manipulated."*

A critical realist position emphasises that the researcher should be able to look further than people's meanings, experiences and subjective understandings to include elements of structure that, according to Layder (1998:95) *"represent the standing conditions confronting people in their everyday lives - and representing what Marx and Engels describe as* *circumstances transmitted and inherited from the past."* Applying this meant investigating if and how HIV-AIDS and women's reproductive choices and options are inheritances from past systemic arrangements that comprised a disempowering landscape for women. Furthermore, it implied a value-commitment to moving reproductive decision-making for women who are HIV-positive from a pre-concluded tale of destiny and to a tale of empowered agency.

The strengths of critical ethnography as a research design for this study, relate to its enablement of the discovery of structures of power and privilege that extended beyond the immediate social and institutional arrangements of health information and service delivery and access for women living with HIV. The production of meaning (the meaning of a reproductively healthy life in the presence of HIV-AIDS) could thus be seen in its temporal and historical situatedeness. Furthermore, it enabled the location of the choices made by the research participants as far as their reproductive lives were concerned in a series of social and economic relations. It made possible the exposure of decision-making about reproductive health as NOT unproblematic, harmonious, consensus-driven and empowered, but rather as fractured processes characterised by disjuncture, rupture and contestation.

The research problem, research thesis, research design choices, theoretical points of departure and analysis scheme represent the knowledge, skills and personal orientation of the researcher to the research issue. This study is therefore informed and limited by these choices and orientations as well as by the thoughts and actions of research participants and gatekeepers in the field.

In the section above, the reasons for adopting a qualitative research design and critical ethnography in particular were discussed. In the next section, the steps in the research design are outlined.

3.3.1 Steps in the research design

Carspecken's (1996:40-43) five-stage framework for conducting critical qualitative research was followed. This framework includes:

1) Compiling a primary record through qualitative collection of data
2) Doing preliminary reconstructive analysis
3) Generating dialogical data
4) Discovering system relations
5) Using system relationships to explain the findings.

Prior to the main data-collection, a primary record (discussed in Chapter 4) was developed. For Carspecken (1996: 41-42 & 44-54), the primary record, based on observation, less structured interviews and discussions, journal entries and documentary enquiry, is monological and an important preparatory step to the dialogical data-gathering to follow. The primary record given in Chapter 4 is based on research experiences in the general area of reproductive health in South Africa since the late 1990s, documentary and literature reviews and on discussions with VCT and ARV service providers and preliminary interviews with women living with HIV.

Carspecken (1996:93) refers to the second stage as reconstructive analysis because it reconstructs into *"explicit discourse, cultural and subjective factors that are largely tacit in nature".* Using the theoretical discussion in Chapter 2 and the primary record as given in Chapter 4, the researcher was able to articulate themes pertinent to the study. The outcome of the reconstructive analysis was the setting up of an interview schedule (discussed below under subheading 3.4.2.1).

The third stage of Carspecken's (1993:42) framework encompasses data-gathering through dialogical interviews with research participants. Validity checks included tape recording each interview, matching observations to interview questions and member checking. The interviews are discussed in greater detail under subheading 3.4.2.

In stages four and five of the Carspecken model (1993:42-43) the analysis moves towards uncovering systems of power and subordination. Carspecken (1996:43) suggests that these final stages are crucial in giving a critical study its force. These steps guided the data analysis, the conclusion and the outcomes are the discussion in Chapters 5 and 6.

3.4 DATA INSTRUMENTS AND DATA-GATHERING

This study relied on in-depth interviews and observation for data-gathering. The details of each method are outlined below. First, problems in gaining access and the selection of the research participants are discussed. This is followed by details on the interviews, the interview schedule and the observational data.

3.4.1 Gaining access to women of reproductive ages living with HIV and sampling research participants

Due to ethical considerations and the rules governing the granting of informed consent, the researcher had to narrow down the age group of women recruited as participants to 18- to 49-years of age. The so-called reproductive lifespan of women as used in quantitative demography is 15- to 49-years of age. Typically, for persons younger than 18 years of age, consent (or assent) for participation in a study must be sought from a parent or legal guardian[1]. Asking someone other than the individual woman living with HIV to grant assent was however counterintuitive given the sensitivity of the theme and the orientation of the study.

Gaining access to people living with HIV proved to be a difficult undertaking. Although it was easier to approach women through community-based structures[2], many were reluctant to come forward as they had not disclosed their statuses to others. In one instance, a woman was eager to be interviewed, but upon discussing her possible participation in the study with her male partner, he refused, sighting that this ***was their domestic issue not to***

be shared with others [Research journal entry]. Since a strong policy of voluntary participation was followed, this woman was not asked to participate, but instead given the details of a support group should she wish to receive further information on testing, counselling and access to ARV therapy. It is possible that such repressive domestic arrangements prohibit many women from presenting themselves for voluntary testing and counselling or from joining support groups.

In addition, the leader of a community-based structure tended to demand more of the researcher’s time for other initiatives he wished to follow. This led to constant re-negotiation of the respective roles and of the aims of the study. This impressed upon the researcher that access to participants in a study of this nature is not a once-off arrangement, but rather a process imbued with the inequities that forms the backdrop to the very problem the researcher wished to investigate.

Access to VCT and ARV sites resulted in slow cycles of negotiation and letter-writing with official gatekeepers at head offices and provincial offices of the Department of Health (DoH). A given person was indicated as the official in charge of reviewing access requests for research. Weeks would pass without feedback from official quarters.

Power hierarchies control the social research agenda and, by extension the products of social research[3]. Government controls official tenders for research into areas of health service delivery. By demanding official clearance letters from a given person in a position of undisputable authority, and actively controlling and minimising such clearances, the social research agenda into health service delivery can be meticulously controlled.

Through the community-based organisation, access to women took the form of referrals in a snowball sampling technique. Women brought friends that have disclosed their HIV-statuses to them and were willing to participate in the study with them to a meeting place. As the support group started forming and delivering an information-giving service, more women came to the fore. At the public health service sites, access was negotiated through

Chief Executive Officers (CEOs), doctors and nurses. Women (fitting the selection criteria) were approached at the services and asked whether they would be willing to participate.

The ten research participants were the maximum number of women living with HIV and meeting the selection criteria that the researcher could reach in the duration of the study. Fieldwork was done in 2006 (at the community-based organisation) and in 2007 (at public health care facilities). The ten participants were willing to participate, available for follow-up interviews and able to give rich descriptions of what it is like to live with HIV[4].

Issues of informed consent are discussed under the subheading of ethics in this chapter. Problems in gaining access energised many thoughts with regard to the experience of being HIV-positive and negotiating barriers and fears in openly "living positively".

3.4.2 In-depth interviews

Multiple interviews with ten research participants (resulting in 22 interviews) form the mainstay of data collected for this study. The profiles of the participants are given in Table 3.1 on the next page.

Table 3.1: Biographical details of the research participants in the study

Pseudonym	Age	No. of living children	No. of interviews conducted with the participant	No. of years since HIV-positive diagnoses (prior to and including 2007)
Lerato	40	3	3	11
Funani	34	4	2	2
Gita	35	3	3	11
Mbali	26	1	2	3
Poppy	42	2	2	13
Tina	28	1	2	4
Selinah	23	1	2	4

Diane	40	1	2	2
Betty	28	2	2	4
Lora	45	4	2	2

The mean number of living children for these participants was 2,2 children.
The mean number of years since HIV-diagnosis was 5,6 years.
The mean age at diagnosis 28,5 years.

As explained in Chapter 1, women living with HIV and accessing public health care facilities were selected as research participants, since being dependent on public clinics and hospitals for information and services to protect one's reproductive health was regarded as an important structural location and marginal position to be in. As such, the women who participated in the study tended to:

- Be unemployed or underemployed
- Have no personal income or a very small income
- Belong to the lower socioeconomic strata.

This study commenced with a few volunteer research participants eager to examine and give voice to perceived problems in reproductive decision-making in the era of HIV-AIDS. These first participants were all living with HIV and/or were rendering volunteer lay counselling services in their communities. Yet the power relations shaping their knowledge and actions were much wider, operating in a multiplicity of interrelations, actions and decisions. This multiplicity of influences shaped and limited the research. Access provided a problem, and unlike descriptive ethnography, the researcher could not confine the data-gathering to a single, fairly stable, geographically situated site. Instead, data-gathering followed points of call where a person dealing with decision-making regarding HIV-AIDS are likely to travel – namely to the offices of doctors and nurses in the public sector, to the premises of community- and religion-based volunteer organisations, the meeting places of support groups, the homes of volunteer lay counsellors and religious leaders, board rooms of government officials, offices of human relation officers dealing with employee assistance programmes (EAPs) and public health facilities.

Research participants were regarded as social actors able to think and act in meaningful ways. Such acts and thoughts were subjected to critical scrutiny in order to uncover power relations at work behind them that perpetuate oppressive structures. This means that the study itself was seen as a political act (Guba 1990) so that the research participants were encouraged to reflect on their thoughts and actions and uncover ways in which they unwittingly collaborate in their own oppression. From this interaction it became apparent that there are oppositional moments in being a woman with HIV that can be examined for their enabling and empowering potential.

Based on the primary record, an interview schedule (see 3.4.2.1) was developed and used for the initial interview with each participant. Transcripted first interviews with each research participant were used to guide second (and in two cases the third) interviews with participants. Second/subsequent interviews therefore consisted of probing in order to provide clarification on important issues. This resulted in a process of concurrent data collection, preliminary analysis, reflection and progressive focusing to maximise the trustworthiness of the research.

In order to add further contextual information to the data and to create the primary record, interviews were also conducted with:

- A woman in charge of a community-based VCT and AIDS-care facility
- A woman in charge of EAPs for a large private business
- A male counsellor responsible for STI and VCT counselling
- Two female counsellors responsible for STI and VCT counselling
- A male community leader involved in community volunteer work in the area of HIV-AIDS.

All the interviews were tape-recorded and notes were taken as back-up. The tape recorded interviews were transcribed by the researcher verbatim and word-processed as computer files (see discussion under subheading 3.7). Interviews typically lasted between 40 minutes to an hour. All interviews were conducted in English[5], but research respondents were encouraged to express opinions in other languages if they so wanted. The field notes and field journal were written in English. Effort was made to establish a trusting relationship, but the researcher was aware that the conversations were personal, intrusive and sometimes emotive. There were instances in which the respondents asked the researcher to turn the dictaphone off. Notes were taken on these occasions and some of these issues were examined again at follow-up interviews. Interviews were at times outlets for the participants' emotions and at times narratives on dealing with illness or "getting on with life". Familiarity with the rhythm and routines of the service provision (gained through observation) and the establishment of a known and trusted role in the community-based organisation assisted in the participatory process and in gaining acceptance.

3.4.2.1 The interview schedule

The schedule was flexible enough to enable ethnographic interviewing and to allow for the emergence of the following levels of data as explained by Rubin and Rubin (1995:24-26):

- Stories or narratives
- Fronts as part of impression management
- Accounts or justifications of behaviour or choices
- Moral messages that can lead to the uncovering of shared myths.

The main issues listed in the interview schedule were:

- Biographical and demographic details
- The circumstances, time of and reactions to an HIV-seropositive diagnosis
- ARV and other treatments and current and previous health statuses
- Disclosure of statuses
- Changes in the participant's personal life following the diagnosis
- Living with HIV in terms of coping strategies, sexual relationships, contraceptive care and reproductive health
- Dealing with stigma, discrimination and isolation

- Experiences with the public health care system and with accessing help and social disability grants
- Social support systems and treatment buddies (emotional, informational, practical and material support and networking)
- Childbearing and childrearing experiences, aspirations and advice to other women living with HIV
- Romantic relationships
- Gender roles
- Health care needs and wants.

3.4.2.2 Collecting stories, allowing voices to be heard: The research participants as individuals

In order to present the participants as people with biographies, a short description of each is given below (pseudonyms are used)[6].

Lerato, a 40-year old woman, had a very positive attitude. She has been living with HIV for the past eleven years. At the time of the interviews, she worked as a volunteer counsellor and was in a relationship with a man who was not the father of her children for the last three years. She was eager to participate in a support group and to share with others her experiences of living with HIV. **Lerato's** main problem was with the insecurity of her remuneration as a volunteer counsellor.

Funani, a 34-year old woman with four children, lost her employment when illness made it difficult for her to continue her work as a shop assistant. This loss of a working status was a difficult issue for **Funani** to deal with. Although her HIV-status had been diagnosis only two years earlier, she experienced serious health concerns at the time of the interviews. A key concern for her was contraceptive care for women living with HIV.

Gita: When the researcher first met with **Gita**, she was withdrawn and seemed angry. The next meeting progressed with greater ease. **Gita** claimed that she had used the money received at the previous meeting (for travelling expenses) to buy oranges at the train station. Eating better was, according to her, a main contributor to her feeling much better. She decided that she would like to start a support group for other women living with HIV in her area (an informal settlement). She reportedly belonged to a support group before, but stopped attending, because:

> ***I could see that support group was not working out. Some women came there to give pap and chicken and people came for the food. But when there was no food they did not come anymore. We did not talk about our problems.***

Gita also explained that her sister wanted her to give up smoking and drinking and that she was trying to do so. The researcher had a third meeting with **Gita** to discuss issues relating to her TB treatment. Shortly after the third meeting, however, **Gita's** drinking problems resurfaced and she was unable to attend meetings or to visit with women who might be interested in joining such a group. At the time of data analysis, the researcher was unable to regain contact with **Gita**.

Mbali, a young woman with one seven-year old daughter, was employed in a part-time job at the time of the last interview and was eager to read any and all information pertaining to reproductive health for women living with HIV. In particular, **Mbali** wanted to find out more about her own options for future childbearing. She had concerns about breastfeeding, the costs of rearing a child and the tenuous nature of her part-time job.

Poppy: The researcher met **Poppy** at a health care facility where she wanted to find employment as a lay counsellor, having done such work previously. **Poppy**

experienced abusive relationships with men in her past. At the time of the study, she shared a home and her life with a female partner. **Poppy** eventually found part time employment outside of the field of HIV-AIDS, but the lack of access to a medical aid continued to be a major concern for her.

Tina was a young mother who discovered that she was HIV-positive during her antenatal visit four years earlier. Her life was fraught with financial difficulties and she felt abandoned by her baby's father. Although **Tina** used Nevirapine during her pregnancy, her baby was a sickly child that required much attention. She felt that the demands of her baby's care were the main obstacles to finding employment in the future.

Selinah: At twenty-three years of age, **Selinah** was the youngest of the research participants. Like **Tina**, she was diagnosed as HIV-positive during her pregnancy and used Nevirapine to prevent the transmission of HIV to her baby. Although abandoned by the father of her baby, at the time of the interviews **Selinah** lived with a boyfriend that supported her financially and emotionally – even though his job as a security watchman paid a very small wage. **Selinah** and her boyfriend shared a shack dwelling with other young people who they described as "orphaned." She accessed a social disability grant and was under the impression that the grant will continue for life. Despite the precariousness of her domestic life and the constant shortage of financial resources, **Selinah** described her current situation as much better than the circumstances of her family life with her parents who were both alcoholics.

Diane was a forty-year old woman who lived with her father and was diagnosed as HIV-positive following serious health problems. She was placed on a second regime of ARVs in the course of the study and was a seriously ill woman when she last spoke to the researcher. **Diane's** husband abandoned her when she disclosed her HIV-seropositive status to him and she was forced to move in with her father.

One of **Diane's** biggest regrets was that, due to ill health and retinal haemorrhages, she was unable to read her Bible - something that she used to draw courage and inspiration from. **Diane** has always been unemployed and relished in her role as "the best cook in the family". This was another role that she had to abandon due to her deteriorating health.

Betty, a 28-year old mother of a four-year old was excited about the prospects of adopting her deceased sister's three-year old daughter. Like **Tina** and **Selinah**, **Betty's** diagnosis as HIV-positive came during her antenatal visit with her first pregnancy. The adoption of her sister's baby was regarded by **Bett**y and her husband as the "right and decent" thing to do. Despite her young age, **Betty** considered a family of two children to be the ideal family size and expressed a need for a more permanent form of contraception such as female sterilisation or a vasectomy. At the time of the interviews, **Betty** was discouraged from this course of action by family planning personnel who cited her young age as the main reason why she should not undertake it. **Betty** was self-employed and worked from home, but this did not provide a steady income.

Lora: At 45-years of age, **Lora** was the oldest of the research participants. Her HIV-positive serostatus was discovered during a stay in hospital in 2005. She suffered from TB as well. While her husband stayed with her and encouraged her to complete her treatments, he refused to be tested himself. Although she was often able to express her fears, feelings and needs in interviews and conversations with the researcher, **Lora** refrained from disclosing similar information in counselling sessions with health care personnel at the public health care facilities.

These brief profiles bear some testimony to the lived experiences of the research participants as women living with HIV. Some of the hardships, material challenges and aspirations of these women are revealed here and offer background to the thematic discussions in Chapter 5.

3.4.3 Participant observation

Observation was used during visits to VCT and ARV service sites and at support group meetings. The researcher was fortunate enough to be granted permission to observe three counselling sessions, one for ARV adherence, a pre-test counselling for a blood test and a post-test counselling for a blood test result. In these three cases, the advisors and the clients/patients granted informed consent.

The researcher engaged in both the “participant-as-observer” and “observer-as-participant” roles. During the in-depth interviews, the researcher’s role was mostly that of “observer-as-participant”.

The researcher engaged the role of “participant-as-observer” during her encounters with the support group. The researcher made her identity known and took an accepted role as a support person. The researcher interacted fully with the attendees at the support group meetings, asked questions, answered questions about the study and did chores handed out to her. Such chores involved sourcing snacks or food for meetings, typing applications for funding, typing and copying letters and minutes of meetings, making telephone calls and connecting with other community-based groups to assist with applications for identity documents and social grant applications. The researcher kept her role in this deliberately small and marginal, heeding Gunzenhauser’s (2004:89) warning: *“Because discovering agency is so significant to helping overcome differential power relations, it is vital that researchers not reinscribe their own notions of agency in the experiences of the oppressed. When this happens, the researcher fails to implicate him or herself in different power relations. Such a mistake is inconsistent with the aim of emancipation and therefore ethically reprehensible.…Researchers need to ensure that through their own actions, through their research or representation, that they do not undermine the agency of their respondents.”*

In the role of “observer-as-participant”, the researcher was present in waiting areas for counselling, testing and ARV-treatment along with other men and women and observed and interacted with people as much as they allowed such exchanges. Within this context, the powerful symbolic meaning of opening a yellow packet to reveal the number of stripes on a rapid test became apparent. In a particular case, the difference between what transpired in an in-depth interview with a participant and a counselling session with a counsellor gave rise to a follow-up interview that uncovered interesting observations about the expectations that women hold over their counselling sessions at ARV-therapy sites. Such observations were written in a research journal and word-processed at home. The notes were used in the construction of the primary record in Chapter 4 and for the contextual analysis of the data in Chapter 5.

3.5 PROBLEMATISING EMIC AND ETIC ROLES

The researcher’s outsider-status should be regarded as potential areas of bias in the data-gathering. Richardson (1990:130) refers to the dilemma of an outsider status as belonging to the *“central postmodernist problems about the researcher’s authority and privilege.”*

Critical approaches and especially feminist approaches to research problematise the researcher-researched relationship as belonging to a world consisting of unequal resources, privilege and power. Feminism makes the strongest case against the canon of objectivity as it affects the researcher-researched relationship (see Maynard 1998:131-132). They actively work towards demystifying objectivity by regarding knowledge of self and knowledge of the other to be mutually informing. The feminist project is to let women speak, to fight against methodologies that would silence women’s voices. The kind of reflexive methodologies upheld by feminists privileges the voice of the subject.

These approaches (critical social science and feminism) endeavour to break down culturally-constructed authority differences so that voices that were previously silenced can be heard. Reflective openness requires that the researcher remains aware of the danger that interpretation might change the story and might silence the voice of the researched. Chamberlain and Thompson (1998:16) warn that the researcher cannot claim to be the pure conduit of the voice of the other; neither can he or she claim that the voice of the other is raw and unadulterated. Instead, the focus is on *"how to unravel the complex layers of construction and meaning in the sources, to show in the words of John and Jean Cormaroff 'how realities become real, how essences become essential, how materialities materialize'."*

Despite the critical social framing of the study and the researcher's own conscious efforts to understand the lives of the research participants, the danger remained that interviewees would be (to some extent) objectified, observed, questioned, interviewed and then left. This required that the researcher had to constantly reflect on the difference between exploration and exploitation. In the final analysis, the researcher took data from these people and with that she took from their stock of trust, interest and attention. As Beaudry (1997:83) puts it:*" Friendships and camaraderie are tainted with the pragmatic uses that could be made of them."* Some of these tensions between the emic and the etic roles were resolved through keeping a field diary, engaging in reflexive debriefing sessions with two of the participants and being actively involved in assisting with the endeavours of the support group.
Reflexivity has become a central issue for assessing the validity of qualitative work (Adkins 2002; Ferrell & Hamm 1998; Hertz 1997; Jennaway 1990; Madison 2005; Vail 2001). Within the critical stance embraced in this study, reflexivity demanded that the researcher inspected the interests served by her own ideological predilections. It also meant that the research encounters with participants became a journey that led to deeper mutual understanding and, for some of the participants at least, to a reappropriation of the human spirit. These considerations, written down in a research journal, also spill over into the ethics of the study, which is discussed under subheading 3.6 of this chapter.

The research journal comprised four types of notes. First, it comprised process notes in terms of methodological issues as dictated by the research thesis and the theoretical point of departure. It also included notes on decision-making pragmatics in the field. Second, it contained ideas on intentions and reactions by the researcher and the participants (both personal reflective ideas and notes on the experiences of research participants). Third, it documented instrument development information on the types of themes to be followed up on in the interviews. Fourth, it documented the pseudonyms of the research participants and their contact numbers or details. This information was guarded as highly confidential materials. For the researcher, journaling was a way of keeping her attention focused and to provide insight into the context of the data-collection. These materials document the researcher's attempts at establishing the trustworthiness of the data (the non-positivist qualitative alternative to replicable reliability).

3.6 THE ETHICS OF THE STUDY

Given the stigma associated with HIV-AIDS and the possible negative consequences to people should their HIV-positive statuses be disclosed to others, the researcher was keenly aware of the need to take extraordinary measures to carefully protect the participant's identities and to represent their stories candidly. Noblit, Flores and Munrillo (2004:3) counsel: *"Critical ethnographers must explicitly consider how their own acts of studying and representing people and situations are acts of domination."* This implied caution not to treat the participants as objectified data sources and the interview as constraining or exploitative. Following the guidelines by Roseneil (1993:197), some of the safeguards built into the design were:

- Full disclosure of the intentions and nature of the study
- Clarifying to the participants that they could opt out of the study at any stage
- Obtaining feedback from the participants on the analysis and interpretation of the data
- Disseminating the findings to participants
- Using dialogical interviews in which stories were exchanged.

Ethical clearance for the research proposal and ethical considerations of the study was obtained. Each volunteer research participant was given an informed consent form (see copy in Appendix A). They were not required to sign the form, as the researcher only asked for first names and did not want to have signed forms that might identify participants. The researcher also gave them a business card with her home and office details. In this way, participants could call the researcher if and when they wanted to discuss the study or related issues. Prior to the start of each interview, participants gave their consent for the interview to proceed on the tape (see Coomber 2002 for a discussion and Rodgers 1999 for a similar strategy).

A nominal fee was paid after the interview was completed as lunch money or transport fees. Participants were not told about the possibility of this compensation before the interview and were asked to keep the receipt of the moneys confidential. The issue of this small incentive was discussed at length with peer debriefers. In terms of the ethical considerations of the study, it could be justly argued that abject poverty is harsh enough without people having to bear the additional burdens of serving as research subjects. The payment of a small incentive did not amount to coercion, undue inducement, unfair distribution of risk, direct harm, encouragement of dependency in the participants, the violation of their personal integrity or to trading on their desperation.[7] In establishing contact with the participants after a first interview, a partnership was established to make sure that needs were not induced that could not be met after the research ended (see Alderson 2004 and Thomas & O'Kane 1998 for similar strategies). Where appropriate, participants were assisted to contact a community-based organisation willing and able to help with obtaining documentation to access the social disability grant and food parcels. In this way, the researcher did not appear in the lives of the participants to disappear after the data were obtained[8], but instead remained committed to building capacity.

Follow-up interviews sometimes took place at the researcher's office on campus and participants visited under the guise of students or prospective students. Every effort was made to protect the participants' true identities and tape recorded interviews were locked away in a safe and personally transcribed by the researcher.

It is important to acknowledge that the research relationship consisted of different subjectivities that are differently situated in terms of power. Though it is naïve to think that the power differences between the researcher and the researched could have been eliminated, they were managed through a careful consideration of the ethical role of the researcher. In critical ethnography, this consideration extends to a contemplation of the social usefulness (or the ethical end and means to which the research aspires) of the research and the ways in which it addresses issues of social justice[9] and ethical integrity. Each of these considerations is discussed in greater detail below.

3.6.1 Social justice

Madison (2005:84) declares*: "As critical ethnographers, our commitment to social justice becomes an ethical duty of the first priority based on social change and the wellbeing of others."* This imperative is served by documenting the stories of women living with HIV and by uncovering power relations and possible empowerment away from oppression. The findings are intended to sensitise the research community to the implications of policy and practice for the reproductive lives of women living with HIV. A summary report of the findings will be presented to the Department of Health.

3.6.2 Ethical integrity

The researcher was committed to the protection of the rights and welfare of the participants. Informed consent was sought and re-negotiated at each encounter[10]. Participation was voluntary and the research did not interfere with the participants' ability to receive medical care at the public health care facilities. These issues were carefully discussed with the CEOs at the public health care sites. Identities were protected and peer debriefing and member checks employed to preserve the trustworthiness of the data. Some discussions were distressing in nature, but emotional and informational support was given where appropriate. Through follow-up discussions, research participants were not questioned and left, but involved in the research and encouraged to participate in forming a support group. In serving a moral duty to the research participants, they are given feedback on the findings of the study.

3.7 TRANSCRIPTION OF INTERVIEW DATA AND DATA-ANALYSIS

Transcription, the matching of the interview data with field notes and the field journal and the analysis of the data were important considerations in the representation of the voices of the research participants. These steps were guided by the research objectives, concerns over participant confidentiality and the framework for a critical ethnography as formulated by Carspecken (1996).

The taped interviews were transcribed to reflect verbatim depictions of speech (see Oliver *et al*. 2005). The transcription was not completely naturalistic, since the goal was not to analyse the intricacies of spoken language, but rather to analyse the informational contents of the talk and the substance of the narrative. In other words, the grammar used by the respondents was not corrected and pauses were added where necessary (depicted in the quoted vignettes in the form of three full-stops). However, the transcription did not include detailed notes on involuntary vocalisations (such as coughing, sneezing, sniffing, laughing or crying), non-verbal gestures, overlapping speech (such as where the interviewer and interviewee speak at the same time or is interrupted by another person) or the duration of pauses as would be the convention in conversational analysis. This form of denaturalised transcription follows faithful, verbatim transcription but accuracy relates to the meanings created and shared during the interview. Oliver *et al.* (2005) regard this approach as relevant to the model for critical ethnography as posited by Carspecken.

Two research participants were willing to listen to extracts from the transcripts (read to them by the researcher) and to comment on it. The input from the two women was used as a reflective exercise, as peer debriefing and as member checks (this is also referred to as testimonial validity). Woods (1999:4) refers to this as a search for authenticity in ethnographic work and describes it as emphasising how understandings are shaped, how meanings are negotiated, how roles develop, how identities are structured and transformed.

The analysis commenced with reading and rereading the transcripted interviews, field notes and research journal. Data analysis followed Carspecken’s (1996) approach that seeks to understand experiences (in this case the experiences of women living with HIV) and link it to larger social forces so that positionality (in this case empowerment versus disempowerment) can be situated in social dynamics and power relations.

A list of codes was developed for analysing the data. First low level codes, based on little abstraction and inference (see Carspecken 1996:146-7) were used. Codes were used as heuristic devices and not as an exhaustive list of concepts to be tallied by how frequently they occurred in the transcripted narratives. The list of codes was discussed with a research participant willing to assist (separately to protect her identity) and with two colleagues working in the field of HIV-AIDS research and training. This discussion resulted in adding a few more codes. In the discussion of the low level codes with the peer debriefers, the intent was to see whether the codes constituted a contouring of experiences of women of reproductive ages living with HIV and accessing public health care facilities. Such a discussion of initial codes is recommended by Carspecken (1996:201) as a validity requirement for stage four of a critical ethnography. Table 3.2 shows the list of initial themes and codes.

From the low level codes, high-level codes were developed, guided by the aims of the study, the theoretical discussion in Chapter 2 and the primary record as given in Chapter 4. The intent was to reorganise the codes into tighter themes that relate to power relations. This enabled the analytical discussion as represented in Chapter 5 with special emphasis on material, health and social-psychological needs of the research participants (see

Carspecken 1996:205). Carspecken's (1996) stages four and five were followed which calls for the discovery of system relations and for seeking explanations of the findings through social-theoretical models.

The critical stance adopted demanded a consideration of the historical and structural context and the emancipatory potential of the data. Rather than accepting the subjective beliefs of the research participants on face value, the goal was to examine them critically in the context of a broader historical or structural analysis. This enabled the researcher to locate "lifestyle choices" in a series of social and economic relations – to look beneath the surface of everyday experience in order to reveal broader historical and structural forces.

Reason and Rowan (1981) refer to catalytic validity as the degree to which a study reorientates, focuses and energises research participants towards transformational action. Chapter 6 provides a summary of the study and a reflection on the way that the study contributed to liberation of the research respondents from restrictive assumptions, repressive power relations, inhibited autonomy and voicelessness.

Table 3.2: List of initial themes and low level codes

Initial theme	Low level code
1. Biographical details	1.1 Age
	1.2 Number of children
	1.3 Domestic arrangements
	1.4 Level of education
	1.5 Employment history & changes
2.The HIV-positive diagnosis	2.1 Year diagnosed
	2.2 How diagnosed
	2.3 Behaviour/reactions/contestations

	2.4 Emotions
	2.5 Anxiety
	2.6 Other
3. Comparisons with a former self prior to the HIV-positive diagnosis	3.1 Changes in personal life
	3.2 Self-image
	3.3 Loss of a former self
	3.4 Empowering/disempowering examples
4. Medical “speak” following the diagnosis	4.1 Examples of CD4-counts, tests
	4.2 Treatment decisions
	4.3 Side-effects from ARVs
	4.4 Medicalised self
	4.5 Experiences with counselling
	4.6 Experiences with treatments
5. Stigma, discrimination, isolation	5.1 Experiences of stigma
	5.2 Experiences of discrimination
	5.3 Experiences of isolation
	5.4 Self-stigma
	5.5 Horizontal violence

Table 3.2 continues on the next page

Initial theme	**Low level code**
6. Personal relationships and living with HIV	6.1 Changes in relationships
	6.2 People disclosed to
	6.3 Husband/partner’s reaction
	6.4 Belonging
	6.5 Relationship choices
	6.6 Relationship challenges
	6.7 Social support system
	6.8 Support group involvement
	6.9 Treatment buddies
7. Structural challenges	7.1 Economic constraints
	7.2 Employment

	7.3 Social grants
	7.4 Economic empowerment
	7.5 Economic disempowerment
8. HIV-positive, childbearing and child-rearing	8.1 Influence on future childbearing
	8.2 Desired number of children
	8.3 Caring for current children
	8.4 Pregnancy
	8.5 Treatment decisions
	8.6 Experience with Nevirapine
	8.7 Breast feeding
	8.8 Advice to other women
9. Being HIV-positive and a sexual being	9.1 Consensual sexual relationship changes
	9.2 Contraception
	9.3 Discussion with consensual sexual partner(s)
	9.4 Other issues
10. Living positively	10.1 Expectations
	10.2 Goal-setting
	10.3 Therapeutic performance
	10.4 Coping
	10.5 Not coping
	10.6 Religion
	10.7 Activism “speaking out”
	10.8 Activism “policy recommendations”

The final issue to be interrogated in this section is the generalizability of the research findings of this study. The data were gleaned from a small scale critical ethnography of VCT and ARV service sites and women living with HIV allowing for - at most - moderatum generalisations (see Payne & Williams 2005; Williams 2002). Payne and Williams (2005:296) define moderatum generalisations as resembling *“the modest, pragmatic generalizations drawn from personal experience”.* Hammersley (1990) refers to this as subtle realism about the plausibility and credibility of the claims made by theory and data. The critical approach of the study is based on the assumption that being a woman living with HIV and dependent upon public health care services entails involvement in enduring disadvantageous relations. Such disadvantage predates the research participants’ current situations, but the theoretical point of departure (see Chapter 2) also allows for volitional agency within the constraints of disadvantage. Moderatum generalisations[11] were therefore enabled through the merging of the claims of critical theory and the possibilities offered by the methodology.

3.8 CONCLUDING REMARKS

In this chapter the methodological considerations and steps taken were discussed. Key conventions for data collecting that are typical to a critical ethnography were considered, such as:

- Giving voice to the ***other***
- Spending considerable time interviewing and observing the participants
- Contemplating self-reflexivity by considering the tensions between emic and etic perspectives
- Using a field journal and field notes
- Guarding against exploitation, consulting widely with participants, gatekeepers and peer debriefers and being open and transparent about the purpose and impact of the study
- Uncovering power relations and identifying agency and the prospects for empowerment.

The Carspecken model for critical ethnography was outlined and research steps discussed as they were applied to the study. Attempts at enhancing the validity of the findings, such as immersion in the data and member checking of the transcripted data and of the low level codes were considered. Befitting a critical orientation, a critical reflection on the research process itself and the contribution and limitation of the study are called for and this is discussed in Chapter 6. Ethical commitment in critical ethnography as related to unsettling taken-for-granted assumptions and opening up critical awareness was discussed in this chapter as the ethical responsibilities of the researcher. These issues are also revisited in Chapter 6.

ENDNOTES FOR CHAPTER 3

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[1] It is not known to what extent the changes to the age of consent according to the Children's Act of 2005 (Act No 38 of 2005) which came into effect on Sunday 1 July 2007 would in the future influence the ages of consent for research participation. These changes came into effect after the data were gathered.

[2] One of these women, resident in a poorly resourced informal settlement, expressed her desire to start a support group for women in this area. Intensive discussions about this endeavour and preliminary enquiries about possible recruits for the research and the support group made it clear that people are still fearful of discussing HIV-AIDS openly.

> ***This is a difficult thing that we are trying to do. People run away when I talk about AIDS. They say that they have heard enough and that they don't want to think on that as well. Even if you can see that there a people who are ill. They say that they are proud and cannot just talk to anyone. People are fearful and others tell me that I don't know what I'm doing…they even taunt me and laugh behind my back. Sometimes I get sick and tired of working for the community and nothing changes****.* [Interview with the leader of the community based structure as noted in the research journal.]

[3] Preston-Whyte (2003) expresses concerns about restrictions placed on social research into HIV-AIDS by virtue of the biomedical bias in the review process of research protocols that privileges particular types of methodologies.

[4] For comparable sample selection strategies in critical ethnographic work, see Dowsett *et al* (2001); Grove, Kelly & Liu (1997); Kirshenbaum *et al* (2004); Ko & Muecke (2005); Shambley-Ebron & Boyle (2006) and Wainberg *et a*l (2007).

[5] Women accessing public health care facilities in Gauteng, South Africa, converse in English with doctors, some of the counsellors, social workers and dieticians. Bourdieu (1977a:652) reminds us that: *"Just as, at the level of relations between groups, a language is worth what those who speak it are worth, so too, at the level of interactions between individuals, speech always owes a major part of its value to the value of the person who utters it."*

[6] The presentation of narrative portraits of research participants is compatible with the criterion of immersion in the lives of participants in a critical ethnography. For an extended example, see Averill (2002).

[7] See Madison (2005:114) and Truman (2003) for similar considerations in providing small incentives.

Endnotes

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[8] Conquergood (quoted in Madison 2005:125) refers to this as the “custodian’s rip-off”, where researchers enter the field with the sole intent of obtaining data and are unconcerned with the effect that their research has on the dignity, safety and health of the participants.

[9] In biomedical research for HIV-positive patients, controversial revisions to the Declaration of Helsinki of the World Medical Association in 2000 make commentators question whether utilitarian ethics in clinical trials will erode distributive justice in terms of access to the best clinical care for economically vulnerable people in the developing world (see Botbol-Baum 2000). Countries where clinical trials are conducted are often too poor to pay for medicines that are successfully tested, therefore the people recruited for such trials are unlikely to benefit from the kind of medical care that participants in trials in developed countries can expect.

[10] For a discussion of similar strategies in informed consent, see Cutliffe & Ramcharan (2002) and Miller & Bell (2002).

[11] Malcolm Williams (2002:139) describes it thus: “*The moderatum generalizations I advocate are, then, the bridge between the ideographic and the nomothetic. Such generalizations can be only moderate, but need only to be so. They can provide testable evidence of structure and outcomes of structure.”* This understanding of generalisations articulates well with the critical approach followed in this study.

CHAPTER 4

HIV-AIDS AND REPRODUCTIVE HEALTH IN SOUTH AFRICA: THE PRIMARY RECORD

4.1 INTRODUCTION

Chapter 4 is the primary record for the study (loosely based on Carspecken's 1996 recommendations for a critical ethnography) as it works to open up the next phase in the research process. It is built up from observation, interviews and documentary research that extends beyond the ethnographic present. This primary record shows that, despite some gains made in the empowerment of women in the new democracy, sexual violence, the legacies of apartheid and of patriarchy and the HIV-AIDS epidemic, remain as serious obstacles to free, safe fertility and reproductive decision-making in South Africa. Befitting a critical orientation to the research problem, the primary record illuminates how lineaments of oppression have historical roots that hold consequences for present problems.

It has been said that South Africa achieved a relatively fast fertility transition in the absence of significant empowerment of women (Camlin, Garenne & Moultrie 2004; Moultrie & Timaeus 2002; Potts & Marks 2001; Swartz 2003). The consequences of this lack of empowerment, its historical roots and present consequences are discussed and analysed in this chapter as it relates to fertility decision-making in the era of HIV-AIDS. This is also evidenced, amongst other things, in the words of **Lerato**[1]:

> ***My new partner wants me to have a baby with him. He said I used ARVs with my first baby and there were no complications. My daughter tested positive at birth, but after some time she tested negative. My partner says this means***

> ***we can also have a healthy baby – he wants a child of his own with me. But I don't know…. I don't know what another pregnancy will mean for me.*** [**Lerato**, 40 years old] [1]

This woman's words are illustrative of trends in reproductive decision-making in South Africa in 2007. Although she is at the lower end of the reproductive age group, worldwide the largest proportion of HIV-infected women are at an age when they are under strong social and cultural pressure to bear children (Esu-Williams 2000; Gregson, Zaba & Hunter 2002; Orubuloye, Caldwell & Caldwell 1993; Rao Gupta 2001). Many of these young women only learn about their HIV-status once they have fallen pregnant and attend antenatal clinics. This is certainly true in South Africa, where voluntary testing and counselling (VCT) for all South Africans is not yet well established and fear about stigma still keeps people from voluntarily testing their HIV-statuses. According to a report by USAIDS/UNAIDS/WHO/UNICEF/The Policy Project (2004:32) only 0,9% of adults in South Africa received VCT in 2002. In fact, in sub-Saharan Africa many men and women are unaware of their HIV seropositive statuses unless they are specifically tested (as in the case of antenatal clinic attendants) or when they become ill. The question arises: How do couples or individual women react upon learning about their own HIV seropositivity as far as their reproductive careers are concerned?

Evidence from sub-Saharan Africa suggests that fertility is between 25% and 40% lower in HIV-positive women than amongst uninfected women (Allen *et al* 1993; Ryder *et al* 1991; Zaba & Gregson 1998). This holds two important consequences: First, the lower fertility performance of HIV-positive women implies that HIV-data based on antenatal surveillance will increasingly understate the true levels of infection amongst women of reproductive age, thereby giving a false impression that new infections are decreasing (Gregson, Zaba & Hunter 2002:3). At present antenatal surveys are the major sources of information on HIV prevalence in South Africa, despite scepticism regarding the methodology. Second, HIV affects fecundity via its link to other sexually transmitted infections (STIs). HIV-AIDS mortality removes from the denominator those women with lower parity due to STI-induced infecundity, thereby increasing the overall level of fertility (Gregson *et al* 1997:96).

In addition, women or couples may decide to postpone permanent unions or marriage (or childbearing) due to socioeconomic insecurities brought about by high levels of adult AIDS-mortality. The structural changes in population characteristics and processes due to HIV-AIDS mortality that will result in changes in fertility are at present the stuff of speculation and armchair modelling – and speculative modelling of prevalence figures and assumed impacts make up the bulk of research outputs in South Africa on the social demography of HIV-AIDS.

The figures and discussion provided in this chapter aim to demonstrate that the South African fertility transition is moving along of its own accord. From the mid-1980s to the mid-1990s, the total fertility rate in South Africa declined by an average 15% per annum (Anderson 2003). Analyses by Camlin, Garenne and Moultrie (2004) indicated that most of the South African fertility decline could be attributed to factors (such as contraceptive use) other than HIV-AIDS. Notwithstanding the possible fertility repressive effect of HIV-AIDS, however, it is a transition without empowerment and thus fraught with problems for the women who live through these transitions.

In the next section, the history of reproductive health service delivery in South Africa is examined in order to further analyse the structural basis of lack of female empowerment.

4.2 A BRIEF HISTORY OF POLICIES AND PROGRAMMES GOVERNING REPRODUCTIVE HEALTH IN SOUTH AFRICA

Before discussing various issues relating to reproductive decision-making in South Africa, a brief history is given of the policy context that contributed to (and continues to shape) the trends and problems that can be observed today. The intention of this historiography of the macro-events that shapes the landscape of reproductive health today is to demonstrate how problems in reproductive health are located in social, political, cultural and economic realities. The confusion, pain and lack of freedom to make informed decisions that affect individual’s reproductive health are, however, felt most keenly at the micro-level.

4.2.1 Family planning policy and programmes in South Africa

State support for family planning in South Africa started in the 1960s, driven by Malthusian fears of rapid population growth and a fear that the faster growth rates among Africans will swamp the relatively smaller number of whites (Brown 1987). A National Family Planning Programme (NFPP), backed by substantial funding was introduced in 1974. The aim of this programme was to lower the fertility of Africans by establishing clinics to facilitate access to contraceptives (Klugman 2000). Although initially confined to the urban areas, access to government funded contraceptive services was later extended to the peri-urban and some rural areas. This programme's main limitations were: the lack of privacy and confidentiality in mobile units, limited counselling services as an adjunct to the distribution of contraceptive methods and the absence of a public marketing campaign. Important characteristics of African fertility, in which the male and his family play a dominant role in the decision-making process, were neither considered nor accommodated in the development of the service. Couple counselling was seldom given, and the programme was mainly directed at women.

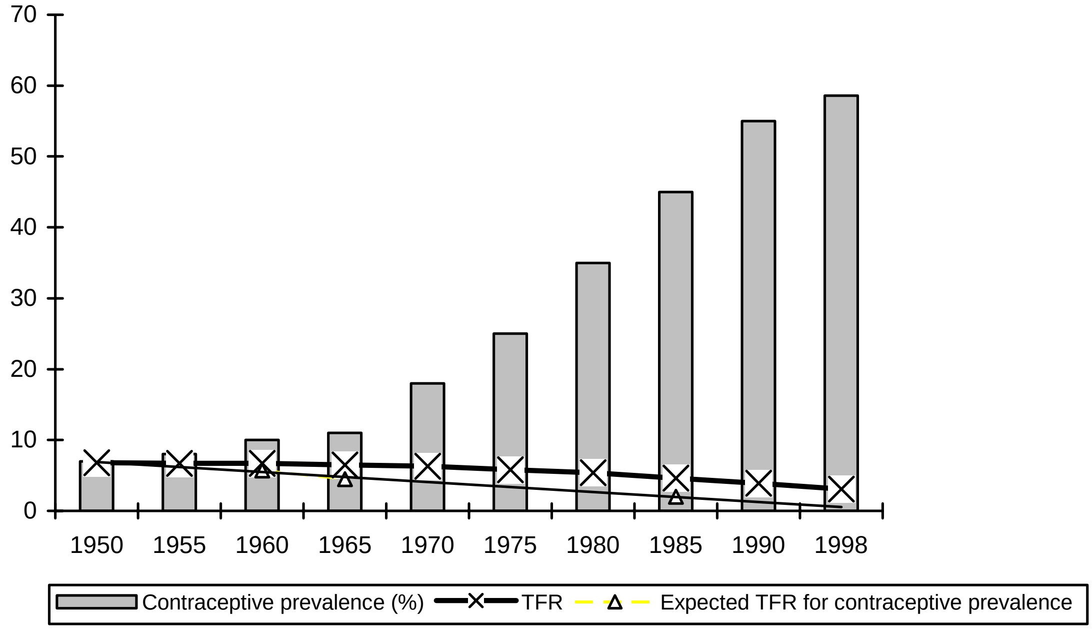
The apparent popularity of injectable contraceptives (Depo-Provera) can also partly be attributed to the women's expressed desire to keep their contraceptive use secret from their male partners. Consequently, the process of discussing sexual matters and contraception on an equal footing with males and females was never instituted in counselling sessions, a tragic fact that leaves HIV-AIDS Information, Education and Communication (IEC) programmes in South Africa with a difficult obstacle to overcome. Contraceptive use for some women became a secret means by which they could exert at least some control over their lives.

In terms of encouraging contraceptive prevalence amongst women, however, this programme was successful. Some observers also remarked on the coercive attitudes of family planning nurses and their reluctance to inform women about the broad range of contraceptives available to them (South African Government, DoH 2001). The family-planning programme offered no recourse to women with unwanted pregnancies after contraceptive failure (or other unwanted pregnancies for that matter). Moreover, any long term planning in domestic and family life was rendered virtually impossible via apartheid – women lived precarious existences in which family life was undermined by the migrant labour system, strict controls over urbanisation, insecurities in property and residential rights and unstable employment in the so-called “white” areas that was cut short when an African woman became pregnant.

Apartheid differentially influenced African men and women, thereby undermining family formation. African men were subjected to a migrant labour system[2], whereas African women were left behind in the so-called homeland reserves. The migrant labourers hardly received a living wage, so that even when wages were remitted to women and children left in the homelands, these were hardly enough to sustain a family. Women left behind in the homelands, however, were dependent on these remittances to feed their children. As the homelands fell into deeper and deeper poverty, some women migrated to mining and non-mining areas in the hope of finding some kind of income –albeit in the shadow economy of prostitution or beer brewing. Looking after children and the elderly increasingly became the domain of women and marriages and unions suffered under the strain of forced absences of men (Campbell 1997; Kaufman 1997:16-24).

The uptake of modern methods of contraception was high following the NFPP, especially amongst African women. By 1988, for example 44% of African women in South Africa were using modern methods of contraception (Klugman 2000; Leisanyane 1995; Moultrie & Timaeus 2001). The transition in African fertility (in terms of children ever born), however, was less rapid than the uptake of contraceptive use, since women used the methods to space rather than to limit births (Kaufman 1997. See Figure 4.1 in which the contraceptive prevalence of African women is juxtaposed with the fertility rate). As explained above, spacing of births was due to economic considerations by African women, whose tenuous stay in urban areas depended largely on finding employment (mostly as domestic workers for white households). For such women, a pregnancy could signal a prompt dismissal and a return to the impoverished rural areas.

Figure 4.1: Contraceptive prevalence and TFR for Africans, South Africa 1950-1998



(Sources: Leisanyane 1995; Mostert, Hofmeyr & Oosthuizen 1997; Swartz 2003; United Nations 1989)

In 1983 the Science Committee of the President's Council into Demographic Trends in South Africa proposed that a Population Development Programme (PDP) be instituted to ensure that population numbers be brought into line with the availability of resources. The NFPP then changed to the Population

Development Programme (PDP) in the early 1980s. The PDP tried to underplay the population-limitation rhetoric of its predecessor and instead emphasised the health benefits of family planning and linked family planning with other primary health care services. To achieve this, the PDP had to ensure intersectoral collaboration with other government departments to reach a demographic target of a total fertility rate of 2,1 by the year 2010 (Board of Population Growth Development SA. 1991; Development Bank of Southern Africa 1994).

The PDP had some serious inadequacies. Ideologically it was still rooted in the neo-Malthusian approach and argued that the natural resources of South Africa (in particular water) had a limited carrying capacity of a population of eighty million people. The problems of inequity, misdistribution and inadequate management of resources were not considered. The following was stated in a marketing brochure*: “Scientific research indicates that in view of socioeconomic factors and the availability and renewability of natural sources of subsistence, South Africa cannot provide meaningful housing, education, employment and medical care for more than approximately 80 million people”* (Board of Population Growth Development SA 1991:2). The fact that Africans were denied access to the same share or the country’s natural resources was ignored.

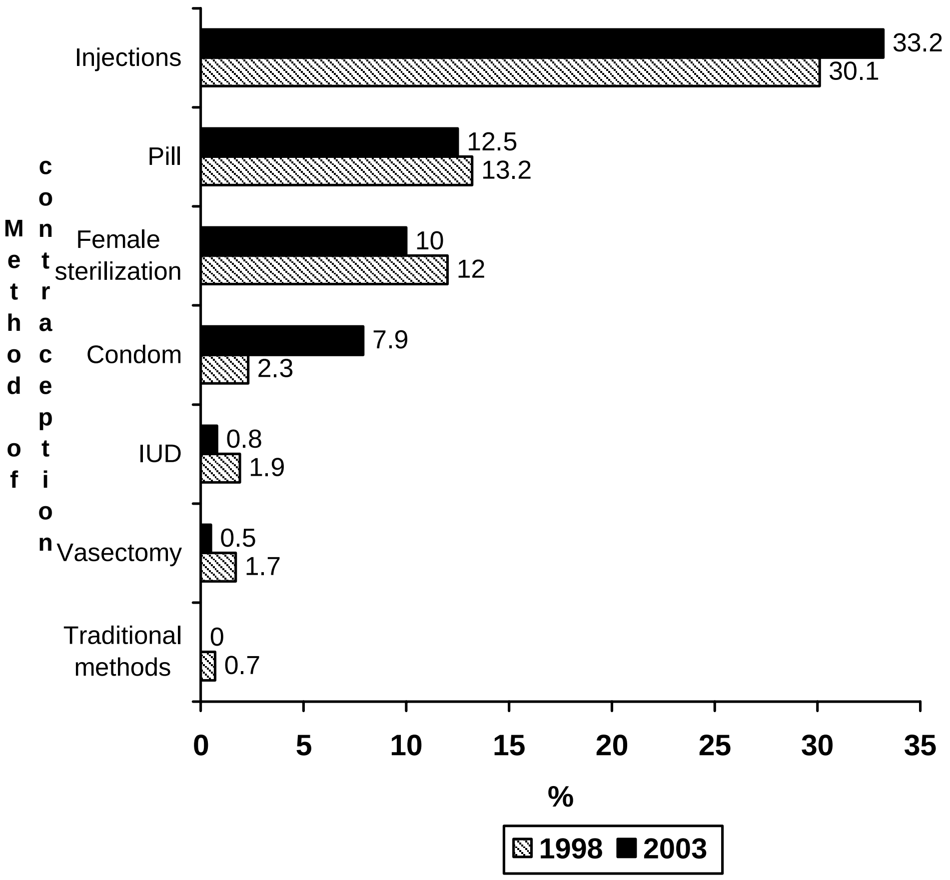
In another brochure, an appeal was made to every woman to limit childbearing to prevent South Africa from slipping into a Malthusian trap*: “When a teenage girl falls pregnant, it causes tremendous problems within family life. It disrupts her future and sometimes brings an end to her education and her opportunities to develop skills and eventually to get a good job. It also places a heavy financial burden on the family and contributes substantially towards infant deaths and overcrowding”* (South Africa 1991). The blame for the "problems" of fertility and poverty was squarely placed on what was perceived to be irrational procreation by young women. This statement clearly ignored the seminal work by Preston-Whyte *et al* (1990) on the complex factors surrounding teenage pregnancy in South Africa. The PDP did not challenge the obvious obstacles to equitable development in South African society under apartheid, such as the migrant labour system, inequity in access to training and employment, the breakdown in the family system, lack of recreation for teenagers or the problem of care for aged Africans. Furthermore, although it widely advocated the strategy of self-help, it had very few resources at its disposal to finance development programmes. These programmes were mostly instruments designed to fit the cause of the protagonists of the apartheid ideology (African National Congress 1994b; Development Bank of Southern Africa 1994).

In 1994, the same year in which the International Conference on Population and Development (ICPD) took place in Cairo, the political situation changed locally and the South African Government of National Unity initiated a review process for its population policy. This process not only took cognisance of the Cairo Programme of Action, but also incorporated a lengthy local consultation process. In the area of health, the Reconstruction and Development Plan (RDP) adopted in 1994 allowed for free health care for children under the age of six and for pregnant women (African National Congress 1994a:45).

South Africa's current population policy fits into the overall framework of the macroeconomic policy GEAR (Growth, Employment and Redistribution) and reflects similar sentiments regarding sustainable development to those expressed in the Cairo Programme of Action. In addition, the Constitution of a democratic South Africa guarantees human rights, including comprehensive reproductive health rights. In the pre-transition years, community-based and non-governmental organisations (notably amongst these the National Progressive Primary Health Care Network) agitated for and provided in the scanty primary health services available to Africans. Many of these activists actively participated in plans to redress the past inequalities in basic health needs. Despite these promising features of a new perspective on population and reproduction, transformation in service delivery proved to be painfully slow since 1994. Redressing the ills of the past, providing housing, water, toilets, immunisation and electricity proved to be an arduous task for the government. For example, a survey published by the Health Systems Trust in 1997 found that less than half of the public primary health care clinics in rural South Africa had telephones, a further one out of every five clinics were without tap water and without electricity (South African Institute of Race Relations 1998:184).

Benatar (2006:103) also comments that *"many of the newly built primary health care clinics are not yet functioning optimally. Indeed, as a result of the pace and manner in which cutbacks and changes are being made, existing public health services are becoming increasingly dysfunctional….two-thirds of the country's doctors currently work exclusively or almost exclusively in the private sector, caring for about 20 per cent of the population (both whites and blacks) who have health insurance….Reform of the public health system and the problems facing a bloated private sector thus have both immediate and long-term implications for public health issues such as HIV/AIDS."*

Figure 4.2: Contraceptive use amongst sexually active women, South Africa 1998 and 2003



(Sources: South African Government, DoH 2004b; Swartz 2003:13)[3]

The policies of the apartheid government and the NFPP and PDP were successful in establishing contraceptive use among South African women (The SADHS established a contraceptive prevalence rate of 61,2% for 1998). Despite the political agenda of these programmes, black South African women accepted contraceptive methods because of the socioeconomic hardships they had to face. Women bear the brunt of childrearing in South Africa – a situation initially created by the migrant labour system, the creation of ‘homelands’ and the use of influx control. Men migrated to urban areas in search of work and women and children were left behind to fend for themselves (see Jewkes, Penn-Kekana & Rose-Junius 2005:1816). The choice of method, even in 2003, still clearly shows the dependence on injectable contraceptives for the majority of women (see Figure 4.2)[3].

Since 1994, many laws and policies affecting reproductive health have been passed, such as:

- In 1994, the DoH announced free public health services for pregnant women and children under the age of six
- In 1995, the South African government ratified the United Nations Convention on the Elimination of All Forms of Discrimination Against Women
- In 1996, the Choice of Termination of Pregnancy Act was passed
- In 1997, maternal mortality was made a notifiable condition and the Patients’ Rights Charter was launched
- In 1998, a new Population Policy was announced, the South African National AIDS Council was formed and the Domestic Violence Act was passed
- In 1999, the Prevention of Mother to Child Transmission of HIV Programme was launched in the Western Cape province
- In 2000, the National Guidelines for Cervical Screening Programme was launched and the South African Gender Based Violence and Health Initiative was formed

- In 2001, the Prevention of Parent to Child Transmission of HIV Programme was launched in Gauteng
- In 2002, the Prevention of Parent to Child Transmission of HIV Programme was extended countrywide, the National Contraceptive Policy Guidelines were launched and post-exposure prophylactic treatment for HIV-infection for rape survivors was approved
- In 2003, ARV-treatment via the public health sector was approved (Cooper *et al* 2004:72 & 77)

These changes in legislation and policies were accompanied by restructuring in public health care administration, but problems relating to the implementation of programmes, monitoring and evaluation, low morale among health care providers, shortages in human and financial resources and difficulties in retaining trained personnel remained and impacted negatively on policy implementation (Cooper *et al* 2004:73). In the next section, the policy context of HIV-AIDS services is examined.

4.2.2 HIV-AIDS services: The policy context

The AIDS policy landscape in South Africa has been marked by conflict and contestation that, unpredictably, increased in intensity after the transition to a democracy in 1994 (Nattrass 2004; Schneider & Fassin 2002; Schneider & Stein 2001:723). Although in the pre-1994 years the government's response to HIV-AIDS was at best subdued, the beckoning democracy promised a change in policy (Nattrass 2004:420). The sphere of AIDS service delivery in South Africa has always been characterised by strong involvement by non-governmental organisations (NGOs) and there was great hope for an impressive and wide-raging addressing of HIV-AIDS once a democratic government came into power. Promising policy developments prior to 1994 fuelled this belief – for example:

- The AIDS plan that was written in 1992 by the National AIDS Committee of South Africa (NACOSA) which comprised representatives from within the ANC, NGO-sector and the DoH. This plan was ambitious, comprehensive and inclusive

- In response to pressures, the apartheid government repealed its coercive, control-and-contain stance towards HIV-AIDS in 1993 by removing AIDS from its list of communicable and notifiable conditions (South African Law Commission 1995)
- The fact that in 1994, AIDS was declared a *“Presidential Lead Project*” and the NACOSA-plan was adopted. This was followed up in 1999 by the establishment of an inter-ministerial committee chaired by the South African president to deal with HIV-AIDS *“as a national emergency*” (Nattrass 2004:43-44; Schneider & Stein 2001:725; South African Government, DoH 1999a:21).

The promise of a strong, united approach to AIDS was thwarted, however, by the following problems:

- In 1994 the AIDS Programme was placed in the DoH and therefore “*within a narrow health and biomedical framework”* (Schneider & Stein 2001:726)
- A quasi-federal political system consisting of nine provincial governments was introduced. Each province holds the responsibility for implementing AIDS programmes. Consequently, AIDS budgets vary hugely between provinces (Schneider & Stein 2001:725). Further decentralisation of health programmes to district level[4] also took place with confusion around co-ordination of efforts and poorly defined responsibilities for coordinators (Lush & Makoala 1998)
- The AIDS Programme was too ambitious and had insufficient financial, institutional and human resources to meet its goals (Whiteside & Sunter 2000)
- A series of controversies shook the South African AIDS arena. In 1995 there was the *Sarafina II*- musical about AIDS which allegedly cost R14,2 million and which caused a public outcry due to lack of consultation and transparency. This was followed in 1997 by the discovery of a so-called breakthrough drug called *Virodene* which turned

out not to have been put through the most elementary testing and was subsequently turned down by the Medicines Control Council. In the same year, the government tried to make AIDS a notifiable disease and this again sparked outcry and controversy about confidentiality and coercion (Nattrass 2004; Schneider & Fassin 2002; Schneider & Stein 2001; Whiteside & Sunter 2000)

- In 1998 the Treatment Action Campaign[5] (TAC), a NGO, was formed and became a formidable force in taking the Minister of Health (Minister Tshabalala-Msimang) to court over antiretroviral roll out for pregnant women in 2001 (High Court Case no. 21182/2001). Although the High Court ruled in favour of the TAC, the state appealed to the Constitutional Court, claiming that the ruling was an improper intrusion into the policy-making authority of the executive branch of government. The Constitutional Court ordered the Minister in July 2002 to commence with ARV-treatments to curtail mother-to-child transmission of HIV (Minister of Health and Others versus Treatment Action Campaign and Others Number 2 2002, 5, SA 721 CC)[6]
- The TAC also attacked the current state president, Thabo Mbeki, for his so-called *denialist*[7] stance regarding the link between HIV and AIDS and Minister Tshabalala-Msimang for questioning whether HIV-AIDS is indeed the leading cause of adult mortality in South Africa. In addition, the TAC campaigned against the high costs of ARV medication due to profiteering and patent abuse by pharmaceutical companies[8]. The government eventually sanctioned the ARV[9] roll out in 2003, but the bitter battles between the TAC and the DoH meant that scandals and controversies persisted in the AIDS policy arena (Friedman & Mottiar 2004)
- In March 2002, a document entitled *Castro Hlongwane, caravans, cats, geese, foot & mouth and statistics: HIV/AIDS and the struggle for the humanisation of the Africa* was circulated in certain politically influential circles and eventually leaked to the press. In this controversial document, scientific research about ARVs, the HIV-AIDS causal link and other matters were attacked and the so-called dissident view was put

forward (http://www.virusmyth.net/aids/data/ancdoc.htm). This document led to a rift between some scientific researchers and the dissident groups and these tensions still shape the delicate balance between research and the search for realistic treatment options in South Africa

- The former deputy president of South Africa, Jacob Gedleyihlekisa Zuma, made controversial statements about showering after unprotected sex with an HIV-positive woman during his rape trial (a charge of which he later was acquitted) in April 2006 (Ratele 2006). This statement caused confusion and the National AIDS Helpline was inundated with telephone calls from people wanting to know whether bathing or showering after unprotected sex (or even rape) can prevent the transmission of STIs and HIV (*"Zuma's 'shower theory' causing confusion".* The Star 10 April 2006).

Although the government devised a new national strategy (called the HIV-AIDS & STDs Strategic Plan for 2000-2005; followed up by the Operational Plan for HIV/AIDS treatment in November 2003 and the Broad Framework for HIV and AIDS and STI Strategic Plan for South Africa, 2007-2011 in November 2006) and set a target of ARV treatment for 53 thousand people by March 2004 (this is a fraction of the estimated 5,5 million HIV-positive South Africans), by late 2004, only 19 thousand people were receiving ARVs. The number of people receiving ARV-therapy increased to 138 thousand in mid-2005 and to 225 thousand by mid-2006 (which translates to 32% of the estimated 711 thousand people in need of ARV-treatment in 2006), but three quarters of these services are concentrated in only 3 provinces and a mere 113 sites (Dorrington *et al* 2006; Kates & Leggoe 2005). The shortage of health workers, the fact that ARV-treatment is complex, the effect of AIDS-morbidity and mortality among health professionals themselves, the brain drain in medically trained personnel and the urban bias in treatment provision are only some of the obstacles to this process. The Minister of Health blamed lack of capacity for the slow pace of the roll out (Plus News 2004:18). Hasnain (2004:85) cites lack of capacity for counselling and testing and the constantly changing policies and practices governing the availability of ARV-drugs as important obstacles in this regard. In addition, the London-based AIDSMAP (AIDSMAP News 19 June 2007) organisation estimates that, even with an unattainable rapid roll-out of ARVs in order to reach 90% to 100% of those people who need it (and are eligible for it based on CD4-counts), 1,16 million South Africans will die of AIDS-related diseases between 2007 and 2010.

At the same time, vertical transmission of HIV-infection between mothers and children also causes concern. According to the report by Statistics South Africa (2007:8-9) on mortality and causes of death in South Africa in 2005, child deaths in the birth to 4-year-age group represented 10,4% of all deaths – the highest proportion across all age groups. Furthermore, HIV is listed as one of the ten leading causes of death for children aged one to four years (Bradshaw *et al* 2003; Statistics South Africa 2007:22). According to the ***National HIV and Syphilis Sero-prevalence Survey in South Africa 2006*** (South African Government, DoH 2007), almost one third (29,1%) of pregnant women in South Africa were HIV-infected 2006. This translates to a probable one third of all South African newborns in 2006 potentially losing their mothers (their primary nurturers) to AIDS-related diseases. Maternal death affects infant survival negatively. This is supported by studies suggesting that the mortality rates (and morbidity) of HIV-negative children whose mothers are HIV-positive are higher than the mortality rates (and morbidity) amongst other HIV-negative children of the same age (Brahmbhatt *et al* 2006; Esposito *et al* 1999; Kotchick *et al* 1997; Newell *et al* 2004; Nozyce *et al* 1994; Peterson *et al* 2001).

On the positive side, state budget allocations for HIV-AIDS have been steadily increasing over the years (Human Rights Watch 2004:28). In addition, South Africa offers prevention of mother-to-child-transmission (PMTCT) services at 2 000 health sites, which means that South Africa ranks among the largest PMTCT programmes globally (Kates & Leggoe 2005). As with other matters pertaining to the health of women and children, however, the pace in redressing past inequalities is painfully slow, creating and compounding problems in its wake. In the section to follow, the analysis moves to the level of individual decision-making.

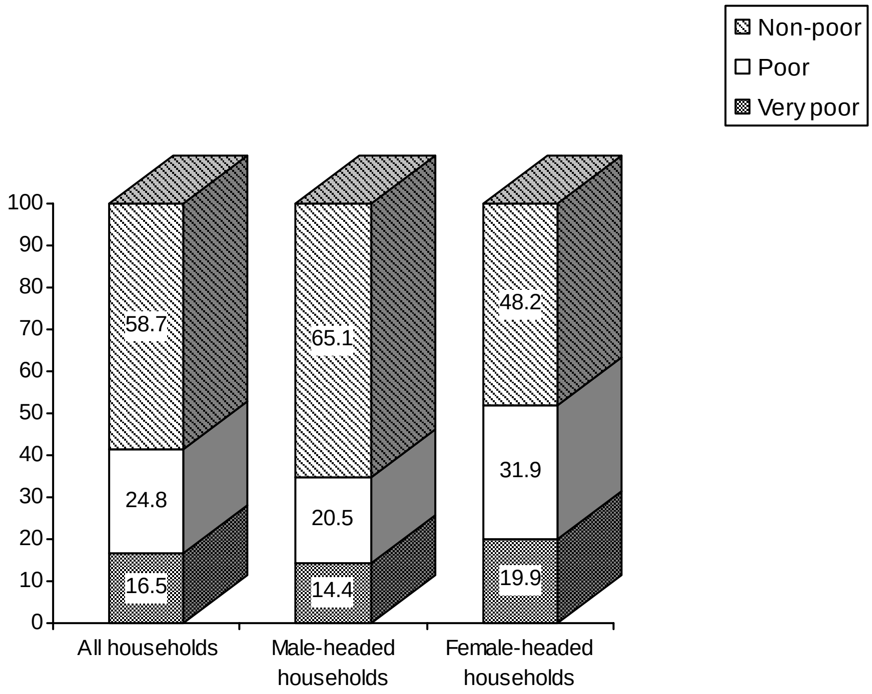
4.3 REPRODUCTIVE DECISION-MAKING IN SOUTH AFRICA: THE INTERSECTION OF THE BIOLOGICAL AND THE SOCIAL AT THE LEVEL OF INDIVIDUAL DECISION-MAKING

The problems South African women face in reproductive decision-making should be seen within the wider historical context, where, through the agency of women, family and domestic life was refashioned in accordance with the constraints enforced by instutionalised racism and social exclusion. In history, racial control was often linked to women's roles as (1) child bearers and therefore the actual reproducers of particular racial/ethnic groups (2) childrearers and therefore the transmitters of cultural practices. In a country in which racism found its ultimate expression in instutionalised form in apartheid, racial hierarchies and gender hierarchies often meshed. The apartheid system methodically expanded state power at the expense of social institutions such as families.

The SADHS of 1998 found 42% of all South African households surveyed to be female-headed and this proportion was 51% for all African households[10]. Analysis from data gathered by Statistics South Africa in 2000, for example, suggest that one in every two female-headed households in South Africa were regarded as poor (see Figure 4.3). Whereas the Nelson Mandela Foundation/HSRC Household Survey (2002:54) concludes that people of all income levels are at risk of HIV-infection, it also points to a correlation between lower socioeconomic status and vulnerability to disease including HIV.

The research participants in this study, recruited at public and volunteer service centres, were predominantly African and socioeconomically vulnerable. These women therefore experienced the pre-existing inequality in reproductive health care services and are faced with new permutations of it in their lives as HIV-positive women and mothers. Since access to a social disability grants (in the amount of R780 per month)[11] for underprivileged HIV-positive persons in South Africa is determined by their CD4-counts and lack of financial resources (when the CD4-count exceeds 200 per cubic millimeter of blood the beneficiary no longer qualifies for the grant), bureaucratic obstacles and biomedical definitions hold the key to essential moneys to care for dependents (Hardy & Richter 2005). Women may find it more difficult to navigate obstacles that stand in the path of first-level and continued access to such grants due to lack of funds for transportation or lack of childcare facilities and help in order to visit the necessary offices to secure such a grant. One of the women, who initially expressed interest in becoming part of this study, was held back by threats from her husband that participation in the study might result in her being "forced" to use ARV-medication and that the family would subsequently loose their grant. Hardy and Richter (2005:92) refer to this as the possible "perverse incentives" of the disability grants. Not only would underprivileged people living with HIV be faced with the possible dilemma of choosing between ARV treatment and access to a grant, but it could be argued that desperate people might be tempted to contract HIV in the hope of accessing such a grant.

Figure 4.3: Poverty distribution, South African households 2000



Very poor = a total household expenditure of R600 or less per month
Poor = a total household expenditure of between R601 and R 1000 per month
(Source: Statistics South Africa 2000).

In addition to the social disability grant, underprivileged people living with HIV or accessing ARV treatments are also eligible for nutritional support in the form of food parcels or supplementary meals and nutrient supplements (Hardy & Richter 2005:88). But even this crucially important issue in dealing with HIV-AIDS is beset by troubles, such as administrative problems in processing food parcel applications, logistical delays, a shortage of social workers and dieticians to assist in the process, inadequate supervision and a lack of clear guidelines for the distribution of nutritional support (Hardy & Richter 2005:85-86). It is important to note that HIV-related illness can incur greater monthly expenses to the afflicted person in terms of moneys needed for monthly travels to the nearest VCT and/or ARV treatment site as well as additional nutritional needs.

Coming back to the issue of stigma and discrimination, it should be noted then that HIV-discrimination attaches itself to pre-existing racial and sexual minority-related stereotypes and stigma. In fact the very spread of HIV is linked to racism, poverty, intolerance and inequality. This is because HIV-transmission is linked to underlying sociopsychological vulnerability. Vulnerability cuts both ways, however, with the infection following the contours of social exclusion, and the disease's impact, once it has taken hold, compounding the existing inequality. Schneider and Fassin (2004:S49 &S50) point out*: "As with ill-health generally, AIDS in South Africa is a highly unequal phenomenon, reflecting the gradients of racial advantage under apartheid….In the case of South Africa, more than a century of racial segregation, then overt apartheid, has produced the roots of the disease through huge economic inequalities, high levels of social violence and large-scale dislocation of households and communities."* The HIV-AIDS epidemic intensifies the problems of vulnerability as approximately 11 million South African children aged birth to 18-years of age live in poverty that is on less than R245 per month (Guthrie 2002). Furthermore the unemployment rate of between 26,2% (for a narrow definition by Statistics South Africa 2005) and 38,8% (for a broader definition by Kingdon & Knight 2006) implies that many people face and will continue to face socioeconomic vulnerability that will negatively affect their health and wellbeing.

In South Africa, most HIV-infections occurred in the mid- to late 1990s and HIV-AIDS is now reaching its morbidity and mortality peaks. This might lead to the idea that childbearing should be put on hold. There is, however, a paucity of empirical information to confirm whether individuals will act in accordance with this view. In fact, the little evidence available seems to suggest that there are little significant responses to HIV-infection in the form of sexual or contraceptive behaviour. In 1989, Prof. Caldwell predicted that HIV-AIDS would hasten the onset of the fertility transition in Africa and would transform reproductive regimes. Almost a decade later, and after careful review, he concluded that although fertility declines were in evidence, behavioural change in response to HIV-AIDS was not (Caldwell 1997; Caldwell, Orubuloye & Caldwell 1999).

Although there are not many studies in sub-Saharan Africa that focus on the ways in which consciousness of HIV-AIDS is or is not transforming reproductive strategies, the results render a confusing and contradictory picture. Fear of stigmatisation and community rejection seem to keep fertility desires amongst HIV-positive couples high in Abidjan, Côte d'Ivoire (Aka-Dago-Akribi *et al* 1999). Husbands' insistence on having more children and wives' fear of abandonment is cited as reasons for the non-adoption of contraception amongst HIV-positive couples in Zimbabwe (Meursing & Sibindi 1995). Rutenberg *et al* (2000) conclude that HIV-AIDS indirectly affects the fertility preferences of couples in Zambia. According to these researchers, fertility preferences irrespective of HIV-AIDS are already transforming toward a smaller ideal family size and it is the concern about the economic burden of caring for orphaned family members that indirectly exerts further downward pressure on fertility preferences in Zambia. Baek and Rutenberg (2005: 3) in a small-scale study in Kenya found that HIV-positive women were much more likely NOT to want another birth than HIV-negative women were. Is this possibly a reason for the perceived increase in birth intervals in South Africa too? Unfortunately, the survey data at our disposal cannot provide us with clear answers to this question.

Another level at which HIV-positive status as a physical reality operates to feed into the social is in the area of stigmatisation. A woman who wishes to adhere to the social obligations and rewards of reproduction may wish to protect herself against possible social rejection and abandonment. Falling pregnant and giving birth (and even breastfeeding – see discussion later on) would then have the social currency of dispelling any possibility that the woman is too ill to bear children (Rutenberg, Biddlecom & Koana 2000). These fears may even fuel a wish to have more or more closely spaced births (Lutalo *et al* 2000; Rutenberg *et al* 2000; Temmerman *et al* 1990; Temmerman *et al* 1994).

Extreme examples of the social consequences of HIV-AIDS stigma for women in South Africa are the murders of Gugu Dlamini in December 1998, Mpho Motloung in August 2001 and Lorna Mlosana in December 2003. Mpho was killed by her husband after they both went for HIV-tests. Gugu, open about her seropositive status and working as an activist, was stoned to death by a mob. Lorna was gang raped and beaten to death in a bar in Khayelitsha after revealing her seropositive status (http://www.tac.org.za; Human Rights Watch 2004:12). These tragic deaths indicate how fear and ignorance about a disease quickly escalated into the feminisation of blame and violence against women.

HIV-positive women develop strategies for self-protection that may result in forms of self-stigmatisation that place limits on their mobility and social interaction. This issue is discussed in greater detail in Chapter 5.

4.3.1 Parent-to-child-transmission of HIV

The risk of vertical transmission[12] without any antiretroviral (ARV) intervention ranges from 15 to 50%. With advances in ARV drug therapies, however, the transmission rates from infected mothers to their children can be as low as 2% (Chen *et al* 2001:144; Conner *et al* 1994; Fowler *et al* 2000; Simonds *et al* 1998). Transmission can occur during pregnancy or delivery. Breastfeeding introduces an additional risk of HIV-transmission. In developing countries, an estimated one-third to half of all HIV-infections is transmitted via breastfeeding (UNAIDS 1998b: 48). Vaginal delivery and breastfeeding carry a greater risk of HIV-transmission to the baby. Kirshenbaum (2004:1) provides a more detailed account of the estimated risks of mother-to-child-transmission (MTCT) as reproduced in Table 4.1.

When the HIV-positive woman is asymptomatic, pregnancy or childbirth will not affect the progression of HIV or the onset of AIDS. Pregnancy and childbirth will however, adversely affect the progression of illness in women with a more advanced level of CD4-count depletion. All babies born to HIV-positive women have HIV-antibodies in their blood until 18 months of age at which stage seroconversion can be more conclusively tested. About 20% of HIV-infected children develop serious illness within their first year of life and most of these children die by their fourth birthdays (UNAIDS 1998a). Other factors beyond vertical transmission also play a role in HIV-infection amongst South African children. The 2002 Nelson Mandela/HSRC Study on HIV-AIDS, for example, found that 5,6 % of children aged 2- to 14-years of age in the sample was HIV-positive and that the majority of these infections were not due to MTCT, indicating sexual abuse as the vehicle for transmission (Human Rights Watch 2004:12; Shisana *et al* 2005:xii).

Table 4.1: Estimated risk and timing of MTCT of HIV

Timing	Transmission rate (%) in the absence of prophylactic medication during pregnancy		
	No breastfeeding	Breastfeeding through 6 months	Breastfeeding through 18 to 24 months
During pregnancy	5 to 10	5 to 10	5 to 10
During labour	10 to 20	10 to 20	10 to 20
Through breastfeeding			
Early (first 2 months)		2 to 10	2 to 10
Late (after 2 months)		1 to 5	5 to 10
Overall	15 to 30	25 to 35	30 to 45

Timing	Transmission rate (%) with the use of prophylactic medication during pregnancy
Early pregnancy	2
During labour/delivery/after birth	12-13

(Source: Kirshenbaum 2004:1)

In terms of vertical transmission of HIV, so-called biological cofactors that elevate the risk to both the mother and the baby are often discussed in ambivalent terms. So, for example, caesarean section, hypothesised to reduce the risk of vertical transmission by lowering the baby's exposure to blood and vaginal secretions, is termed a "compromised benefit" (see Campbell 1999:42) due to the increased risk of maternal morbidity. In fact, poor women, without medical aid benefits and not near well-equipped medical centres, are more likely to have vaginal births or be denied caesarean sections even if they wanted it.

Moreover, the following glib remark is made in respect of another important cofactor, breastfeeding: *"It is recommended that* (HIV) *infected women not breast-feed their infants. In developing countries, however, because of their high infant mortality rates from infection and malnutrition and their lack of clean water to mix formula, breast-feeding is viewed as the best way in which children can be fed"* (Campbell 1999:43). The official South African guidelines (South African Government, DoH 2000a:7) also state that breastfeeding *"contributes to a significant risk of MTCT HIV transmission."* This document is riddled with confusing statements such as the following ones: *"If breastfeeding is chosen, the feeding can be made safer by expressing the milk and boiling it briefly and allowing it to cool before feeding with a cup. Ideally this should be done as often as possible but it may be too impractical for most mothers….It is recognized that, where appropriate, formula feeding will be advised to many HIV positive women. For HIV negative women, and many HIV positive women, breastfeeding will still be the method of choice….In general, breastfeeding must be vigorously promoted and must remain the dominant method of infant feeding in South Africa"* (South African Government, DoH 2000a:22-23). Again, the message is if you lack the financial and other resources, there is little you can do about protecting yourself and your children from the ravages of HIV-AIDS. Surely, the provision of safe drinking water is given a further impetus with HIV-AIDS and cannot be used as a reason why an important risk cofactor cannot be addressed in a poor or middle-income country.

It should be noted, however, that a study of 549 HIV-positive women and their newborn babies (that is 549 mother-baby-pairs) at two perinatal clinics in Durban revealed that those babies exclusively breastfed for the first three months were significantly less likely to become HIV-positive through MTCT than those babies who were either bottle-fed or fed on breast milk with other supplementary feeds (Coutsoudis *et al* 1999; Coutsoudis *et al* 2001). The current policy in South Africa is to encourage exclusive breastfeeding when an HIV-positive mother does not opt to bottle-feed her infant (Hasnain 2004), yet one of the participants in this study said:

> ***They always told us at the clinic that 'breast is best'. People look funny at a black woman with baby bottles…. You see it's not our culture…*** [**Mbali**, one of the participants]

A report by Shisana *et al* (2005: xii) includes with this important observation regarding breastfeeding: *"In view of the relative high HIV prevalence found among South African children both in the 2002 survey and in this survey, we strongly recommend that the government reviews the 'baby-friendly' breastfeeding policy and encourages HIV-positive women not to breastfeed their children but rather supplies them with ready made breast-milk substitute."*

Whilst listing poor nutrition, low socioeconomic status and limited access to health care amongst *"additional risk factors for poor pregnancy outcomes"* in HIV-positive mothers, Campbell (1999:47) makes the following assessment: *"Indeed, in assessing the impact of pregnancy on HIV disease it appears that these factors have a more adverse effect on HIV disease than does pregnancy itself."* It seems a strange sorting-out of which risk factor belongs where and in what sequence. HIV-infection moves along the social fault lines of inequality and disempowerment and it is almost commonplace that these factors are related with higher rates of maternal, child and general mortality and morbidity. In the fictional absence of HIV-infections, poor mothers who are malnourished and lack access to good quality medical care are at risk of maternal and infant morbidity and mortality.

The SADHS-results show that approximately 10% of South African babies from birth to 3 months of age are exclusively breastfed, whereas 73% of these babies are fed a mixture of breast milk and other supplementary feeds. The proportion of exclusively breastfed infants for the age groups birth to 12 months of age in South Africa is a low 3,5% (SA Government, DoH/MRC/Macro International 1999:12). It was not possible to trace comparable data for earlier dates to ascertain whether these figures represent a decline in full breastfeeding. Dorrington *et al* (2006:ii), however, suggest that breastfeeding results in approximately 26 thousand new infections among infants in 2006.

In populations with low levels of contraceptive prevalence, the absence of breastfeeding might put pressure on women to curtail post partum abstinence in order to prevent their partners seeking other sexual partners. Moreover, increased infant mortality at young ages due to HIV-AIDS may further reduce post partum infecundity periods, thereby inflating fertility. Nonetheless, asking an HIV-positive mother not to breast-feed her baby is fraught with difficulties in South Africa. First, some women see it as a give-away sign that you are HIV-positive when you do not breastfeed. Second, milk formulas are expensive and beyond the reach of many mothers. Third, access to clean drinking water and to bottle-sterilisation equipment is equally biased towards the minority who can afford these options (see Latham and Preble 2000, for an in-depth discussion on infant feeding by HIV-positive mothers and Nattrass 2004:65-98 for an in-depth analysis of the affordability of various MTCT prevention strategies in South Africa).

As pointed out before, South African officials proudly pronounce that a fertility transition has been accomplished in the absence of female empowerment. In this chapter it is argued that the absence of female empowerment in the arena of reproductive health has left South Africa in a tragic state of affairs in dealing with the HIV-AIDS-crises and in supporting the reproductive decision-making of women who discover their seropositive statuses at an antenatal screening[13].

In relation to HIV-AIDS, surveillance studies and routine antenatal screening for HIV-infection are prime examples of how (female) populations are constantly investigated for signs of abnormality and infection. The South African government's reticent stance on the deployment of antiretroviral treatment smacks of a frantic fight to "control" the disease via the establishment of state-run surveillance facilities. Even with ARV-roll out present at some of the facilities, the research participants in this study spoke about the narrow, relentless clinical focus on "disease control" and "adherence" to drug regimes, as one of them stated:

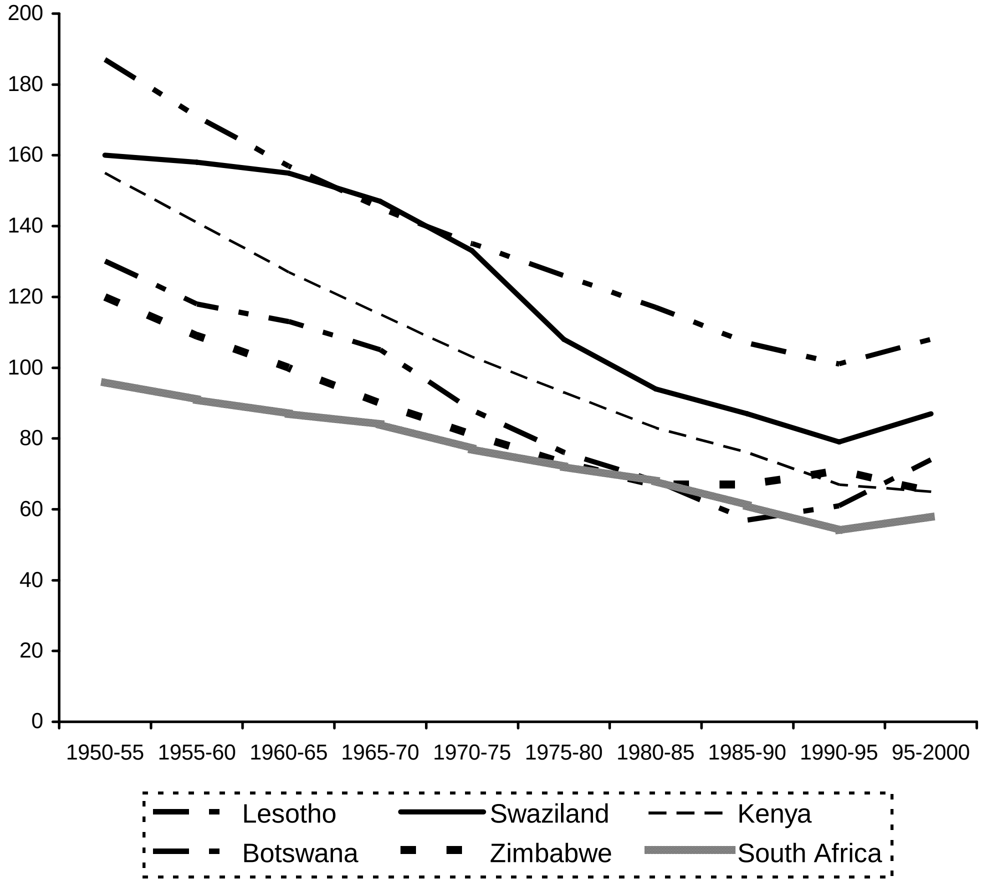
> ***The nurses talk about Masakane, Batho Pele and Khomanani... Khomanani is only for the newspapers and television.... They say we must drink it in front of them – they want to see us drinking the pills*** [**Gita**, 35-years old].[14]

In this section, facts and perceptions regarding parent-to-child-transmission of HIV in South Africa has been explored. As an extension of this theme, the following section is a brief exploration of the notion "safe" motherhood in South Africa in general.

4.3.2 "Safe motherhood"? Trends in childhood and maternal mortality in South Africa

South Africa has always had a relatively high rate of infant mortality relative to its fertility transition (see Figure 4.4). Anderson (2003:37) provides an analysis of SADHS-data for 1998 that clearly shows greater infant mortality rates for Africans, people in rural areas, women with poor access to antenatal and delivery care, households without piped drinking water and households without toilets in the home (see Table 4.2). It should therefore be apparent that even within the hypothetical absence of HIV-AIDS, infant morbidity and mortality in South Africa is unacceptably high and reflects the inequalities of the past. In addition, South Africa has a high maternal mortality rate of between 150 to 200 deaths per 100 000 live births (Cooper *et al* 2004:75; South African Government, DoH 2000a:20 & 2002; see also Figure 4.5).

Figure 4.4: Infant mortality rates for selected African countries, 1950-2000



(Sources: Anderson 2003; Mostert *et al* 1998:71; South African Institute of Race Relations 1998)

These statistics, along with other indices of child health in South Africa, reflect that even the PDP with its claim to encompass wider primary health ideals than the narrow family-limitation goals of the NFPP, did not redress the inequalities affecting women and children in South Africa. Rossouw and Jordaan (1997), reporting on a series of mother-and-child health studies undertaken between 1988 and 1992, report that only 48% of the 2 183 African children aged 12-23 months in their sample were fully immunised[15]. Childhood immunisation is the most basic primary health intervention, yet even this was under strain prior to

1994 and is still a problem. In addition, the majority of the African mothers in Rossouw and Jordaan's study only commenced with antenatal care in the second or third trimester of pregnancy (this is supported by the 1998 SADHS finding that women were a median of 5,2 months pregnant at their first antenatal visit). They also found that, whereas 15% of births in their study were by caesarean section, only 13% of African women reported this mode of delivery versus 29% of white women – a clear indication of exaggerated surgical intervention amongst the group with the greater access to private health funding.

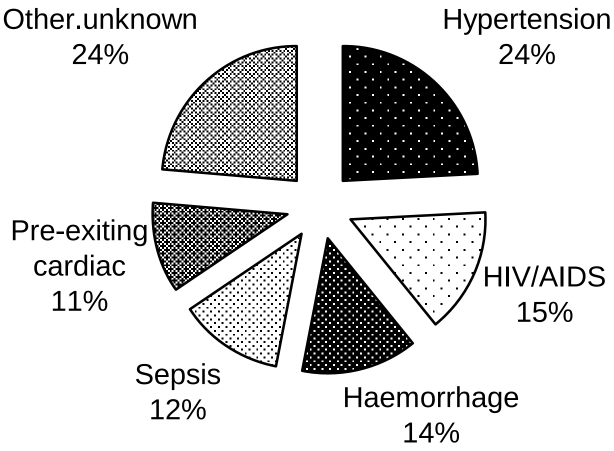
Table 4.2: South African infant mortality rates for the 10-years preceding the survey from the SADHS of 1998*, by selected household characteristics

Characteristic	Infant Mortality Rates
All	42[16]
Urban	33
Rural	53
African	47
White	11
Rural African	54
Mother received no antenatal or delivery care	43
No piped drinking water in dwelling	64
No toilet in the dwelling	64

(Source: Anderson 2003:37)

* Updated, corrected, weighted infant mortality data from the 2003 SADHS were not available to the author at the time of writing.

Figure 4.5: Causes of 676 maternal deaths, South Africa 2000



(Source: South African Government, DoH 2000d: 20)

The grim picture of child health, reproductive health and access to ARV therapies should be seen in the context that there is still a two-tier health care system in South Africa comprising private health care and public health care.[17] Private health care in South Africa is largely first-rate and enormously lucrative, but the costs mean that only a minority of the population has access to it. Public health care is characterised by uneven service, as some centres are excellent, whilst others suffer under appalling circumstances of neglect and poor infrastructure – especially in rural areas.

So-called sperm washing or artificial inseminations are alternatives to safe conception for HIV-serodiscordant couples wishing to become pregnant after diagnosis. However these options are only theoretically available to people able to afford private health care fees (AIDSMAP 2005). A representative of a community-based organisation suggested*: "Many HIV-positive women just take the chance to fall pregnant, you know, and they hope for the best, without discussing it with their doctors. They do not even know their CD4 counts or viral loads or what their husband's or boyfriend's statuses are. I think we should do* *more to inform people fully of what their options are"* [Field journal entry of a personal discussion]. Furthermore, the researcher found in her observations and interviews a rigorous insistence on condom use for HIV-positive women (see Chapter 5) which seems strangely at odds with a liberal view on accommodating the childbearing preferences of HIV-positive persons (see Richey 2006 for a similar conclusion from a study in the Western Cape). Whereas motherhood and infancy are not necessarily "safe" in South Africa yet, "safe sex" proves to be an even tougher issue and this is examined in the following section.

4.3.3 Questioning the assumption of "safe sex"

Since the HI-virus was first identified in 1981, its spread has largely been associated with unprotected sexual intercourse. In this regard, the prevalence of multiple sexual partner relationships was an almost obsessive focal point in AIDS-research. The question arises: Why do women partake in unprotected sexual intercourse? Obbo (1995:81) says*: "The student who needs to receive good grades, a worker who needs to keep a job or to be promoted, or a poor woman with no alternative way to generate an income that constitutes a living wage is in no position to say no to AIDS."* Varga (1997:50-51) mentions a host of reasons, such as female socioeconomic disempowerment, gender-biased culturally sanctioned powerlessness of women, women's emotional intimacy needs, women's lack of intimate communication skills, the powerful symbolic value of condomless sex as indicating trust and love, the stigmatisation of condom[18] use and women's obligations to fulfil gender and familial roles through pregnancy and childbearing. In addition, Dixon-Mueller and Germain (2000:76) declare *that "unwanted sex is a manifestation of the profound inequalities of gender."*

This brings the issues of the social vulnerabilities of women, their socioeconomic characteristics, perceived gender roles, ethnic identity and support systems to the fore. Farmer (1995:18) notes how poverty affects monogamous sexual unions in Haiti, forcing women with dependents into patterns of serial monogamy in a quest to find a financially secure partner.

Fassin and Schneider (2003:496) maintain that *“sexual violence has long been part of the everyday life of townships and inner city areas”* in South Africa and that abject poverty and social vulnerability combined with the normalisation of sexual violence result in young women adopting *“survival sex*”-practices to endure. Orubuloye, Caldwell and Caldwell (1993) cite the economic dependence of women and weakening of lineage ties as reasons for persistent unprotected sex in Nigeria. McGrath, Rwabukwali and Schumann (1993) observe that economic need and culturally sanctioned male high-risk sex are important factors to consider in Uganda. Schoepf (1995:30) mentions that poverty, prolonged economic hardships, structural adjustment programmes with an emphasis on the reduction in public health budgets (leading to the neglect of treatment for STIs that are important cofactors in HIV-infection) and institutionalised male dominance led to multiple partner relationships, widening sexual networks and burgeoning HIV-infection in the Democratic Republic of Congo.

Mpundu and Zulu (1999) point out that the current VCT and ARV services in Africa tend to disregard the fact that HIV-positive women remain sexual beings after diagnosis and are in need of counselling and services in this regard. De Bruyn (2005:6) adds that much of the contraceptive counselling to HIV-positive women in public health care settings is an emphasis on condom use and a discussion of other methods of contraception and their possible interaction with ARV-treatment is neglected.

In terms of fertility, the proportion of women in consensual unions is important, but so also is the age of entry into such unions, the duration of these unions, the sexual frequency in stable consensual unions and the mean number of fecund years spent outside of consensual unions (or spent not being exposed to the risk of conception in the absence of intentional family-planning efforts). Kaufman and James (2001:206) for example, found higher recent fertility rates amongst black South African women whose male partners return home only once a month or less. They conclude *"men's migration plays a decisive role in reproductive outcomes, perhaps not in terms of a conjugal bond, but because of* *the ways in which women cope with the absence or lack of partners, through wage-earning activities or by establishing households on the basis of sibling or parental relationships"* (Kaufman & James 2001:216).

Caldwell (1997, 1999 & 2000) concluded that behavioural change in response to HIV-AIDS is lagging behind fertility transitions in Africa. Data from sub-Saharan Africa confirms that there is very little evidence to suggest that the threat of HIV-AIDS is changing sexual behaviour in any discernable way (Rutenberg *et al* 2000). In 1990, Van de Walle (1990:29) made this bold prediction*: "It would be surprising if a much stricter sexual morality were not to emerge from the crisis. In the long run, sexual behaviour and marriage customs are likely to be profoundly transformed. Two pillars of the present nuptiality system in much of sub-Saharan Africa, the large difference in age at marriage and polygyny are likely to crumble under the impact."* Although this hypothesis still has to be tested with evidence from Africa, the evidence shows that HIV-AIDS flourish conjointly with inequality[19], poverty, and the sex trade (Paicheler 1992:15; Wilton 1997:118).

Van de Walle's (1990) predictions ignore the multifaceted and fractured nature of nuptiality and family formation prior to the AIDS crisis. The role of apartheid, pass laws and the creation of homelands in the fracturing of African families in South Africa is a reality to be reckoned with in any consideration of family formation and fertility. Berger (1992:244-5) points out that women actively responded to these situations through concerted efforts to ensure economic self-sufficiency for themselves and their children. Thus, it was not merely a case of a state-led breaking down of families, but rather a case that through the agency of women; family and domestic life was refashioned in accordance with the constraints enforced by institutionalised racism. As Berger (1992:244-5) explains: "*Family relationships were being reconstructed in new ways that stressed the connection among women, children, and other female kin. This reorganization of family life occurred because so many women became actual or de facto household heads at an early stage of their lives."*

Harrison, Lurie and Wilkinson (1997:106) conclude from their ethnographic study in a rural village in KwaZulu-Natal that consensual unions are fluid and changing. Preston-Whyte (1993:66-67) adds that for many South African women this reorganisation of domestic life implied a break between the sociocultural institutions of childbearing and marriage and unmarried childbearing (by own volition or by default) established an alternative route through a life in which choices were constrained by a lack of freedom and a desperate struggle for survival. Kaufman and James (2001:216) come to similar conclusions regarding Sotho and Ndebele women in South Africa, namely that these women reshaped their identities, and actively recreated their reproductive careers and domestic arrangements to accommodate changing circumstances[20].

Even within stable consensual relationships, dangerous sexual practices such as “dry sex” (the use of astringent preparations such as Dettol, Betadine, powders, small stones, leaves, newspaper, tissues, cloth for douching or wiping the vagina before sexual intercourse) are directly primarily at male pleasure and may lead to abrasions that may increase the risk of STIs including HIV (Halperin 2000:22).

Sexual violence and the fear of violence are more reasons why women might engage in unprotected sex. In this respect, Cooper *et al* (2004), Leclerc-Madlala (1997), Varga 1997 and Varga & Makubalo (1997) point to the threat of physical violence or coercion as an important reason why South African teenagers engage in unprotected sex. The intersections between violence and HIV are multiple, such as:

- The fact that physical, emotional and/or sexual violence limits women’s ability to negotiate “safer sex” and that the threat of violence may prevent them from accessing VCT services or encourage them to drop out of ARV-treatment regimes (De Bruyn 2005)
- The hypothesised link between childhood sexual and emotional abuse and risk-taking behaviour in later life (including street children who left

abusive homes and find themselves vulnerable to sexual exploitation due to poverty)

- The fact that women who divulge their seropositive status can indeed become victims of violence[21]
- The fact that poverty or economic vulnerability can prevent women from leaving violent domestic arrangements (De Bruyn 2005)
- The fact that HIV can be transmitted via rape[22] and in particular via gang rape (Human Rights Watch 2004:11; Maman *et al* 2000).

Results from the South African Demographic and Health Survey (SADHS) reveal that 19,2% of 5 077 (this is almost one in five women) currently married women suffered “economic abuse” from their partners in the form of withholding of money to buy food or pay the rent or bills. In addition, 6,3% women reported physical abuse by a partner in the 12 months prior to the survey and 4% of all ever-pregnant women reported that they were abused by their male partners during their pregnancies. Furthermore, this study reported that 4,4% of the women reported having been raped and a further 3% coerced into sex (a staggering finding for a general survey). Only 15% of these women reported their rapes to the police (SA Government, DoH/MRC/Macro International 1999:21-23).

Human Rights Watch (2001) reports a 20% increase of rape and attempted rape in South Africa between 1994 and 1999. According to police statistics there were 51 249 cases of rape[23] reported in South Africa in 1999; 52 107 in 2002 and 55 114 in 2004 (Human Rights Watch 2001 & 2004). Since it is estimated that only 1 in 9 rapes is reported, these numbers represent the tip of the iceberg. Hirschowitz, Worku and Orkin (2000: 21-24) report that for the period 1996 to 1998, girls aged 17 years and younger constituted 40% of all reported rape and attempted rape victims. Police statistics show that more than 40% of rape survivors reporting rapes between 2002 and 2003 were younger than 18-years of age and 14% of them were 12-years and younger (South African Police Service 2003:37). Observers mention the “virgin cure myth” as a possible cause behind the increasing numbers of younger girls being raped or forced into sex (Human Rights Watch 2001), but Jewkes, Penn-Kekana and

Rose-Junius (2005: 1814-15) point out that the “virgin cure” is much less important in the normalisation of sexual violence than discourses that shape male sexual desire as uncontrollable, unpredictable, dangerous and linked to power and privilege.

These statistics, although disputed by some, provide a picture of women[24] whose reproductive health cannot assume to be a matter of free choice and informed decision-making. The slow roll out of post-exposure prophylaxis (PEP) and ARVs to assist women infected via sexual violence and the fact that the only NGO in South Africa that is funding ARV-therapy to rape survivors is an organisation called GRIP[25] (the Greater Nelspruit Rape Intervention Program) in Mpumalanga, underscores the extent to which sexual violence and female disempowerment have been normalised in South African society (Human Rights Watch 2004:22). From July 2002, 25 808 clients received PEP services from 52 facilities in Gauteng, but a quarter of these presented later than 72 hours after the incident and a low 27-30% completed their treatments (Gauteng DoH 2005:45). Cooper *et al* (2004:77) blame uneven political support and under-resourced public health systems for the slow roll out of PEP services countrywide.

The provision of PEP to child survivors of sexual violence remains a difficult issue in South Africa, as an HIV-test is a provision for receiving PEP and children younger than 14-years could until 2007, not consent to medical testing, including HIV-tests. Where a parent or legal guardian cannot consent to a test (and these people may be the perpetrators of the sexual violence), PEP will be denied. PEP is also not generally available in rural areas (Human Rights Watch 2004:2). The age of consent for HIV-testing and to use contraceptive methods was lowered to 12 years when sections of the Children’s Act of 2005 (Act No 38 of 2005) came into effect on Sunday 1 July 2007.

The 2007 Criminal Law (Sexual Offences and Related Matters) Amendment Bill [henceforth referred to as the Sexual Offences Bill] broadens the definition of rape and makes clear reference to the link between HIV-infection and rape. Whereas the Sexual Offences Bill reaffirms the availability of post-exposure prophylaxis (PEP) services to prevent HIV-infection (already available since 2002), it does not make provision for the compulsory HIV-testing of offenders. Under the Sexual Offences Bill, rape survivors can obtain a court order for alleged offenders to be tested for HIV and for the results to be declared to them. The Sexual Offences Bill does not make provision for psychological counselling, prevention of pregnancy or the treatment of sexually transmitted infections as a result of the rape. Furthermore, a previous draft of this Bill included a clause in which it was stated that when a person intentionally fails to disclose his/her HIV-status to a person with whom he/she has sexual intercourse that person is guilty of unlawful conduct. Whereas this clause might have offered some protection to some women, it was also thought to have a possible opposite effect. Since women are more likely to know their HIV-statuses (due to for example antenatal testing) coupled with the fact that they are often reluctant to disclose their statuses to their husbands/partners for fear of violence or abandonment, it could have resulted in many women being charged in terms of this offence. In addition, the criminalisation of intentional transmission of HIV has the potential of opening the door to all other forms of mandatory testing (Ezeilo 2003).

Even in consensual monogamous unions between HIV-positive individuals, safe sex becomes a difficult issue, for example:

> ***Anybody in a long term relationship will tell you that one stops using condoms after a while….it is not a reliable method.*** [Funani 34-years old]

Currently, clinical evidence on re-infection (or superinfection) with HIV is sketchy and incomplete. It is now known that dual HIV-infection, defined as the presence of two distinct HIV strains in a patient, can occur. HIV-positive people, may apart from contraceptive reasons or for protection against re-infection, opt for safer sex to protect themselves against other infections that are life-threatening to people with HIV such as the cytomegalovirus (CMV), some forms of hepatitis or genital herpes (for a discussion, see Fang *et al* 2004; Jost *et al* *2*002; Zhu *et al* 1995). The use of condoms is important in the prevention of re-infection and condom use in general as a “safer sex” practice is discussed in the following section.

4.3.4 Condomising[26] and the use of contraceptives

Before discussing voluntary adoption of condoms as a method of contraception and as a prophylactic against HIV-infection, the issue of choice in family planning *per se* is examined. As is evident from the discussion so far, South African women are left to exercise vigilance for their own reproductive health as ever more complex structures of power, domination and surveillance emerged.

Using condoms in sexual relationships is not a straight-forward rational negotiation (Holland *et al* 1991; Sobo 1993). The assumptions of rationality in sexuality, individual choice and personal responsibility that underlie many public health care education campaigns ignore the dynamics of relative power and different types of reasoned agency in sexual relations. This has the further discursive effect of transferring women’s difficulties in translating knowledge about sexual risks into practice to the level of individual excuses (Richardson 1994:51).

On the other hand Kline, Kline and Oken (1992:447, 450, 455-456) come to different conclusions regarding low levels of condom use. Instead of ascribing this to a female lack of agency in negotiating sexual matters, they cite women’s low perceived susceptibility and a transition in gender roles as reasons for them engaging in unprotected sex. The researcher’s own interpretation of the trends in fertility and contraceptive use patterns in South Africa brings her to a different interpretation: that of free agency in decision-making in reproductive matters that were continually challenged and often subverted by other, more powerful agents.

The high prevalence of the hormonal injectable contraceptive, Depo Provera, are attributed to women’s desires to postpone births (as opposed to stopping births) in order to remain in employment and to keep their contraceptive use secret from male partners who tended to interpret contraceptive use as indicative of sexual infidelity. It was also borne out of a need for a method that lasted longer (normally for 3 months, but due to high dosages and excessive use its contraceptive effect sometimes extended to between 6-18 months) as visits to clinics and mobile units meant hours away from work. The injection also did not curtail breastfeeding (an important social norm) and its postpartum application was therefore jokingly referred to as the fourth stage of labour. It also rendered control over contraception to family planning nurses. Whereas the use of Depo Provera became a normalised part of life for women wishing to postpone births, it left them without protection for STIs and HIV-infection, which cannot be prevented by methods that are invisible, long lasting and exclusively applied by health workers. The National Contraception Policy of 2002 and the Service Delivery Guidelines of 2004 attend to issues of contraceptive method choice, restrictive access to contraceptive services, provider coercion and the involvement of men in reproductive and contraceptive health care and counselling. Despite these promising changes, injectable hormonal methods still dominate as the main form of contraception, male condoms are still the only widely available barrier method, emergency contraception is unknown and underutilized and teenage pregnancies remain a concern (Cooper *et al* 2004:74).

The docile female body, accepting family planning advice from a health expert who knows best is a sad legacy of family planning programmes under the apartheid regime that enabled a fertility transition in the absence of actual female empowerment that leaves HIV-AIDS education and the containment of new infections in the doldrums.

Although it is almost impossible in a macro-level analysis to sort out which proportion of the contraceptive prevalence rate is attributable to HIV-AIDS prevention and which proportion to spacing and limiting of births, evidence suggests a substantial increase in condom use in Africa (see Table 4.3 and 4.4). Evidence from the SADHS suggests that condom use is more common amongst younger, unmarried and urban women (South African Government, DoH 2004; SA Government, DoH/MRC/Macro International 1999:16-17). What is concerning is:

- That in 2003[3] half of all sexually active teenage women have never used a condom (see Table 4.3)
- The low usage of condoms at the last sexual encounter (see Table 4.4) in provinces such as Mpumalanga and the Free State which have an almost 30% HIV-prevalence rate.

Notwithstanding these apparent increases in condom use, the stigma attached to condoms has an institutional antecedent. The previous family-planning programme tended to compartmentalise family planning services from STI care delivery systems with the former emphasising female hormonal methods for spacing and limiting births and the latter emphasising the prophylactic use of condoms for male protection against STIs. This, at least in part, informed a lay discourse that linked condom use to “loose sex” and banished it to non-stable sexual unions.

Table 4.3: Percentage ever use of condoms (various DHS-rounds)

Country	**1988-1994**	**1996-1999**	**2003[3]**
Côte d’Ivoire	14	23	No data
Ghana	4	14	33[27]
Togo	4	16	No data
Zambia	9	17	42[27]
Zimbabwe	13	18	43[27]
Uganda	10	17	55[27]
South Africa (SADHS-data)	4,6	22,2	38,6
Sexually active teenagers (15-19 years)	No data	28,4	49,0[28]
Urban women	No data	31,2	38,6
Rural women	No data	16,2	38,5
Cameroon	9	22	47[27]

(Sources: SA Government, DoH 2004; SADHS 1998)

The only available study on dual method use in South Africa (that is, the use of condoms in conjunction with another contraceptive method) indicates that the prevalence of this is low. Moreover the study finds that the decision to use a condom is more often the sole domain of the male partner (Myer *et al* 2002). However, as Caldwell and Caldwell (2002:109-110) observe, the ICPD ideal of integrating STI and family planning services is not a feasible ideal in sub-Saharan Africa. The reasons put forward for this by the Caldwells is that perceptions, actions and behaviours regarding these two reproductive health issues (STIs and family planning) and the people and sexual dynamics involved differ to a large extent.

Table 4.4: Percentage condom usage during the last sexual encounter amongst women 15-49 years of age by province, South Africa 1998 and 2003[3]

Province	1998	2003[3]
Kwa-Zulu Natal	6,7	46,6
Mpumalanga	9,5	27,0
Gauteng	10,4	35,3
Free State	10,9	28,3
Northwest	9,0	33,1
Eastern Cape	6,1	31,2
Limpopo	6,4	26,5
Northern Cape	5,0	20,3
Western Cape	8,1	23,8
South Africa	8,2	33,3

(Sources: SA Government, DoH 2004:17; SADHS 1998)[27]

Emergency contraception, which can eliminate unwanted pregnancies and even the need for termination of pregnancies in the case of unprotected sex, method failure or condom failure, has been down-scheduled in South Africa since November 2000. This means that emergency contraception is theoretically available over the counter at pharmacies, but few people know of its existence or try to access it via the public sector (Smit *et al* 2001). Furthermore, there is a paucity of conclusive clinical research on the use of hormonal contraceptive methods for women living with HIV and/or using ARV therapies as far as disease progression and possible drug interactions are concerned (Cates & Morrison 2007). Cates and Morrison (2007:15) suggest: *“The only evidence so far that hormonal contraceptive use might affect HIV disease progression comes from a prospective study conducted among sex workers in Mombasa, Kenya. This evidence suggests that using hormonal contraception at the time of infection – before women know that they are infected – may accelerate HIV-related deterioration of the immune system and thus speed the natural course of the infection.”* The heavy reliance on injectable hormonal contraception in South Africa is therefore cause for alarm, yet this important issue is still neglected. Staying with reproductive health issues, the issue of sexually transmitted infections is discussed in the next section.

4.3.5 Involuntary infecundity: HIV and the epidemiological synergy of STIs

Earlier on, biological factors associated with HIV-infection and AIDS that may affect fecundity were mentioned. In conjunction with HIV, there are also other STIs that may lead to pathological sterility. The World Health Organisation (WHO 2001) estimates that 12% of 15- to 49-year-olds has a curable STI, whereas other studies suggest that 2% to 7% of pregnant and contracepting women have cervical gonorrhoea, Chlamydia or syphilis and anything between 4% and 34% of such women have trichomoniasis (Askew & Baker 2002:77). The prevention and cure of STIs are an important public health goal in its own right, but the presence of STIs commonly enhances the sexual transmission of HIV (Askew & Baker 2002:77).

In South Africa, STIs are a major concern amongst young adults and a study in the Hlabisa district in KwaZulu-Natal found that 10% of young adults have at least one STI per year (Wilkinson *et al* 1997). Rotchford *et al* (2000) found that 9% of all pregnant women attending antenatal care at public clinics in Hlabisa between June and October 1998 had syphilis. Results form the SADHS show that 12% of adult men in South Africa have had symptoms of an STI in the three months prior to the 1998-survey. These percentages were higher for men residing in non-rural areas (16%) and for the 25-year to 34-year age groups (SA Government, DoH/MRC/Macro International 1999:16-18). Harrison *et al* (1997) found from an ethnographic study in rural KwaZulu-Natal that 50% of all women clinic attendants have at least one STI and that there are many obstacles mediating partner notification in the case of a STI. Based on various smaller site studies in KwaZulu-Natal, researchers at the Medical Research Council (MRC) estimate that around 25% of women in South Africa have at least one STI and that about half of these are asymptomatic conditions that remain undetected and therefore untreated (Wilkinson *et al* 1997). It should be kept in mind that STIs commonly affect women's fecundity. Moreover, the treatment and prevention of such infections in the general public, leading to a reduction in the incidence and prevalence of STIs can potentially lead to increased fertility.

Wilton (1997:61-63 and 126-144) provides an interesting history of the social construction and the feminisation of STIs in which female sexuality began to signify a sex/disease/death package that converged around notions of contamination and excess. Wilton (1997:62; 65) points out that public health education regarding STIs shifted from the attentive gaze directed at the body of the innocent male victim onto a gaze of the body of the guilty female source of infection. She (Wilton 1997:68) explains how, once it became apparent that people who were not gay men could and had become infected with HIV, the familiar old hetero-binary narratives took effect again. Within these narrative female bodies are regarded as the reservoirs of infections, the wellspring of contamination and the prime indices for the spread of the disease. It is not difficult to see how this construction of STIs and HIV-AIDS feeds a surveillance methodology that focuses primarily on pregnant women within the academic field and a myth that condoms are for protecting males against STIs within lay discourse. Violence against women who have disclosed their seropositive statuses is indicative of this feminisation of blame.

A related issue in reproductive health is that of cervical cancer and its link to the human papilloma virus (HPV, an STI). Cervical cancer is not only a defining condition of AIDS in HIV-positive women, but also accounts for a quarter (25%) of all cancer deaths among black South African women (Cooper *et al* 2004; Moodley *et al* 2006). In addition, HIV-positive women are three to five times more likely to contract HPV than seronegative women. South Africa has no formal Papanicolaou smear programme (commonly referred to as pap smears or screening for cervical cancer)[29] although the DoH's (South African Government, DoH 2000b) National Guidelines for a Cervical Screening Programme make provision for one free Pap smear every ten years for women over the age of 30[30] in the public health sector. In developed countries, however, all HIV-positive women receive a pap smear in the first year after a seropositive diagnosis and a follow up annually. Whereas access to ARV-treatments can prolong life in women living with HIV, the high incidence of cervical cancers can offset any gains made.

4.3.6 Termination of pregnancies: Putting women's empowerment to the test

Although there might be a slight increase in the incidence of pregnancy terminations (induced abortion) in Western Africa, it is unknown whether HIV-AIDS contributes to this rise. Termination of pregnancy may prevent an unwanted and potentially HIV-positive baby, but it does not prevent HIV in the mother. In addition, fecundity may return more rapidly after an abortion than after a full term delivery, due to the absence of breastfeeding and post partum abstinence, necessitating both barrier and other contraceptive methods (Gregson, Zaba & Hunter 2002:12). Although abortion on demand[31] is available to women in South Africa (only since 1 February 1997 on the basis of the Choice of Termination of Pregnancy Act 92 of 1996), there are moral, religious and service barriers that restrict equal access to legal pregnancy termination services in South Africa (Camlin, Garenne & Moultrie 2004; Cooper *et al* 2004:75; Guttmacher *et al* 1998; South African Government, DoH 1999a; SA Government, DoH/MRC/Marco International 1999:49). In 1997 there were 31

312 legal terminations of pregnancies performed in South Africa and almost all of these were carried out in urban hospitals (Dickson-Tetteh & Billings 2002:145). This figure increased to 53 510 in 2002 (Reproductive Health Alliance 2002).

Camlin *et al* (2004) point out that the training manual for health workers published by the University of the Witwatersrand explicitly mentions that HIV-positive pregnant women should be counselled and assisted to make informed decisions about the continuation of their pregnancies as well as their future childbearing options. Voluntary termination of pregnancy (where safe procedures are available) is also mentioned as an option to be examined by such women during HIV post-test counselling. In this study, none of the research participants spontaneously mentioned abortion as an option, but Lerato mentioned*:*

> ***My friend found out that she was HIV-positive during her antenatal visit. She is crying all the time; she would really like to speak to you. She says she wants to speak to everybody and find out everything…. She is a Christian and therefore does not want to consider abortion, but now she says that she wants to die herself.***

It should be kept in mind that due to the already discussed late commencement of antenatal visits amongst women (especially those who live in rural or remote areas) plus the fact that many women discover their seropositive status during antenatal testing implies that safe terminations of pregnancies, even with informed consent, may not always be an option. In addition, Cooper *et al* (2004:75-76) point out that: *"A great challenge stems from the shortage of health care providers willing and trained to provide abortions. Access is further hindered by providers asserting conscientious objection. In spite of a legal obligation to refer to a willing provider, many providers try to discourage women from having an abortion, presenting a fundamental barrier to care."*

4.4 CONCLUSION: USING THE PRIMARY RECORD TO SITUATE THE QUALITATIVE STUDY

This chapter is the primary record for the study intended to inform the next phase in the research process. In this chapter, available evidence on the interrelatedness of HIV-AIDS and fertility in Africa and South Africa was discussed. Although some interesting trends emerge from the available data, a rather muddled picture of the reproductive health status in South Africa emerges. In many instances, the complexities, diversities of, and transitions in reproductive and sexual decision-making cannot be captured, measured or interpreted with any certainty. A confusing picture emerges in which the contextualities of reproductive decision-making are obscured. Macro-analysis makes it almost impossible to partial out the independent effect of HIV-AIDS on fertility change. In addition, many commentators of the progression of the fertility transition in South Africa (Kaufman 1996; Moultrie & Timaeus 2001; Swartz 2003) conclude their analyses with the observation that a fertility transition occurred for African women in South Africa in the absence of their full empowerment.

The researcher agrees that more than four decades of institutional discrimination severely truncated the personal, economic and social freedom of African women. She also concurs that the gradual demise of apartheid, the introduction of a vigorous family planning programme and the transition to a democracy have gone some way towards emancipation. Much, however, remains to be done to address the deep wounds of the past. Many of same factors that established a particular engagement with contraceptive use are at play in establishing risky reproductive health environments for the women of South Africa.

Within the fraternity of demographers in South Africa, there are those who are scornful of small-scale qualitative studies and demographic work in the HIV-

AIDS field instead focuses on building models and estimates of HIV-infections and AIDS morbidity and mortality[32]. These estimation models have all the trimmings and trappings of scientism and appear as objective and detached. Moreover, such models typically take on the characteristics of Malthusian doomsday-scenarios, whilst reifying risk notion categories. In addition, these models do little in helping people already affected and infected with HIV to make decisions that will be to the benefit of themselves, their children and their communities. These limitations in social research foci underscore and widen the chasm between research interests and disease prevention, between demographic scenario building and fostering a social climate conducive to female empowerment.

The shortcomings of structured interviews in disentangling the factors that influence South African youth's reproductive decision-making in a context of poor female empowerment and the HIV-AIDS epidemic is summarised in the report by Rutenberg *et al* (2002:21): *"Most important the data do not allow us to understand the causal mechanisms governing the relationship between perception of risk and fertility preference. We do not know, for example, whether girls who want to become pregnant convince themselves that they are at little or no risk for HIV, nor do we know whether young people want to have children especially at a time when they think they might soon acquire a fatal disease[33].* "

In this study research respondents spoke of relentless questioning by health workers and researchers alike about their preventive habits and comment on the many Knowledge, Attitudes, Beliefs and Practices- (KAPB-) questionnaires they had to endure. As a research respondent, Funani commented to me on my first introduction to a support group for HIV-positive women:

> ***You are not the first to ask us questions. Students came from somewhere. They left questionnaires for us to complete. We never heard from them again.***

It should be apparent to even the most casual observer that superficial research engagements such as the one Funani told me about, is in and of itself disempowering.

The fieldwork for this thesis took the form of extended engagements with volunteer research participants and uncovered many areas of female reproductive health that are never discussed in surveys. One of the participants was convinced that she became infected through exposure to her sister's blood that she cared for when she was dying of AIDS. In group meetings and one-on-one interviews, these issues were examined as well as the absence of a national focus on the provision of female condoms and microbicides.

The researcher has found the available quantitative analyses of fertility preferences unable to offer a conceptualisation of a woman's dynamic role in her own reproductive career - or to as Phillips (1992:19) suggests: *"regard persons as actors located within social and historical webs of meaning".* The researcher has found just how tangled these webs are in a qualitative study as it proved to be very demanding and difficult on many layers. The fact that the study progressed by such fits and bounds, to some extent, mirrors the experience of women in need of reproductive information, services and support in a post-apartheid South Africa.

The nature of the data-gathering strategies used meant that the researcher was able to gather deeply personal reflections on womanhood, relationships and identities. In so doing, the central aim of the study, namely to investigate women's perspectives and experiences of HIV-positive statuses and how that impacted on their decisions and actions regarding future pregnancies, reproductive health, autonomy and empowerment, was met. The researcher was made deeply aware of how past inequalities still bear bitter fruit in a democratic South Africa. If either past patterns or future possibilities are denied, the reproductive health environment of South African women (both those infected or affected by HIV) will be impoverished, stunted and halted. This will mean transitions in the absence of the empowerment of women - a situation that for far too long sat easily in the minds of demographers who should be alarmed by the very presence of such an aberration. As long as South African women are not free to live full lives as women, enjoying the security provided by a supportive environment that makes sexual freedom, reproductive health and the value of women its highest priority, the ravages of any disease that follows the contours of inequality will be devastating.

ENDNOTES FOR CHAPTER 4

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[1] Pseudonyms have been used for all research participants.

[2] Although the migrant labour system commenced prior to apartheid, it (along with the pass law system and forced removals of Africans from the so-called "white" areas) eventually became the system's mainstays to enforce racial segregation. By the end of the 1950s, pass law legislation set up clear categories for those Africans allowed to stay in the so-called "white" areas. African women, dependent children, the aged, the non-able bodied, professional people and "well-to-do" Africans were regarded as non-essential and therefore as unwelcome in these areas (Posel 1991:234).

[3] The 2003 data from the South African Demographic and Health Survey should be viewed with circumspection, as there were methodological and other issues that influenced the data. These are preliminary results and the final weighted data were not available for use by the author at the time of writing.

[4] South Africa has nine provinces, 42 health regions and 162 health districts.

[5] For a detailed analysis of the TAC, its mandate, successes, challenges and political identity, see Friedman and Mottiar (2004).

[6] Ezeilo (2003:68-69) suggests that the Constitutional Court ruling in favour of ARV-treatment roll out should be seen as a test of the strength of the country's legal regime and constitution. In addition, it should be regarded as a watershed decision in respect of the law and human rights within the area of HIV-AIDS.

[7] The "denialist stance" refers in part to South African President Thabo Mbeki's "flirtation" with the AIDS dissident community. The dissidents questioned the link between HIV and AIDS, regarded AIDS and the treatment policies related to it as conspiracies by the West, emphasised the role played by poverty in the epidemiology of infectious disease and seriously warned against the toxicity of ARV-drugs (Human Rights Watch 2004:19). In 2002, however, Mbeki formally distanced himself from the dissident scientists. Schneider and Fassin (2004:549) provide an alternative interpretation of Mbeki's engagement with denialism when they suggest: *"The position of the President can thus be seen as an attitude of defiance towards official scientific knowledge, a deliberate act to challenge established truths of AIDS, whether biological or social, and an identification with those on the margins, whether of science or society. Such heterodoxy takes place often on behalf of Africa and within the framework of the ideological model of African Renaissance, emphasizing the necessity for the black*

continent to find its own solutions to its own problems." These authors also point to a second aspect of denialism, namely justice denied in the form of reticence in ARV roll out as the denial of constitutionally entrenched rights. This form of denialism has infiltrated general discourse in South Africa. One of the research participants commented*: "**I often think: God what have we done to deserve this?**"* This is indicative of an understanding of justice denied to the South African population at the very stage when the country was victorious in a democratic transition. The notion "the government is in denial" now crops up in statements by commentators and community leaders when discussing a broad range of issues befalling South Africa of late, such as strike action by workers demanding better pay for lower levels of staff, breakdown in primary health care or the shortages of health workers.

[8] As an example of this, the TAC challenged the pharmaceutical company Pfizer in 2000 to lower the price of the drug fluconazole. At that stage the price of a 200mg capsule of fluconazole was double that of the price for a generic alternative. The TAC argued that pharmaceutical companies use the HIV-AIDS crisis to their benefit to make large profits out of essential drugs. As an extension of this campaign by the TAC, they requested major pharmaceutical companies such as Glaxo Wellcome, Bristol-Meyers Squibb, Pfizer, Boehringer Ingelheim, Abbott and Roche to provide the South African government with licences to manufacture generic equivalents of their patented drugs (see http://www.tac.org.za/Documents/DefianceCampaign/defiancecampaign.htm).

[9] The clinical assessment criteria for ARV-treatment in South Africa were explained in Chapter 1. A single dose of Nevirapine given to the mother during labour and to the infant shortly after birth has also been proven to be highly effective in reducing MTCT (Human Rights Watch 2004:20). It is generally recommended, however, that HIV-positive women start ARV therapy in their first trimester. In this chapter it has been mentioned that many pregnant South African women postpone antenatal visitation to late in their pregnancies. This implies missed opportunities for early intervention. In addition, CD4-cell count test are not generally available at all antenatal clinics in South Africa.

[10] Moultrie and Timaeus (2001) report similar findings in the proportions of female-headed households in South Africa.

[11] See Hardy and Richter (2005) for a detailed discussion on social disability grants for destitute people living with HIV. The terms of the grant – that is whether it is permanent or temporary and extends over three months or five years – seem to be a matter of confusion among recipients and administrators alike.

[12] Some commentators prefer the term perinatal transmission; others refer to this as parent-to-child-transmission of HIV in order to include the father's possible culpability in the baby's infection.

[13] In a previous chapter the problem of antenatal testing in normalising pregnant women as the lone sentinel groups for the epidemiological tracing of HIV incidence and prevalence was mentioned. The following advice is given in a policy directive by the South African DoH (2000a: 13): *"Issues of stigma and discrimination are also major problems experienced by people with HIV/AIDS. It may also be a disadvantage for only*

the woman to be tested in the absence of her partner being tested as this may result in undue blame and other negative consequences. Ideally, the woman and her partner should be tested at the same time which promotes joint responsibility and decision-making regarding sexual practices, reproduction, maternal care and infant care." Whereas this statement demonstrates some insight into the problems that women may face, little directive in terms of how to promote egalitarian decision-making in reproductive health is given in this document.

[14] The words, *Masakane*, *Batho Pele* and *Khomanani* are used as slogans in national campaigns in South Africa to represent notions of caring and community effort in people working together. *Batho Pele* is a Sesotho word meaning "people first" and in adopting this slogan for the public service sector, the South African government tried to convey the idea of placing people first on the socioeconomic development agenda of South Africa and of delivering a good service to all citizens. *Khomanani*, which means "caring together", was adopted as a slogan for public health care service delivery in the area of HIV-AIDS in particular. In fact the national communication campaign for HIV-AIDS in South Africa is known as the Khomanani campaign.

[15] The South African DoH (2000d: 21) reports the following figures for full vaccinations of children aged 12- to 23-months: 68% in 1993; 63,3% in 1994 and 63,4% in 1998. These figures are for the population as a whole and reflect a downward trend in immunisation coverage.

[16] UNICEF reports that the under 1-years of age infant mortality rate for South Africa is 53.

[17] This is, of course, a bit of an oversimplification. The role played by traditional healers as an alternative to formal health care systems is still very important in South Africa. Traditional healers are keen to operate alongside and in collaboration with biomedical health providers and are an important resource in the fight against HIV-AIDS (Campbell 1997; Hasnain 2004).

[18] Mostly where the word "condom" is used, it refers to the male condom. Although female condoms were introduced in June 1998 and distributed to primary health care sites in various areas, data on use in the general population are not available at this time. None of the research participants in this study reported that they have used this method, although some of them knew about it or saw it demonstrated. The Gauteng DoH (2005:55) reports a decrease in the supply of female condoms due to a delay in supplies.

[19] In South Africa various factors contribute to women increasingly becoming the sole income-earners in the household. Such factors are, for example, rising rates of under- and unemployment (especially amongst men), the relocation and closing-down of industries, a trend of jobless economic growth, labour shedding in commercial agriculture, an already overcrowded informal economic sector and the prevalence of serial polygamy. Many of these factors hold antecedents in South Africa's colonial and apartheid past and continue to shape configurations of deprivation that contribute to the feminisation of poverty. Conjugal conflicts over household incomes and resources are greatly exacerbated as men transfer their anxieties about the loss of jobs and their declining opportunities for creating a positive sense of self into the domestic domain. As economic conditions continue to worsen, the social fabric is further tearing apart

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(Campbell 1997; Niehaus 1994; Sharp 1994). Friedman (2002) also point out that high unemployment excludes many of the poor from access to trade unions and other organisations typically used by the poor to help reduce inequalities. He warns, however, that the perception of deteriorating economic conditions for the poor is not strictly accurate.

[20] The researcher has some reservations about these authors' use of ethnic categories as measured by language in large scale sample surveys to conclude a link between "shifting ethnic identities" and reproductive behavioural change. Kertzer and Arel (2002:19) sum this problem up best in saying: "*The problem with this approach is that, by focusing mainly on the technical aspects of measurement, it takes for granted the existence of the category itself. This is unproblematic when categories refer to objective markers such as age. But to assume that categories denoting cultural affiliation can be enumerated as objectively as age is to assume that identities can be reduced to an essential core within each individual, a core that exists outside of politics."*

[21] Camlin, Garenne and Moultrie (2004) mention that in 2000 a staggering 22% of 500 rape survivors treated at the Albertina Sisulu Rape Crisis Centre were HIV-positive at the time of the assault.

[22] The so-called Rapex device was introduced in South Africa in 2005. It is a tampon-like device that latches onto a rapist's penis with fish-tooth like hooks in order to prevent him from completing the sexual assault and also to identify him as the perpetrator since the device can only be safely removed by the surgeon. The obvious problems with this are:

- First, in order for the devise to protect a woman from rape, she should accurately predict when rape might occur in order to fit the devise;
- Second, that the rapist might murder the woman in revenge for injury caused.

[23] These are only rape cases and in the future, in terms of the 2007 Sexual Offences Bill, indecent assault will be included in this definition.

[24] It should be noted that young men in South Africa too, often face threats against their reproductive health, of which the deaths of teenage boys during initiation rituals is but an example. For a nuanced discussion on the HIV-vulnerabilities of men in the mining industry in South Africa, for example, see Campbell 1997. The ubiquitousness of sexual violence in South Africa compels us to consider the socialisation of young men in terms of intimate relationships and sexual agency. The Human Rights Watch (2004:3), for example speaks of *"the dual epidemic of rape and HIV-AIDS"* in South Africa.

[25] Apart from GRIP, public hospitals that offered PEP since 1997 were Grote Schuur and G F Jooste hospitals in Cape Town, the Albertina Sisulu Rape Crisis Centre at Sunninghill hospital in Johannesburg, the Rainbow Clinic at Coronation Hospital and the Teddy Bear Child Abuse Clinic. GRIP remains the only non-profit NGO offering PEP. Providing PEP to survivors of sexual violence to all citizens was declared official policy in April 2002 (Human Rights Watch 2004:1 & 15). Another scandal in the rocky history of AIDS and treatment options in South Africa was the firing of Dr. Thys Von Mollendorf from his post as superintendent at the Rob Ferreira Hospital in 2002 for allowing GRIP to operate from the hospital's premises. Although this decision was

overturned in 2003 and Dr. Von Mollendorf awarded costs, he did not return to his post at the hospital.

[26] The word "condomising" comes from a slogan initially used in South African public health education campaigns on HIV-AIDS, known as the ABC-campaign which advocated ***a***bstinence, ***b***eing faithful and ***c***ondomising (using condoms) as the best prevention strategies.

[27] These condom use figures are for the age group 15 to 24 years only. All other condom use figures (unless stated otherwise) in this table are for the age groups 15 to 49-years of age.

[28] The analysis of the 2005 South African national HIV household survey by Rehle *et al* (2007:198) found that 72% of all sexually active respondents in the 15- to 24-age group reported that they had used a condom at the last sexual encounter. The report by Shisana *et a*l (2005: 65) confirms such high rates of use in this age range (73% for males and 56% for females) with 38% of all males and 33% of all females aged 15 years and older reporting condom use at the last sexual encounter – percentages close to the 2003 figure reported in Table 4.4. An important observation in this study by Rehle *et al* (2007:198) is that there were "*contradictions between the biological data and self-reported sexual behaviour, indicating some reticence in providing detailed information about sexual behaviour in a cross-sectional survey".* Quantitative measures should, ideally, be augmented with in-depth qualitative work.

[29] Although not directly related to HIV-AIDS, but related to women's health, it should be mentioned that screening for breast cancer by mammography is not available in the public sector (Cooper *et al* 2004:76).

[30] In America, cervical cancer screening begins three years after the onset of vaginal intercourse, but no later than 21-years of age (Saslow *et al* 2002). The South African DoH's recommendation of screening from the age of 30 years should therefore be seen in context. According to the SADHS of 1998, the mean age of sexual debut for South African women is 18,4 years, whereas the report by Shisana *et al* (2005:xxviii) puts the median age of sexual debut for both sexes at 17 years of age. This means that there is a possible period of 13 years between the age of sexual debut and the recommended age of cervical screening. Moreover, the age of consent is effectively lowered due to the Children's Act, which in turn might influence the age of sexual debut and along with that lead to an increased period of vulnerability to infection.

[31] Between February 1997 and September 2001, the majority of terminations of pregnancies undertaken at public facilities in South Africa were on unborn babies less than 12 weeks of age (SA Government, DoH 2000a: 17).

[32] A South African Sociological journal recently published a debate and controversy resulting from one sociologist's criticism of the methodology followed in antenatal HIV-testing and its extrapolation to the entire population (plus the modelling and estimation that follows from it). The same sociologist also commented on the overestimation of so-called child-headed households in South Africa because of HIV-AIDS mortality amongst adults. Both the original article by the sociologist and the reply and comments (despite its to and fro disparagement) concluded in a call for a general population survey and further quantitative research to obtain better estimates on prevalence and

household composition (see Gazi 2003; Ziehl 2002; Ziehl 2003). Whereas this surely has merit in obtaining better estimates, the debate seem to detract from the important point made in the original article that there is a gap in our understanding of domestic life in South Africa. Family life was already severely disrupted by four decades of apartheid, in some cases it is stretched to limits due to poverty and, since the 1980s had to deal with the added stress of HIV-AIDS. A study of family and domestic life in a democratic South Africa should therefore position it within a context of rights and provide a nuanced understanding of institutions (such as “the” family) as fluid, extraordinarily relational, shifting, changing constructs that react to stresses and in turn, are deeply structuring of life chances. The questions that arise are: How does one capture family-level coping mechanisms in a survey? How much about people’s suffering and muddling through falls through the cracks of once-off standard questioning and who will speak for them?

[33] This reference to HIV-infection as a fatal disease should be seen as a dominant discourse in South Africa. Certainly, the government’s recalcitrant stance on the roll out of ARVs meant that most HIV-infected people, who could not privately afford treatment, were left with no recourse but to live through the ravages of the disease and find their own ways of dealing with it. In the First World, HIV-infection is nowadays often discussed as a serious chronic condition that can, through steps taken by the infected, still offer the sufferer a good many healthy years. Social scientists (and in particular demographers) and the official discourse on HIV-AIDS still link the disease to certain death. The TAC and many activists groups in South Africa actively challenge this discourse.

CHAPTER 5

RESEARCH FINDINGS AND ANALYSES

5.1 INTRODUCTION

This chapter contains a discussion of the findings of the study. The discussion follows main themes that emerged from the coding and reduction of the data and offers quotations from the transcripted interviews. The goal of this study was to move beyond description to uncover power relations that inhibit empowered decision-making by HIV-positive women in the area of reproductive health. From the primary record and the coding of the data the following analytical moments or themes were identified and use as scaffolding for the presentation of the findings:

- Describing the biographical details of the research participants as a backdrop to the chapter
- Revealing evidence of the hegemony of biomedicine relating to an HIV-positive diagnosis, learning to live with HIV, using contraceptives, accessing counselling and accessing ARV-therapy
- Uncovering the structural bases of power in respect of material circumstances, gender roles and expectations of what the state should do
- Exposing power in intersubjective states in reference to social support systems, conceptions of motherhood and dealing with stigma
- Delineating individual decision-making with reference to reproductive decision-making, biographical reconstruction and the contestation and rejection of objectification.

5.2 BIOGRAPHICAL DETAILS OF THE RESEARCH PARTICIPANTS

Some background information to the ten research participants were given in Chapter 3. The participants ranged in ages from 23 to 45 years of age. Four of the women were in the age group 20- to 29-years of age; two in the 30- to 39-year age group and four in the 40- to 45-year age group.

All of the women had some level of secondary education, with their educational attainment ranging from grade 8 to grade 12. Two of the participants had post-school training in counselling people for voluntary testing for HIV-AIDS. Only three of the research participants were employed of whom one was self-employed in the informal sector. A fourth participant had been unemployed for four years, but found employment during the time of data-gathering. All of the employed women, however, held part-time jobs that offered small salaries and no benefits such as a medical aid.

All of the women were mothers. The highest number of children per woman was four and the lowest parity was one child. Only two of the women did not live with their children – the other eight all looked after at least one child that was financially dependent upon them. Six of the participants were teenagers at the time of the birth of their first child[1]. One of the participants was single and never married, one was divorced and living with a female partner, two participants were separated from their husbands, four were living with a male partner and two were married.

The domestic arrangements of the participants exemplify the hardships they have to contend with. Only three of the research participants lived in a formal dwelling that they shared with a husband or close partner. Four of the participants lived in shack dwellings in an informal settlement and another three lived with their elderly mothers. In fact, for many of the respondents, older women (sisters or mothers) who were also impoverished provided stable long-term emotional and material support (see the discussion under sub-heading 5.5.1).

Unemployment, underemployment and financial hardships, financial dependency (on parents or other family members, male partners, boyfriends, husbands or on the state via a social disability grant), and poverty were defining conditions in the lives of the research participants. All of the participants reported that the overriding problems in their lives were having too few financial and material resources and not having the means to change this. **Gita**, for example, explained:

> ***I have been unemployed since 1996. Since so very long I have not had job, because I am sick. Me now, I don't do anything. I used to live with my sister who was sick. Now, she is dead…. Now I stay with my youngest sister in the informal settlement…. But my problem I think is that I do not eat…. Some days I don't want food, but we are also very poor…. I don't think its right that I am so sick. I cannot work – since 1996 and I have no money. They*** *[referring to counsellors at the VCT/ARV sites]* ***say you must have a blood test for the*** *[social disability]* ***grant. Why must we have a blood test really? We need food now…. Before 1996, I did not know about AIDS. I could work and earn money for me and my children. But when I first became sick, I was tired all the time. Now, I cannot work. People think that you are lazy, but you feel so tired that you cannot work. The nurses they say that HIV is not an excuse not to work. They ask why we don't have jobs…*** *Interviewer: Would you like to find a job?* ***There is no job for someone like me.*** *Interviewer: What do you mean: "someone like you"?* ***I am sick with the TB too and people would not want me to work for them.***

For **Selinah**, access to a social disability grant did not alleviate her financial hardships, since the rent for her dwelling increased when she told her landlord about receiving grant payments. She said:

> ***We are too much poor all of us. I don't have a house. We all live in a shack and the landlord takes all the moneys I get from the grant for the rent of that shack. We are many young ones living in that one shack and there is no money left to buy food. We are really suffering. The landlord said that if we don't pay for the rent, he will throw us out and have other people move in. I don't have a choice, but it is not a nice place to stay. It is very cold and often I cannot sleep, because I am feeling too cold.*** *Interviewer: How much of the grant money do you use for rent?* ***Everything, it is little money anyway and after I pay rent, there is nothing left.*** *Interviewer: And your boyfriend – does he work?* ***He is trying, but***

> ***there is no job for him. He had a job as a security guard, but I don't know what happened – he came home and said that he was no longer working. He does not like to talk about it.*** *Interviewer: You said that there were many people staying in your house. Do they contribute to the income? Do they work or bring in money?* ***No, they are too young to work. We are all children actually – living together, because we have nowhere else to go.***

Even the three employed research participants found the temporary nature of their employment and their small incomes to be major concerns. **Lerato**, a lay counsellor at a public VCT and ARV service site, spoke about her apprehension about the irregular payment of the stipend that lay counsellors receive:

> ***But I only wish that the government would think more about the volunteers, because we are doing a lot of work. We*** [lay counsellors] ***are working more than the permanent staff here and we are not given anything at the end of the day. And they*** [the DoH] ***don't recognise us. They do not hesitate to tell us that we are nothing and they will give you the stipend when they want to give you. They will pay you on the thirty-second of the month and if they don't want to pay you, they just stay with their stipend. It is not a regular pay, so now you cannot open an account. It is a big worry. And, also because we don't have a permanent job we don't have a medical aid.***

Betty, who as self-employed and worked from home, was also concerned about the irregularity of her income. She feared becoming too ill to continue with her work and worried about the expenses of childrearing. She had a four-year old of her own and was looking after (and in the process of legally adopting) her late sister's three-year old child. From the verbatim quotations below, it becomes apparent that poverty, as it reverberates through the lives of people, is stressful to deal with *per se* and also inextricably linked to health. When poverty combines with living with a life-threatening disease such as HIV, it exacerbates many aspects of "coping" or "healthy living" that may be taken for granted in the health care advice given to people living with HIV. **Betty** explained:

> ***I feel that the government must do a lot more to support people financially. You know bringing up a child is expensive and also a person must eat healthy food when you are HIV-positive. I do not eat a lot, because I don't have an appetite, but we cannot follow a diet like the one they suggest at the clinic with this little money. I think money is the new God today, because everything is about money. If you don't have money, you cannot live, you cannot enjoy life. You cannot put money away for your children when you are no longer there. And you sit and worry about your money all the time and wonder how you are going to make it. Then they tell us that if you have the virus you must learn to handle stress. The government must not concern themselves with this and that policy, they must ask people and do research to see how people are coping with money. Then they will see that they cannot give grants where they think, they must address poverty and people will take care of their health when they have safe places to stay and are able to look after their children.***

These women had to contend with the threat of homelessness, joblessness, malnutrition and real or threatened abandonment. Read against the primary record as presented in the previous chapter, HIV-AIDS becomes still another life-threatening problem that matches other serious health problems (including reproductive health problems) that were already experienced by poor women. Health care messages, such as the ABC-campaign, ring hollow in this context, as deprivation is not a lifestyle choice. Structural factors (including persistent poverty) intersected with gender inequality to shape the health risks these women faced and continue to face.

For some of the research participants, not having the economic capital to protect themselves against ill health spilled over into not having the symbolic capital[2] to keep their HIV-seropositive statuses confidential. If not officially and biomedically defined as HIV-positive and as having a (dangerously) low CD4-blood count, they could not access life-saving ARV-medication or a social disability grant. This attests to the hegemonic role of biomedical testing and framing of the "woman living with HIV" and this is examined further in the section below.

5.3 HEGEMONY OF BIOMEDICINE: FINDING OUT ABOUT HIV AND LIVING WITH HIV

The narratives assembled in this critical ethnography give meaning to the visible and invisible hand of biomedical hegemony and female disempowerment. The aggregate interpretation which emanates from the data illuminates the impact of biomedical hegemony and disempowerment upon the research participants as the construct "a woman living with HIV" pervaded their lives following an HIV-seropositive diagnosis.

In the section below, the question of how meanings are shaped following a positive diagnosis for HIV-infection is examined from the stories told by the research participants. It shows that an HIV-seropositive diagnosis leads to a life that becomes highly medicalised, shaped by a new ascribed objectivity as a woman living with HIV and controlled by biomedical audits (in the form of adherence counselling, pill counting, directly observed therapies and adopting the role of the adhering therapeutic agent). Aspects related to encountering the public health care systems and the structuring of decisions that flows from it are discussed under the subheadings of the HIV-diagnosis, learning to live with HIV, condomising, becoming a therapeutic subject in HIV and ARV counselling and using ARV-therapies.

5.3.1 The HIV-positive diagnosis

Six of the research participants were diagnosed as HIV-positive following serious health concerns. What is striking is that many of them discovered their HIV-seropositivity fairly late in terms of the progression of opportunistic infections. This is evident from the fact that six participants were symptomatic with serious opportunistic infections related to HIV-infection, such as tuberculosis (TB), herpes simplex virus (HSV), cytomegalovirus (CMV) retinitis, cardiac abnormalities, pelvic inflammatory disease (PID) and mycobacterium avium complex (MAC) disease at the time of their first diagnosis. Some had very low CD4 blood counts and high viral loads. These women did not consider themselves as being in particularly poor health or as being "at risk" of HIV-infection. **Lora** explained:

> ***I was diagnosed in 2005. I went to the doctors, because I was really sick…. Sick for a long time…. They*** [the doctors] ***could not find out what was wrong with me. I was coughing and I had these really bad headaches and I felt weak all the time. I stayed in the hospital for four days. I also did not know what was wrong and did not think that it was AIDS. Then, one morning the doctor came and said that I must be tested for HIV. Then I received the news that I was HIV-positive and that I also had TB. I spent some time at the hospital for TB as well, since I first had to complete the treatment for the TB before I could get treatment with ARVs.***

Diane tolerated symptoms for a long time before seeking health advice:

> ***For a long time I was having stomach problems, with diarrhoea and weight loss and then it was the thing with my eyes. I thought that it was part of getting old. Eventually, because nothing helped for the problem, my doctor suggested that I get tested. I tested HIV-positive in 2005. Now, at the last blood test they found that my CD4 count was only 27.***

Funani, a mother of four, was unable to fall pregnant again and suffered symptoms of pelvic inflammatory disease (PID), as she explained:

> ***…So I went to the hospital. There they referred me for VCT. I found out that I was HIV-positive in 2005. Now, with my latest test, my CD4 count is 10 and my viral load it is 70 thousand or something….I think…. and the doctor she said that I can use***

> ***ARVs now. I have gone for my counselling to start my treatment next week.***

Lerato's diagnosis came as a shock since her main medical concern was a cardiac-related problem which she did not associate with her own perceptions of symptoms of HIV-infection:

> ***Then I was having a heart problem and I went to the doctor. But I was not suspecting that I had the virus, since I was not getting thinner or anything like that.***

For **Poppy**, diagnosed as HIV-positive in 1994, there were positive changes in the testing and treatment for people living with HIV since the 1990s, yet these changes came too late to change her husband's attitude:

> ***In 1994, I was ill and taken up in hospital. You know in those days things were different about HIV and AIDS. Now, I think people talk about it more and we have ARVs and so on. When I was diagnosed I thought that I was going to die very soon. And people did not talk about it much, so you thought that you are going to die for sure and there is nothing else. Even my husband thought so. He divorced me when he found out that I was HIV-positive. He said that I will die and that he did not want to be around. I was really mad at him for walking out on us.***

Four of the research participants discovered their HIV-positive statuses during antenatal blood tests. For **Mbali**, who had thought that an HIV-test was a normal part of antenatal care, the HIV-seropositive result was a great shock. She did not accept the validity of the initial test results and repeated the test at another facility:

> ***I was diagnosed in 2004 during pregnancy. I thought that all the*** *[other pregnant]* ***women were having these tests as routine and that I will be negative. It was such a shock to see my results. I cried and thought that it must be a mistake. I went cold inside and I did***

> ***not want to believe it. Then I went to SM*** *[another public health care clinic in Tshwane].* ***I had another*** *[blood]* ***test and the result came back positive too. I had a miscarriage with that pregnancy and I think it was*** *[due to]* ***the stress and the sadness I felt. I wanted to sleep all the time and I did not want to eat. I did not think that this would happen to me….. My viral load is still undetectable, so I'm not using ARVs yet. I do have HSV*** *[Herpes Simplex Virus]* ***which causes a lot of discomfort.***

Betty's reactions to her HIV-positive diagnosis during her pregnancy were similar to **Mbali's**, although she claimed to have found acceptance:

> ***During my pregnancy in 2003, I had a blood test and found out that I was HIV-positive. I used medication to prevent my baby from getting HIV and he is fine…. When I was first diagnosed, I was really upset and worried and I cried a lot. I was scared for my baby and that I will not be able to look after him….Then, as time went by, I learnt to live with this disease and now I'm OK with it…. The thing that I have really big problems with is herpes zoster. That I had even before I was diagnosed as HIV-positive you see and I still really suffer even though I am on ARVs now. You see my CD4 count is 207 so the reason why I am getting the ARVs now is to deal with the herpes zoster that is making me suffer.***

For **Selinah**, the discovery of an unplanned pregnancy (with a man who abandoned her prior to the child's birth) coincided with a diagnosis for HIV-seropositivity and these two life-altering events merged into one distressing experience. She said:

> ***Because the baby and the HIV happened at the same time for me, I see them going together….. I think that if I can look after my baby, then I'll be OK too…. He was born on*** *[date]* ***at the*** *[public hospital in Tshwane]* ***hospital. He was OK, but I felt so tired after the birth and I did not have nice things for my baby. The baby's father was still at school and he did not help us with anything. I felt so sad that***

> ***my baby did not have nice things.***

In the follow-up interview with **Selinah**, she revisited the painful experience and emphasised that the unplanned pregnancy, the abandonment by the baby's father and the HIV-seropositive status were serious psychological issues for her to deal with:

> ***I cried so much and the sister said that I must not be like a baby, because I am a mother now and my baby will be OK with the ARVs. I just kept my hurt inside from then, but this is not how I thought it would be – to be a mother.***

Selinah's psychological distress was clearly not followed up by the health care personnel that attended to her birth and postnatal care. This demonstrates technocratic control that builds on the Cartesian mind-body duality which is so dominant in Western biomedicine.

From the narratives it can be seen that receiving an HIV-positive diagnosis initiated a profound status passage for these women – from being mothers, wives and women to being "women-wives-mothers-living-with-HIV". As will be demonstrated in this chapter, the diagnosis presented a biographical disruption that dislocated relationships, marriages, practical concerns and taken-for-granted assumptions about gendered embodiment and everyday life. The diagnosis forcefully drew the women into encounters with public health care giving and set the moral context within which they had to negotiate their identities as women living with HIV. It also emerged that the use of ARVs (or, perhaps more importantly for some, not yet needing to use ARVs) became the next important status passage in the broken trajectory of HIV-AIDS.

The diagnosis not only marked a status passage for the research participants, but the shock of it also made them involuntarily receptive to a socialisation process intended to inculcate in them the core values of the biomedical technocratic control over the disease. During counselling sessions, HIV-positive persons are encouraged to disclose their statuses (to at least) a confidant that can act as a "treatment buddy" when embarking on an ARV treatment regime. For the research participants, being poor and dependent on a public health care system spilled over into not possessing the symbolic capital[2] to control their disclosure. In fact, they were encouraged by the health care personnel to disclose their statuses to close friends, family members, spouses or lovers (refer to Chapter 1 in which the psycho-social requirements for treatment readiness are discussed).

Although it seems from the quoted research exemplars that "late" diagnosis of HIV-infection (in terms of the disease progression *vis-à-vis* opportunistic infections) represents a threat to the health of women, it should not be construed as a call for mandatory antenatal testing[3]. **Mbali's** narrative shows how easily HIV-testing can be interpreted as a "normal" part of antenatal testing (this problematises the notion of informed consent for testing), whereas **Selinah's** story demonstrates the psychological pain of an HIV-seropositive diagnosis heaped upon the shock of an unplanned (and for the father at least also an unwanted) pregnancy. This inability of the dispossessed ***other*** to control disclosure has the added effect of reifying the notion of risk groups. People who possess the necessary economic and cultural capital to keep their HIV-statuses confidential are likely to be excluded from the epidemiologically-informed "high risk groups".

It is also possible that the six participants who were tested due to health complaints and not as part of antenatal screening were not regarded by health care practitioners as fitting the profiles of "at risk" groups, since they already had children and were in stable relationships at the time of their consultations. Since they were not pregnant at the time, they were also not part of the sentinel group. This perceptual block that defines who are the best candidates for testing for HIV-infection is a legacy of biomedical hegemony that obscures the possibility of an HIV-infection to the point where a woman's health has deteriorated to such an extent that testing for HIV-infection becomes the only feasible option left to explain her ill health. It also demonstrates a bias towards antenatal testing for the epidemiological tracking of new infections. Given the reactions of shock to their diagnosis as demonstrated in the quotations above, it is also likely that many of the research participants shared these perceptual blocks and did not see themselves as being at risk for HIV-infection.

5.3.2 Living with HIV

As has been demonstrated in the discussion above, an HIV-positive diagnosis for a woman dependent on public health care creates a new trajectory of oppression situated in the nexus of biomedical hegemony and gender power relations. Biomedical hegemonic power is asserted through a labelling process – a process in which a person is ***named*** as being HIV-positive, being HIV-positive and pregnant, being HIV-positive and having TB, being HIV-positive and having an opportunistic infection, being HIV-positive and having a given CD4 count or viral load and so on. Testing and treatment regimes are tailored to fit these categorisations of HIV-statuses, but once labelled as HIV-positive the label is immutable and ineradicable. For some of the participants, they became their label:

> ***… I hated the virus and I hated the disease. It was threatening me and it was threatening my baby. But then I thought – if I hate HIV then I hate myself, because I have the virus.*** *[Betty]*

> ***...But I feel dirty- like a person with dirty blood….because I have this virus in my blood. When I look at my blood, it looks like anyone else's blood. But I have a virus in my blood and sometimes I feel like I am the virus.*** *[Mbali]*

This shaping of subjectivity also enables the determination of the "problematic" client/patient who does not follow strict guidelines for testing, living with the infection and treatment. All the research participants were able to report on their blood tests results and used concepts such as CD4-counts and ARVs to situate their lived experiences in the biomedically defined trajectory of HIV-AIDS, for example:

> ***I'm not yet on ARVs. I'm fine. But mostly today I have a problem with sore throat and blocked sinuses. That is the problem that I'm having now. With my last blood test, my CD4 cell count was 296. But with my second last blood test, in October 2006 it was 401. I am not too concerned with the last test, as I know I had an infection and was sick then. I am sure that my next test will show***

> ***a higher count.*** [*Lerato*]

Biomedical labelling and economic need combine seamlessly to produce new forms of female vulnerability. A need to enforce compliance and to control new infections from the side of the health care service providers and a need to survive the ravages of illness and poverty from the side of the service recipients have the potential of polarising issues of woman's empowerment in new and complex ways. A woman with HIV has to comply with the diagnosis and treatment regimes in order to protect an unborn child against infection, access ARVs or access a social disability grant. This allows little space for contestation and reinterpretation of hegemonic discourses on what it means to successfully "live with HIV." The encroachment of biomedical control over a life lived publicly as HIV-seropositive was evident in many of the narratives and the research participants' lives were primarily conditioned by their material circumstances and their HIV-statuses. **Lora**, for example, felt frustrated that health care personnel tended to reduce all her medical complaints to the influence of HIV-infection on her life and never sought alternative causes for her symptoms. She also felt that, once the HIV-positive diagnosis was made, her medical treatment options were reduced to the management of HIV and that her value as a patient depreciated:

> ***The headaches have returned – the same ones I had when I first went to the doctors. They are as bad as ever, but now all they say is that it is the HIV that is causing these headaches. I don't know whether there perhaps is something else. I feel that they only see me as HIV-positive and expect me to live with symptoms. It's like they don't want to waste money and time on looking why you have these headaches, because you are only HIV-positive and that's it.***

As examined in Chapter 2, hegemonic conceptions of illness relate to moral judgements about personal integrity and competence and therefore "living with HIV" requires the demonstration of a moral identity that is competent, knowledgeable, rational, and reasonable and has concern for the well being of others. "Living with HIV" in the narratives of the research participants were articulated in the language of moral agency and compliance and around gendered ideals of personal and/or maternal responsibility:

> ***At first this was a bad thing for me*** *[the HIV-positive diagnosis]****. Then I went for training to be a*** *[HIV-AIDS]* ***counsellor and I started doing work in that area. Then I thought that I am good with this and that I am really helping people with this problem that is there for us all to deal with. I would never have thought to become a counsellor if this disease did not pick me. Now I see that this is what I can do very well. I feel that when I help other people, I feel happier and stronger and that my life was meant to be this way.*** *[Poppy]*

> ***….. I used medicine to prevent my baby from contracting the disease…. My baby does not have HIV and he is healthy, because I am a good mommy…. I think that if I can look after my baby, then I'll be OK too…*** *[Selinah]*

> ***I am a weak woman now. I am not like I used to be. But I want to live with this thing*** *[HIV-infection]* ***and show others that it can be done. When you come here next year, I want you to see me still.*** *[Diane]*

> ***I am healthy, because I look after myself. So I'm not yet using ARVs. I used medication during my pregnancy and I take my child for follow-up visits.*** *[Tina]*

> ***Before I knew my status, I was just living. I did not care what was happening….But after the diagnosis, things changed, because some of my friends decided to stay away from me. So I knew that I was supposed to have changes in my life – you know, sometimes you must leave something that you like the most, just to sacrifice for your health…. My friends – I don't want to lie to you – before I knew my status we were having a group. So every month we***

> ***would have this get-together. We would pool and top up money to buy the liquor and what. It would be a nice thing you know? Then after I was diagnosed with HIV, I told myself that I must stop living that kind of life. It would not help me – instead it would only make things worse….A lot of things then started to change, because I started to have goals for my life - long term goals and short term goals. I started to join those funeral things, but not because I was telling myself that I was going to die. I never wanted my loved ones to suffer, because I knew what was happening. Then I started to plan for my children - to put something away for them. I have three memory books. I started to compile a memory book for each of my children. I write down in them everything that I want my children to remember about me and about what I know about them since they were babies.*** *[Lerato]*

For **Betty**, giving a convincing performance of "living positively" was driven by another need:

> ***I see a psychologist regularly. I have to see the psychologist and the doctor and the social worker to get the adoption*** *[of her late sister's child]* ***finalised. I want them all to see that I am coping well and living strong and positive.***

From the above quotations it is also evident that following a diagnosis, the majority of the research participants started focussing their energies on living with the disease and this, paradoxically seemed to have become a relatively more controllable aspect of their lives. For some, it even entailed developing some future orientation. Deconstructing this notion, however, it seems that this "controllability" is elusive and bounded by what the rules of biomedical hegemony allowed. These women's illness careers and consequently the nature and extent of "control" they had over living with the disease were curtailed by their material circumstances and carefully calibrated for them by the assumptions inherent to the biomedical treatments and care to which they had to surrender. It could be argued that the research participants bought into an illusionary empowerment in terms of Bourdieu's notion of symbolic violence (see the discussion in Chapter 2). For the research participants, their particular accumulation and use of capital (in the field of VCT/ARV public health service delivery) regulated their identities as “women living with HIV”.

Living with HIV also involves accessing and controlling information about the disease and managing stigma. These two issues are examined in greater detail under sub-headings 5.5.3 and 5.6.2 in this chapter.

It can be argued that the knowledge about how to deal with (or live positively with) HIV as transmitted by the public health care facilities is not neutral but created by the field, its discourses and understandings of the disease and its policy emphasis on the containment of the spread of new infections. The research participants' therapeutic performances as women living with HIV are not measures of individual competence or of the lack of understanding of the disease, but rather indicative of their command of specific symbolic capital[2] acceptable to the field. This brings the discussion to one of the main points of emphasis in counselling for people living with HIV, which is the use of condoms to prevent further or new infections.

5.3.3 Condomising and the use of contraceptives

HIV-AIDS disrupts the seemingly valued link between heterosexual sexual intercourse and procreation. In the absence of HIV, pregnancy manifests female fertility, male virility and the procreational success of the marital union. In the presence of HIV, pregnancy manifests a dangerous situation for the vertical transmission of a lethal infection to an unborn child. Consequently, taken-for-granted notions of heterosexual sexual agency collapse under the demands for a new type of rationality. A woman living with HIV becomes constructed as a potential vector for the spread of the disease and the solution is reduced to the mechanical implementation of biomedical prescriptions. The burden of a personalised contraceptive-cum-prophylactic responsibility is gendered as being a feminine one, for example:

> ***It is important that you understand that every time that you have***

> ***sex, you must use a condom. You must keep condoms with you all the time, even if you are telling me that you no longer have sex, I want you to have them with you.*** *[Fieldnotes: Advice from a counsellor to a woman attending ARV treatment adherence counselling]*

Four of the participants claimed that they no longer had sexual relations since their HIV-positive diagnosis, two used both male condoms and the hormonal injection, three used only male condoms and one used no form of protection since she regarded her same-sex sexual relationship as low risk for the transmission of HIV. Six of the respondents reported loss of libido which they attributed to the stress of living with HIV-infection. One woman’s experience with male condoms demonstrated that this method cannot be controlled by women only:

> ***I don’t have a boyfriend at the moment. They keep telling me at the clinic that if I get a boyfriend again, I must use a condom always. Anybody in a long term relationship will tell you that one stops using condoms after a while…it is not a reliable method.*** *Interviewer: Why do you say that – can you explain to me why you see condoms as a problem?* ***Hey, this is difficult to talk about, but I’ll tell you. A year ago I had this boyfriend – a man I met at the support group. I went with him for a while and I was open about my status and that we must use condoms. And I used condoms with him every time. Sometimes we would fight about it, you know. He said that he was HIV-positive too so what does it matter. And I told him but it does matter….I told him what they said at the clinic. Then my period stayed away for a long time – a long, long time. I was so frightened that I was maybe pregnant and I thought: How can this be? We used the condoms every time. I was too scared to tell them*** *[health care personnel]* ***at the clinic about this, because they will see me as someone who does not take responsibility. Then one day, I was sitting there crying and he said that he had to confess something to me. I did not know what he wanted to tell me, but I could see that it was really bothering him***

> ***and he told me that he remembered a time when the condom slipped off during sex and he never told me. He just pretended that all was well and kept quiet about it. I was so cross with him. I felt that I did everything they told me to do and then a man can do what he wants and how can I help for it? I did not want another child, not be pregnant and live with HIV. I did not feel that I could cope with that. I did not want to go back to the clinic and tell them that I was pregnant. But then I found out that I was not pregnant after all. I could not cope with that relationship and we split up. But this is why I tell you that people think condoms are easy to make a part of your life, but we women do not control the condoms.*** *[Pseudonym not mentioned due to the sensitive nature of the narrative]*

This participant's narrative demonstrates her internalisation of the condomising-messages given at the public health care sites and her fear of being judged as "irresponsible" for falling pregnant by using a barrier method only. It also showed that her hopes and expectations for open negotiation about the successful use of the method in a consensual relationship have not been met. The assumption, central in the ABC-campaign, namely that the disease can be controlled through the application of rational knowledge about protective measures is therefore incompatible with the lived realities of the research participants.

At the level of discourse, the very issue of having to ask how male partners can be involved to a greater extent in protecting the reproductive health of women, implies that women are not free. As far as a female-controlled barrier method is concerned, none of the research participants have ever used a female condom before, although three knew about it and two of them saw a demonstration of female condoms at the hospital.

Diane, who was 40-years old and abandoned by her husband, explained how HIV-AIDS disrupts the link between heterosexual conjugal relations and the taken-for-grantedness of procreation:

> ***I am happy that this*** *[HIV]* ***virus was not the problem when I was pregnant with my son*** *[21 years ago]****. You see, I did not even have to think on it. I was married and I wanted to have a child with my husband and I gave birth to my son. It is the way life goes – without thinking or worrying too much. A girl with HIV now, she must worry about things that were a normal part of a young married woman's life. I think that is very hard for them… I am not sleeping with my husband anymore. He has a girlfriend and he stays with her. He moved out when he learnt that I was sick. But I think it is better for me this way…he can stay with that girlfriend and she can have trouble with him and his ways.***

The use of condoms moves contraception closer to the act of sex (as opposed to other forms of contraception such as hormonal methods). Sex for the woman living with HIV becomes a medicalised space in which she should approach intercourse with rational foresight and emotional detachment. But even within this space, women are not allowed to make their own decisions. **Betty**, who was young, but regarded two children as an ideal family size, spoke about her frustrations in being discouraged to adopt a non-reversible contraceptive method by the family-planning personnel:

> ***My husband and I, we use condoms and I also take Depo*** *[Depo Provera injectable contraceptive].* ***I am adopting my late sister's child. She passed away last year and I am the only one who would look after this child the way that she should be looked after. My husband and I have decided that this will be our family - our boy and my sister's child. That will be enough for us. Child care is expensive and we have very little money. But now I was even thinking about sterilisation, because we really do not want more children, but at the family-planning clinic there at*** *[the name of a district hospital]* ***they say I am too young and I have only had one child and that this is not the method for me.***

There seemed to be paradoxes in the reproductive health care messages given to women living with HIV:

- Women living with HIV are counselled to use male condoms
- Female condoms are not actively promoted and are irregularly available in the public health care sector
- Women living with HIV are discouraged from falling pregnant without discussing it with their doctors first
- Women are discouraged from opting for surgical contraception (tubal legation) due to youthful age and low parity and
- Women are not told how to deal with the possible failure of condoms.

In addition, it seems that in the setting of public health care giving to women living with HIV an open discussion about these issues is not actively encouraged:

> ***I split up with my daughter's father before she was born. I have met someone who is also HIV-positive and he is my boyfriend. We use condoms and I get the injection. But many times I feel like I don't want to have sex….I only do it because I don't want to be alone and I worry that he will leave if I refuse him. I also think that he will find another girlfriend. But I cannot talk at the clinic about what happens at home – about what happens in my bedroom.*** *[Mbali]*

Mbali's narrative shows a reading of the norms of heterosexual consensual relations as extremely vulnerable to a female-led imposition of conditions on sexual intimacy. Missing from the prevention discourse for women living with HIV is the woman living with HIV as an active object of sexual desire, and a person with active sexual expression. Yet, as demonstrated by **Diane's** narrative, the story of condom failure and **Mbali**'s account of loss of libido, sexual negotiation remains an affront to the taken-for-granted codes of romantic attachment, true love and of the successful heterosexual conjugal relationship. Ironically the woman who is best able to protect herself would be the one who can break these codes and negotiate safer sex, better protection methods and recourse for barrier method failure.

5.3.4 Counselling and the construction of an idealised therapeutic woman living with HIV

The description of the counselling encounter in this section of the chapter draws heavily on observations made during site visits to public ARV treatment and VCT service sites and is supplemented by the interview data. The single-minded focus on compliance[4] (for testing and adherence to treatment regimes) was not only evident in the counselling sessions, but also apparent from the posters and reading material made available at the site. One of the most prominent displays, for example, was a multitude of A4-size word-processed posters clearly stating: ***"We** [the clinical site, clinic or hospital]* ***do not hand out social disability grants".*** These posters also stated that the doctors' recommendations regarding the patients' CD4-counts were important for accessing a social disability grant. Such messages signify the powerlessness of clients by serving as a reminder that some of them are in need of material assistance and that the CD4-count as certified by the doctor holds the key to such assistance. These messages also signify the dispensability of the clients by reminding them that they should not waste the clinical personnel's time with unnecessary enquiries.

Counselling sessions took the form of instrumental preoccupations with completing tasks and ticking boxes on standard questionnaires[5]. In the counselling sessions, statistics were typically filled out rendering the woman not as an individual, but as a consumer and object of a therapeutic encounter. Counsellors saw danger in non-compliance by ARV service recipients and for the virological possibility of breeding drug-resistant strains of diseases:

> ***You must never skip medication. If you skip, your regime will fail and we will see this in your viral load tests. We can pick it up from your results. Then, when the regime is not working for you, there is one more option and then there is noting that the doctors can do for you anymore.*** *[Fieldnotes on advice given during a counselling session]*

The self-sufficient therapeutic woman living with HIV is therefore constructed as someone who does not fall pregnant and stays with her treatment regime. Failing to do so implies inherent personal failings such as being passive, lazy, ignorant or irresponsible, whereas the role of broader material, gender, sociocultural or interpersonal factors is not mentioned. As is demonstrated by the verbatim quotations given below, there was suspicion in the minds of counsellors that poor people might be tempted to stop their ARV-treatments to continue accessing social disability grants. The HIV-positive woman is also sketched in the narratives quoted below as burdened with additional responsibilities to not fall pregnant, or to plan a pregnancy only in accordance with biomedical advice, or to involve her partner in testing and pregnancy planning and to become an avid reader of available literature on living with HIV. Here are three examples:

> ***The main problem we see is that people don't adhere to the medication. That is why the staff asks the patients to show them the container of pills so that they can monitor if the patient actually drinks that medication. I think that this is a good practice. We see patients here who have been on three treatment regimes and they stopped that medication…*** *[Referring to some patients' non-adherence to treatment regimes in general and specifically to the fact that HIV-positive patients are generally advised to complete their TB-treatments before embarking on ARV-treatments, the counsellor continued…]*[6]*….****this is why we are having the MDR*** *[multi-drug resistance]* ***and XDR*** *[extensive drug resistance]* ***with TB. There is very little that we can do to help people who do not adhere to their treatment regimes. There is still so much ignorance, fear and stigma out there. People must start seeing HIV as a chronic disease – like diabetes and so on. Then they might become less ignorant about these issues and come forward to be tested and to get medication and adhere to treatment…. People do not take responsibility for their own health. Also, because they stop the grant when people's CD4- counts improve, some people deliberately stop treatment in order to still access that grant. People must understand how valuable their health is and that with***

better health they might be able to find another way of supporting themselves and their families and not rely on the grant only. *[Interview with a VCT and ARV counsellor]*

Some of the women think that if you are HIV-positive you are not supposed to have a child. So I do inform them that to have a child is not a problem, but they need to sit down with their doctors and explain that they want a child. If they are taking ARV-drugs they must make sure that they involve their doctors in their plans. And there are stages *[of disease progression]* ***that they don't allow you to fall pregnant….*** *[Referring here to the advice given to HIV-positive women to plan pregnancies around CD4-counts and viral loads and for the couple desiring conception to only have unprotected intercourse during the woman's ovulation.] …*___And if you are taking___ *[ARV]* ***drugs while you are pregnant, you must make sure that your*** *[HIV]* ***viral load is undetectable. And you don't just check yourself – you must check your partner. But most of the women they just take the*** *[ARV]* ***drugs and decide to fall pregnant anyway without checking their CD4-counts, viral loads and the status of their partners.*** *[Interview with a VCT and ARV counsellor]*

The only problem we are having – I won't hide anything – is that the people are lazy to read. They don't want to do their own research. Because immediately if they would tell you that you are diabetic, you will need information – you have to find out what you must do, what you must eat and so on. But if you tell a woman that she is HIV-positive and you ask does she understand what it means to be HIV-positive and she would say: "Yes". But when she walks out of here she would forget everything. She would sit down at home until she is sick again, and then she would come back again, but not have any more information. They are lazy to look for information – to read. *[Interview with a VCT and*

> *ARV counsellor]*

Counsellors also saw danger in certain categories of patients, as demonstrated in the following examples:

> ***I am afraid of the prisoners[7] that come here for services. Sometimes there are many of them and I don't like counselling them. They won't listen to the advice anyway they just sit and look at you when you talk.*** *[Fieldnotes on discussion with a VCT and ARV counsellor]*

> ***We are in danger ourselves as counsellors, since we don't have permanent jobs with benefits such as medical aid. And we can get TB from the patients. We sit in poorly ventilated rooms and the TB people cough a lot and they cough everywhere. We are not even tested for TB.*** *[Interview with a VCT and ARV counsellor]*

These two categories of patients, the prisoners and those with TB were seen as unable to conform to the idealised notion of a successful therapeutic agent (see discussion below). In addition, counsellors saw the insistence on compliance to testing and treatment as a corrective to the denialist stance that initially dogged the state's orientation to HIV-AIDS health care giving. They believed their work to be socially transformative and a rational, compassionate reaction to a very real social problem. Non-adherence to treatment prescriptions in this view amounts to a political sin and a moral betrayal against the benevolent intent of public health interventions:

> ***I feel people must wake up and understand that they must protect their own health. We battled so hard to get the ARVs in the public health clinics. Sometimes I feel that I can stand on top of a mountain and shout it out and I feel despondent. There is no need for this dropping out of treatment regimes, as we have the right programmes in place now. If people do not adhere to their treatment regimes, we as a country will never win this battle.*** *[Interview with a VCT and ARV counsellor]*

For the research participants, their HIV-positive statuses became the most salient features of their identities. The counselling session required a performance of the self that:

- Has embraced a sero-positive HIV-status
- Is not in denial, but ready to disclose to all and sundry
- Is in control of her life and self-sufficient in terms of absorbing the health care prescriptions given to her and in terms of strictly adhering to them.

The ideal therapeutic woman living with HIV therefore becomes constructed as a woman possessing extraordinary courage and self-discipline coupled with a keen ability to absorb and access particular forms of knowledge. In addition, she (the ideal therapeutic woman living with HIV) should be someone who can readily produce a support system in the form of a treatment buddy and deploy such a social resource (or such a symbolic capital[2]) in such a way that she can be recognised as confident and composed. She should be a master at negotiating safer sex practices with a sexual partner and at planning a future pregnancy in perfect team-work with her partner, doctor and counsellors. In terms of the actual lived experiences of the research participants (and as revealed in some of the quotations), much of their lives were actually beyond individual control as they lacked secure housing, were unemployed or suffered job insecurity, struggled to stay in a marriage or a relationship and battled with negotiating for contraceptive protection of their choice. The “control” they were able to express in their talk about living with HIV, mostly centred on adopting a positive orientation, improving nutrition and how they handled stress and attempts to avoid further infections or unplanned pregnancies.

By proposing the ideal type of agency during counselling, other forms of being are pathologised, such as the woman living with HIV who is still harbouring anger, who is not adjusting perfectly, who drinks and/or smokes, who simply falls pregnant or who is doubtful of the biomedical advice given to her by her treatment experts. Anything but this idealised other is moralised as being a ***failed other*** rather than a person honestly dealing with confusing feelings and constraints:

> ***One would think that if people are poor, they would use the money they have to buy food. Nutrition is very important for people with a compromised immune system, yet you would find them with drink instead of food. And drink is also bad for the young ones, because when they drink they would forget about condoms and so on and then we find more new infections. You know, people must understand that your health is a choice – no one can coerce you to buy liquor, you can always say no to drinking.*** *[Interview with a VCT and ARV counsellor]*

Bourdieu's concepts of symbolic capital[2], field and habitus enable a sociological reading of the processes of realignment that take shape forcefully within the space of HIV-AIDS health service giving and receiving. The service providers maintained monopoly over biomedical vocabularies and demonstrated their professional familiarity with a whole other world just out of reach of service recipients. They even concurred that, once a service recipient moves out from under their expert gaze and care, that person is likely to return to her bad old ways, for example:

> ***You see, there was a woman here last month, and she stayed at*** *[name of a community-based organization]****. They took her to the clinic and made sure that she took her medication. Her health improved and she went back home. When she was at home, something happened – no money to travel to the clinics and so on. But anyway she stopped her treatments. I think that she has since passed away. This is a big problem.*** *[Interview with a VCT and ARV counsellor]*

> ***You will see a person taking medication for 36 months, but when you ask that person what medication are you taking, she doesn't know the name. But it's three years now that she is taking the medication. So it seems as if they are not serious about their health. Because if they are serious then like now we would not see many patients taking second regime medication which is the***

> ***last option of government to help people. And this is sad, because if the woman failed on the first regime, she would also fail on the second one.*** *[Interview with a VCT and ARV counsellor]*

The deduction can be made that the counselling encounter is an attempt to transform the habitus of the woman living with HIV by means of shaming and instruction. The habitus is to be brought in line with a diligent, self-aware therapeutic HIV-positive other. The consequences for this for accessing and using ARV-therapy are discussed in greater detail in the next section.

5.3.5 Accessing ARV-therapy

Three of the research participants were using ARV-medication due to low CD4-counts and/or due to serious opportunistic infections. Another two participants used Nevirapine during a pregnancy and were also accessing ARV-regimes (due to low CD4-counts) at the time of the interviews; two research participants used Nevirapine during their last pregnancy but were not yet using ARV-medicine; one research participant used neither Nevirapine nor ARV-medication; one participant had used ARV-medication in the past but stopped her regime and one participant was about to start an ARV-regime for the first time at the time of her second interview. The four women who had used Nevirapine antenatally regarded the experience as positive and saw it as part of responsible motherhood, for example:

> ***I used Nevirapine with my daughter*** *[now aged 5].* ***She is HIV-negative and I had no problems. I will use Nevirapine again, because really I tell you no mother would like to give her baby this illness.*** *[Lerato]*

Accessing an ARV-treatment regime due to serious opportunistic infections and/or a low CD4-blood count, however, was seen as a low point in the illness trajectory. Although all the research participants attested to the potential value of the life-prolonging effect of the treatments, they also regarded it as indicative of serious illness, for example:

> ***I had to start with ARVs already. I was hoping that I would wait with that, but my CD4 count is very low and I've suffered from pneumonia a few times now.*** *[Selinah]*

> ***You know I get counselling to start with the ARVs now and I'm OK with it. But they*** *[care practitioners at the public health care facilities]* ***must not talk about this illness as something that is going to kill you. Everywhere you look and listen they talk about this virus killing people if they don't stick to their regime. I do not want to hear that and think about death. When they talk about this or educate people, they should not talk about death.*** *[Diane]*

> ***I am using ARVs since last year. I have no side-effects and I feel a lot better with the treatments. Some of the other patients ask me about the medication and what it is like to take medication for the rest of your life. People are afraid of starting with ARVs – like its saying that you are now dying or something. I say to them that it is normal to take care of your health and that their fear should not hold them back…. ARVs really help and I can see this for myself, really. You did not see me before. Now my skin is better and my hair and nails grow and don't break off. But ARV-medicine is not a cure, so the government should not stop here, but search for a cure.*** *[Poppy]*

In addition, having an HIV-positive status and being on ARV-treatment meant that these women had to tell their stories to fit into categories applicable to a carefully biomedically calibrated sick role. **Lora**, for example, suffered serious side-effects from the ARV-medication. In her interview with the researcher, she revealed:

> ***I have completed the treatment for TB and that is better now. But the regime that I take for the ARVs is very strong and it gives me bad side-effects. Especially I cannot walk or stand for long, because of the swelling in my legs and ankles. I really struggle***

> ***with that you see. I cannot work because of this. I also suffer from stomach pains and vomiting. Maybe I need a different regime.*** *[Lora]*

During her counselling sessions, however, **Lora** did not complain about these side-effects and also did not enquire whether accessing a different treatment regime was possible. When asked about this silence, she responded:

> ***It is not easy to live with this disease. I see many women who cope so well with the medication, but me I get really bad side-effects. I will not stop with the regime, because I do not want to die. You know it's not too bad this service*** *[referring to the ARV-treatment service at a public health care facility]* ***here now. I only feel that the headaches were the reason why I first went to the hospital and now every complaint I have is just the virus talking and nothing else. I think that they do not like to hear me complain.***

Lora felt too intimidated by the authoritarian style of practice by the public health care practitioners to voice her fears, pain and concerns with them. As Stuart Hall (1988:44) attests, hegemonic discourses hold commanding constraining power of dominance over other modes of thought and set the limit *"to what appears as rational, reasonable, credible, indeed sayable or thinkable, within the given vocabularies of motive and action available".* The hegemonic discourse of the ideal therapeutic woman-living-with HIV usurped any discontent with the treatment regime so that complaints were channeled into symptoms of "not coping" instead of given recognition as legitimate experiences of living with HIV and using ARV-medication.

Diane, about to start a regime, was upset with the insistence by the medical personnel that she should bring along a treatment buddy:

> ***I am going on ARVs now. Now they want me to bring someone else to make sure that I take my medicine at the right time. But this is my health and I understand what I want to do with my***

> ***health. I don't need anybody else to tell me when or how to drink the pills. Anyway, I travel from*** *[place name]* ***and I cannot afford to pay for someone else to come with me to see the counsellors. I think this is stupid to have someone treat me like a child.***

Diane, however, eventually capitulated and co-opted another clinic attendee to "act" as a treatment buddy for the sake of the counselling session. **Gita** opted out of the treatment regime completely. In her case, fear that she will be scolded and shamed for missing some of her appointments, made her reluctant to go back to the clinic and she instead hoped that she could access ARV-treatment via a private practitioner. Given her lack of income, this hope had no basis in reality:

> ***I used to take the pills for TB. Then after the TB was over, I took the ARVs. But now I do not use any medication. Hey – I'm not going to use it anymore. At*** *[public health care facility]* ***they make us stand in the hot sun all day. At four o'clock the nurses go home. They tell us to come back tomorrow. Then they are cross if we did not take a pill that day…. So if I skip a pill, they get very upset with me. I'm scared now, you see – I did not go there every time for my appointments. But I need those pills. I can die without them. I need money to go to the doctor. But I am poor; I have no money to go to the doctor. I asked my mother to bring me money – she gets a pension. But she never came. I will use that money to go to the doctor to get medicine, because I am sick.*** *[Gita]*

The biographical project of the therapeutic woman-accessing-ARV-therapies as presented within biomedical hegemony frames the identity and morality of this part of the illness trajectory as utterly compliant and silenced. Women choosing to break these codes of idealised personhood do so at their own peril and might find themselves in a quagmire like **Gita**, unable to voice her anger at her treatment yet unable to transform it or to access it via private funding.

5.3.6 Summary: Professional and cultural hegemony

In this section, quotations from interviews and notes from observations were used to demonstrate how hegemonic processes created silences so that the realm of the lived experience of the research participants remained unvoiced. The ideal therapeutic woman living with HIV created within these processes is not a fully achievable subjectivity – neither is it unified or coherent. The impossibility of achieving this subjectivity was felt keenly in the lived realities of the research participants, yet hegemony, as "manufactured consent" (Gramsci 1971) created a type of domination whereby the research participants participated in and accepted the inequity surrounding them.

The ritual and repetition of counselling sessions that amounted to biomedical audits and a reciting of the rules for adherence reaffirmed that this ideal way of living with HIV is always illusory, always modified to fit the technocratic control of disease containment and always restricted by biomedical hegemony. Without a legitimate voice, the impossibility of achieving the ideal subjectivity was only expressed as internalised anger. Biomedical discourse became a new form of power in the lives of the research participants which in large part ignored the complexities of their dislocation.

The next section examines structural bases of power as they shaped the lived experiences of the research participants. It takes the form of exploring from the ethnographic data themes about material difficulties, gender roles and perceptions of the role and responsibility of the government.

5.4 STRUCTURAL BASES OF POWER

For the research participants, being poor, unemployed or underemployed women dependent on the state for health care and social grants meant having enduring disadvantageous interactions with the structural bases of power. Three issues are examined in this section, namely poverty, gender relations and relations with the state.

5.4.1 Poverty: *“It is expensive out there”*

The research participants’ access to health care was shaped by their lack of economic resources, the cost of transport and the cost of child-care. Poverty increased these women’s vulnerability to HIV-AIDS and, in turn, HIV-AIDS exacerbated their deprivation (see also the discussion under sub-heading 5.2 above)[8]. Their need to survive in everyday life pushed them to tolerate being silenced within the hegemonic biomedical discourse, however, they expressed the need for larger and more stable social disability grants, better housing or transport allowances to the clinics. Accessing public health care included indirect costs, such as travelling expenses and loss of time, for example:

> ***The grant money is too small. The government must look at the cost of housing and the cost of taking care of a small child. After paying rent, there is no money left for food. If I don’t get the tablets from the dietitian, then I would be very sick, because we cannot eat.*** *[Selinah]*
>
> ***The*** *[VCT and ARV-therapy public health]* ***services should be closer to people’s homes or they must try and visit the people there like in mobile units. Public transport is very expensive and the prices keep on going up and up. Maybe the government can subsidise the transport in the taxis for us people who come here for HIV-treatments.*** *[Tina]*
>
> ***You know the services it’s all right here. At least now I can get the medicine, but it takes a long time. You wait for your file and you wait to see the doctor, you wait to see the advisors, you wait to see the nutritionist and then back to the doctor and so on. It takes a whole day. Because of this time and waiting I lost my job and I cannot take another job now, because people*** *[employers]* ***don’t***

> ***give you time off for clinic.*** *[Funani]*

> ***I come here*** *[to the public health care facility]* ***– it's all right, but it takes a lot of your time. I will be late for work today, you see and I'm worried about my job.*** *[Mbali]*

Some of the research participants expressed the view that consulting a private practitioner might expose them to treatments and/or medication that they are excluded from within public health care. For example, **Gita** felt that she should consult a private doctor to help her get back on an ARV treatment regime:

> ***I will take the medication again when I can go to a*** *[private]* ***doctor and he can give me medicine that I can pay for. But for now, I'm not going back to that*** *[public]* ***hospital. I think I am in danger now, because I am not taking the pills and not eating the right food. We are so poor - we eat what we can when we can.***

Mbali, suffering form herpes sores, intimated:

> ***I must go here to the*** *[public health]* ***clinic, because I don't have a medical aid. But I have also been to a private doctor, just to see what he can do for me. This doctor gave me supplements to drink and ointment for the sores. They helped me a lot that medicine, but it is too expensive.***

Betty expressed the view that additional supplements should be given within the public health treatment regimes. She had purchased a given supplement from a retail store and felt that the use of the product had greatly improved perceivable symptoms of HIV-infection, thereby reducing the chances of stigma:

> ***Apart from the medicine they give me at the clinic, I also drink*** *[name of a nutritional supplement]****. That one*** *[the supplement]****, it is expensive, but without it you will cry. Also, you must not drink it at night, because then you will not sleep at all. But if you drink it***

> ***in the morning, along with your** [ARV] **regime, it helps with your skin and hair. I used to have these purple marks on my skin, but as you can see, my skin is beautiful now. People don't see that I am sick now and I have more energy. But I don't know for how long I will still be able to buy it – especially when the price goes up more. I know that I am lucky to still be able to afford it for myself. I think that they** [the DoH] **should add** [the nutritional supplement] **to the regime and give it to everybody.***

Betty and **Mbali's** narrative above can also be read as examples of women-living-with-HIV assuming some sort of agency here by purchasing products that can possibly assist them in their health. It can also be seen from their stories that this agency is grounded in and shaped by the material conditions of their lives. Both these women mentioned that it would not be likely that they would be able to continue with these purchases due to rising costs and the precariousness of living with the disease. Not being able to afford things (specific kinds of food, formal housing, rent, nutritional supplements, ointments, private practitioners' consultation fees or public transport) contravened perceived social norms of readily participating in consumption practices. Moreover, such an inability excluded these women from perceived typical everyday practices that other women (women not dependent upon public health or not living with HIV) might possibly be able to participate in. The denial of these everyday practices, according to Goffman (1963:7) leads to individual experiences of shame.

Accessing social disability grants, another possible cause for shaming, emerged as an issue around which horizontal violence occurred. As examined in Chapter 2, horizontal violence is related to oppressed groups who lack power and as a result *"attack one another in order to vent their frustration and anger with the system they find themselves in"* (Randle 2003:399). This was demonstrated in comments such as the following:

> ***People are poor, yet they must understand that being HIV-positive is not a disability – you are not disabled. Like myself – I told***

> ***myself that I am not disabled. That is why I am not even thinking about applying for a grant. I don't think that if one is HIV-positive you must use the status as a gold-digging tool. I don't want to be one of those women who only go to the clinic only to access the grant.*** *[Lerato]*

> ***I live alone now. I don't see so many of my friends anymore. I don't want to have a boyfriend now. My mother takes care of me and I don't apply for the grant because of my HIV. We keep this our business. You see when I see the others*** *[patients at the site]* ***I really get very scared, because you see that they are suffering. And this is not how I want to be and to beg for money from the government. Did you see that other lady? She could not even walk on her own. I don't want to end up like that.*** *[Funani]*

The discourse of the morally responsible woman-living-with HIV pervaded the research participants' narrations and the emergence of horizontal violence adds a further complication. Horizontal violence tends to show in behaviour that explicitly and covertly marginalises others by commanding compliance with certain ways of being and acting. Horizontal violence can potentially undermine emancipatory efforts based on the articulation of shared experiences and expectations.

Economic considerations influenced the research participants' perceptions on ideal family sizes, for example:

> ***It is so expensive out there. You know I would even have liked to have only two children, because life is so very expensive and I worry about the children who are still at school.*** *[Lora, mother of four children and wanting no more children]*

> ***I see so many people struggling today without money and jobs. I think we are suffering more from poverty now than from AIDS. People must think about money for their children when they plan their family, because school is expensive and the young people take a long time to find jobs.*** *[Diane, mother of one and wanting no*

> *more children]*
>
> ***No, I don't want another baby soon. Right now, life is a struggle for us financially and another baby will make things even harder for us. I haven't thought much about another baby. I would like to get a better place to stay. Living in a shack is no life for a baby and life is so expensive. I would like to get a job and earn money. I first have to look after my child and when he goes to school I might be able to find a job, I don't know. I would like to have a job where they also offer training, since I left school before I finished Grade 9. I am worried every day about rent and food. Bringing up a child is too expensive and that is the main problem.*** *[Selinah, 23 year-old mother of one child]*

The sexual division of labour in a capitalist system distributes jobs, statuses, prestige, benefits and hours of the day differently between men and women. In **Selinah**'s case she was abandoned by her baby's father (he did not pay child maintenance) and her current male partner was unable to find full time employment. In addition to being the main caregiver to her baby, **Selinah** became the sole income-bearer in the household (which consisted of several young people who did not participate in waged labour) as she accessed a social disability grant. Representing a discourse of self-sufficiency (by thinking about finding suitable employment that would also offer training) in her narrative, **Selinah** displayed the kind of positioning of a morally responsible mother-living-with-HIV that is embedded in the hegemonic discourse on living with HIV. This discourse is incompatible with the way that **Selinah** actually negotiated the demands of her domestic life. For **Selinah**, this discourse was also incompatible with the discourse of responsible mothering; therefore she narrated these ambitions in reference to a future in which her child will be able to attend school. Without actual help with childcare, housing, training and access to waged labour, **Selinah's** hopes will remain unrealised. In the next section, gender roles and expectations as emerging from the narrations are discussed.

5.4.2 Male partners, gender roles and women living with HIV

It has been mentioned that the notions of a woman living with HIV as a recipient and a possessor of sexual desire or as a person with active sexual expression are underemphasised in the disease-curtailment messages on how to live with HIV. At the same time, however, HIV-positive women are regarded as possible vectors for the spread of the disease and, as such, are inundated with a deluge of messages about condom use. In their own narratives, the research participants spoke of different subject positions – of being the passive desired sexual object and of being the active seducing partner as well.

For most part, however, the narratives conformed to the heterosexual dominant discourse in which women were required to curtail and be the passive recipients of aggressive male sexual attention. Four of the research participants believed that they were infected with HIV by their husbands. Here are some examples:

> ***My husband no longer sleeps with me. He does not want to get tested*** *[for HIV]**, although I know that he has given this to me. When he gets sick, I can see in his eyes how afraid he is that he has AIDS. But he is in denial and does not want to be tested. I see him watching me when I take my*** *[ARV]* ***medicine and he insists that I keep on taking it, but he does not want to test himself.*** *[Lora]*

> ***My husband left two years ago. I think he must have given me this virus. I only slept with him and was never sick before I met and married him. But I don't see him anymore. I think men think that this is a woman's disease and that they can't get it. I wish I could know his status too. I should have asked him to get the blood test a long time ago, before he left. My youngest she is 5 years old and she has never been sick – never. So I don't think that I had HIV with my pregnancy. So now I think I got this virus later – after she was born. I think that is when I got it from my husband because he had many, many girlfriends. I even know about some of them…. I think husbands must be tested, you know. Just look***

> ***around you here. There are only women at the clinic - only a few men here and there - but there are mostly women, young women and old women and women with babies.*** [*Funani*]

In these narrations, the women placed themselves closer to the position of a victim of HIV-infection than to the position of a vector for HIV-infection. Counselling privileges the self-sufficient woman living with HIV who has dealt with her anger. Some of the participants, however, voiced their anger at contracting the infection in what they regarded as not particularly risky sexual relationships. For them, risk-taking implied autonomy in action, but none of the women willingly exposed themselves to infection. No one wanted to pass the infection onto their children. Although the research participants' experiences of heterosexual sexual relationships as revealed in the interviews were varied and complex, they were not indicative of promiscuous, high-risk sexual relationships. Although it was not possible to ascertain whether the blame put on husbands for being the infective partner or for their infidelity had any basis in reality, for many of the research participants an economy of power in reified notions of heterosexual relationships precluded dialogue or negotiation within their relationships. The participants' feelings of anger and disappointment also stemmed from expectations that being a wife or a partner to a man implied a contractual relationship in which the woman would bring her sexuality and reproductive power into a hierarchical heterosexual relationship and the male would reciprocate with economic support. Infection, abandonment, material neglect and rejection were brutal affronts to these expectations.

Nine of the participants experienced relationship breakdowns of varying degrees following their HIV-positive diagnosis. Most broke up with a partner, whereas some stayed with their original husband or partner, but reported that the relationship had changed[9]. In cases where the relationship broke down, the women consistently reported that the men did the leaving (that is the men physically moved away, a state of affairs that was normalised in the narration). Some formed new relationships with partners they regarded as supportive, suggesting that the disease itself changed expectations and perceptions of intimate interpersonal relationships and its affective dimensions. **Tina**, for example, believed that she would remain celibate following her diagnosis, since:

> ***I am living alone. I don't have a boyfriend and I also don't want a boyfriend. The men leave when there is trouble or when they think that you or the baby is sick.***

Mbali made a conscious choice to restrict her friendships and close relationships to other people living with HIV, as she explained:

> ***I have told you that my daughter's father and I have split up before she was born. Actually, I knew for a long time that the relationship was not working and after the diagnosis, he left. I have met someone a while ago who is also HIV-positive and he is very supportive. After I was identified*** *[diagnosed as HIV-positive]****, I decided only to meet other people who are HIV-positive. I will not take a boyfriend who is not HIV-positive.*** *Interviewer: Please explain to me why you feel this way. Why would you not date a man who is HIV-negative?* ***Because you can only understand what it is like to be HIV-positive if you yourself are positive, you see?*** *Interviewer: Is that the most important reason for you?* ***Yes, my boyfriend understands what it means to live with this disease and he is so supportive – he always tells me not to feel sorry for myself****…. [Laughs] ….****He is the only one that can tell me that – I won't take that from anybody****…. [Laughs]….* ***We live with this virus together. We met at a support group meeting, and when I saw him I knew that I wanted to be with him. I was the one that asked him to go out with me and I persisted.***

Mbali's narrative shows the type of in-group alignment that Goffman (1963:112) associates with the consequences of experiencing stigma. This over-identification with *"the aggregate of persons who are likely to have to suffer the same deprivations",* is intrinsically contradictory as it serves to deepen the social chasm between the stigmatised group and the "normal others" and consequently to deepen stigma. Of particular interest is the moral authority that **Mbali** ascribed to her HIV-positive boyfriend to be the individual sanctioned to tell her to refrain from self-pity.

Read in conjunction with her comments about her fears that this man would leave her should she refuse to have sex with him as discussed above (see sub-heading 5.3.3) the hierarchical nature of this relationship becomes clear. At the same time, however, her story positioned her as the one who actively pursued the man for a relationship – yet this very attempt at rewriting the taken-for-granted codes of a heterosexual relationship left her feeling psychologically vulnerable. For **Mbali**, a safer relationship as a woman living with HIV implied a relationship with someone who biomedically shared her fate.

Those research participants who were in heterosexual relationships at the time of the fieldwork regarded the men in their lives as protectors, providers, comfort-givers, pleasure-givers and key players in their social support systems. Being in a relationship served affective needs, offered opportunities for shared problem-solving and sharing of resources and also provided a semblance of normalcy, for example:

> ***I have never had a husband, but I have a boyfriend now. He supports me. He sometimes gives me money for food. He understands how I feel. You know it is not good to be alone. Now I can still go out with my boyfriend to the beer hall. We laugh and sit there like everybody else – like normal people.*** *[Gita]*
>
> ***The person I can talk to about my illness is my boyfriend, because he understands how I feel. He is better for me, since my parents, they have so many problems…really they have too many problems.*** *[Selinah]*
>
> ***My first one*** *[referring to her eldest son, aged 23 years]* ***does not understand this thing about relationship, you know? He says: "Why don't you just sit Mommy, without anyone? We will look after you". But I tell him: "No but I need somebody. I need a friend that I can share some of these things with." You can't have that same relationship with a child.*** *[Lerato]*

Some, however, confirmed their post-HIV-diagnosis heterosexual relationships to be equally disabling than the relationships they had had prior to the diagnosis. This was especially true in **Poppy**'s case:

> ***We haven't seen him*** *[her husband who had divorced her after she disclosed her HIV-positive status to him]* ***since then*** *[after the divorce]* ***and he defaults on*** *[child]* ***maintenance*** *[payments]* ***all the time. I had another relationship two years ago with this other man. It was good to have someone who helped me with buying things for my kids and stuff like that. Then I found out that he was abusing my youngest child. We laid a charge against him, but he disappeared. I vowed that I would never put my children in harm's way again. You know – we women we want to have husbands and boyfriends, but hey we don't think about all the dangers. It is dangerous to our health and to our children.*** *Interviewer: The abuse of your child must have been a very distressing thing for you both. I realise that this is hard to talk about – but was the abuse sexual in nature? Did your child have an HIV-test?* ***We did go through testing as well for my child, but there are no problems. She is now doing well at school.***

Poppy attempted to rewrite the politics of power in heterosexual sexual relationships after this encounter. She intimated:

> ***I have a relationship with another divorced woman now. She treats me well and makes me forget all my troubles. I am blessed to have such a person in my life. She is the one I confide in, my friend, who lives with me. I know that she would not just leave us one day. She tells me that I am so much more than HIV-positive. And this is true - there is so much more about me than just my status. I feel safe in this relationship and my children are safe too.***

Heterosexual relationships were constructed in the narrations as dangerous, non-monogamous, transitory, precarious, inequitable, but paradoxically also as *de rigueur* and sought after. Insights about gender roles in intimate relationships from the narratives show contradictory positionings and simultaneously conflicting subjectivities of:

- ***Hope*** (e.g. for a better, more stable relationship) and ***fear*** (e.g. of abandonment, loneliness and rejection)
- ***Risk*** (e.g. of being abused, rejected or abandoned) and ***responsibility*** (e.g. of protecting their children against stigma, transmission and abandonment)
- ***Power*** (e.g. to pursue a relationship or the rewrite the codes of hierarchical heterosexual relationships) and ***weakness*** (e.g. in inability to negotiate a more egalitarian relationship)
- ***Innocence*** (e.g. being the victim of a trusted partner's unfaithfulness) and ***guilt*** (e.g. "*we women we want to have husbands and boyfriends").*

The question that arises is whether the research participants' talk about their sexual relationships following their HIV-positive diagnoses revealed conscious shifts towards safer sex? There seems to be evidence in support of this, although it is not the kind of agency-led[10], active adoption of infection containment as favoured in counselling in all cases. As discussed under sub-heading 5.3.3, many of the participants were using condoms, although the use of the male-controlled barrier method was not without problems. **Tina** chose sexual abstinence, not as a safer sexual practice in terms of containing infection, but because she dreaded a further abandonment. Some of the other participants also abstained, but mostly because their husbands or partners allegedly no longer had sexual relations with them. **Poppy** chose a same-sex relationship and considered it as low risk for infection, but her main motivation for staying in that relationship was the perceived benefits it posed to her in respect of acceptance and the safety of her children. Some of the women voluntarily chose new relationships with male partners who were also HIV-positive. These women were aware of the possibility of re-infection[11], but such sero-concordant relationships were preferred for complex reasons of in-group alignment, affective needs and needs for acceptance.

In their talk about gender roles, the research participants did not regard themselves as disembodied subjects without a biography (or without a biology). Instead, their narrations revealed gendered bodies that were shaped and limited by sociocultural constructions of gender. Such constructions, which had started long before HIV entered their lives, prescribed the ways in which a woman should dress or act. HIV-infection challenged and reshaped some of these constructions and research participants reflected on the loss of a former image (or of lived experiences of body-selves) of themselves as women and on attempts to reclaim that image, for example:

> ***What is really troubling me is the swelling in my legs. I now have to walk with a stick, you see. It is really difficult, because we don't have a car in the family and I go to the clinic on the taxi and I find it difficult to walk. I used to be such a strong woman – I could do everything – the cooking for the family. Everyone loved my cooking and I liked doing that. Now I am so weak and tired and I must ask the children to help. I don't like to ask them, although they are supportive. I wanted to be the one that did things for them….My daughter is my biggest support. She is my eldest and she takes care of me and helps me with house work and so on. She brings me clothes and says that we must dress smart, because that helps us feel stronger.*** *[Lora]*
>
> ***My stomach is so big, but my arms, legs and face are so thin now. I don't look like me anymore – I used to be a big woman…. I am a weak woman now. I am not like I used to be.*** *[Diane]*
>
> ***I show people that I can live a full life with this disease. I look well now and I always walk fast and upright. This is the way people have always known me to be – a woman who runs instead of walking. So this is still the way I am even with the HIV. I take the stairs instead of the lift. People see that I am always smiling and that I have energy. They see me and not the virus.*** *[Betty]*
>
> ***I am not well now. I have sores in my mouth and throat that will not go away. I feel weak and I have become very thin…. I really feel sad all the time now. You see I dress nicely and I even put the make-up, and people see me and they see a proud woman. But inside I am sad that I have this problem now. I ask myself all the time why this happened to me. I'm a very nice person and help***

> ***others all the time. So how and why has this illness be placed upon me?*** *[Funani]*
>
> ***I do not have many friends, not like before. Only a few people come to my house nowadays. Then I make sure that it looks really nice at my place and so on. They see I am good with the house and with my baby. But those who do visit don't talk about the disease with me. As long as they see that I am happy, smiling and strong, they don't think about the disease.*** *[Selinah]*

Clothing, doing housework, having a given body shape and being a strong woman were culturally legitimised instructions on corporeality and revealed the body as a gendered text in culture. The contrast between the cultural notions of a "normal, healthy" woman and the therapeutically constituted woman living with HIV who has accepted her fate and her appearance reasserts old gender configurations against attempts at transforming what it means to be a woman living with HIV. Therapy (as an extension of governmentality) purports a text of docility inscribed on the bodies of women, inculcating acceptance of the appearance of markers of disease on the body (such as weight loss, skin blemishes or weakness). By contrast, the text of culture written on bodies of women had a storyline that celebrated big, strong, smiling, useful, active women who "*did things for others"* and maintained the image of health and femininity according to a given (albeit changing) cultural standard. Living-with-HIV and traversing the abyss[12] between the ideal therapeutic woman living with HIV and "passing for normal" thus required a studied posturing for a particular configuration of femininity. This posturing is a blend of cultural prescriptions and of unconscious self-surveillance to render a particular subjectivity (or technology of the self) in the research respondents.

Apart from these expectations about the body and gendered relationships, the research participants also held certain expectations about citizenship and what the state should do to assist them and others affected by HIV and AIDS. These issues are discussed in the section below.

5.4.3 What the state should do: *“We didn’t deserve this…”*

Within the field of public health care-giving to women living with HIV, the government, via its policy directives becomes a subtle, yet commanding force. The research participants regarded state support as critical to counter a series of injustices and inequalities that befell the disadvantaged before the transition to democracy and still have not been properly addressed. As service recipients they saw the usefulness of the VCT and ARV services and its possible access to state support via social grants based on CD4-counts. For example:

> ***I often think: God what have we done to deserve this? We have gone through a lot in this country and now we have this disease as well. We didn’t deserve this.*** *[Mbali]*
>
> ***The problem I see is that I understand that when your CD4- count is above 200, then the government stops the grant. But now people are poor, and they cannot live without that grant money. They were poor even before we had AIDS.*** *[Lerato]*
>
> ***Back in the time when I was first diagnosed*** *[this was 1994]**, many people saw HIV as a death sentence. Now things are a lot different, but I think people are still uninformed and they wait a long time to get tested. When they get tested they are already stage 2 or stage 3. If you get tested sooner, you can deal with this disease and learn to live your normal life with it. Also, we have the ARV-treatments now. But some people are still being left behind by the government, because they are not being educated about these things. The government should give education so that there is not so much fear around the issue of being tested.*** *[Poppy]*

If President Mbeki is indeed convinced that *“AIDS is not a disease itself, but rather a collection of poverty-related illnesses which have existed in Africa since well before the age of HIV/AIDS”* (Redding 2003: 76), then the research participants’ experiences of dealing with state support for their economic hardships show that attempts at alleviating poverty as a driving force of the South African epidemic leaves a lot to be desired. Research participants who lived in informal settlements felt abandoned to the ravages of poverty, isolation and despair:

> ***The*** *[ARV and VCT]* ***services should be closer to people's homes or they*** *[the DoH]* ***must try and visit the people there. Somebody must come and see what it looks like in the informal settlement, because the people are suffering a lot there. I think there are many people with this problem of HIV, but they are stuck there and nobody bothers about them.*** *[Tina]*

> ***I would like to see that hospital change. The government must give us that medicine – the treatment must be given to everyone who cannot work. And I don't want to go to hospital. The government they must give us the treatment near to where we stay - even they must bring it into our homes. They must come there to the informal settlement and look there where we stay. It is not a nice place…it is too bad to live like this. You must take pictures of where we stay and what it looks like there so that the people can see…even you must put the pictures in your report. And also the attitude – you know the attitude of the nurses. They must not tell us to come there on that other week. "Where were you?" "Why you don't find a job?" Sometimes, we wait in the sun or in the rain. There's no nice place to go like when you see a private doctor. I want to take a small tape*** *[recorder, referring to the dictaphone]* ***like you have there and tape what those nurses say there and take it to the newspapers. When the nurses know you live in*** *[name of an informal settlement]* ***they think that you are nothing really.*** *[Gita]*

> ***I am happy about the services at the clinic, but traveling is expensive and I wait for the whole day and come back late in the afternoon to my home. I think we should have more services close-by where people stay. The government must come and look***

> ***at where we have to live and what we pay rent for.*** *[Selinah]*

Some of the research participants recounted the disease containment rhetoric and regarded the government's most important role as educating people to prevent further infections, for example:

> ***People must be educated not to get this in the first place – especially the young ones. No, but people must prevent this from happening in the first place you see. People must be educated.*** *[Lora]*

> ***I think that the government should help many more people to be working in the community telling people to get tested and not to think that this will not happen to you. But maybe people would not like that – to be bothered in their flats and houses with the story of AIDS.*** *[Mbali]*

This wholesale belief in the power of information and education to prevent new HIV-infections or to change behaviour seemed strangely at odds with the lived realities of the research participants. When responding to the question of whether HIV-AIDS education would have prevented their own infections, both **Lora** and **Mbali** responded in the negative, claiming that they would not have regarded themselves as being "at risk" at the time – thereby acknowledging the flaws in the current information given about the transmission of HIV. They felt, however, that young people might be more receptive to the idea that everyone is potentially at risk for contracting HIV, for example:

> ***I think it will be different for the young ones now, because they can be told about these things at school still. They can be told that you are not safe and that you must be tested before you have sex. It can be different for them, because they see what is happening around them with people getting sick and dying****. [Lora]*

> ***But I think many young people must understand that this can***

> ***happen to anyone.*** *[Mbali]*

Preventing new infections, however, will not prevent poverty or alleviate the burdens of care that are already placed upon women as caregivers. The research participants were aware that the formidable task of dealing with the consequences of HIV-AIDS morbidity and mortality will fall on the already overburdened shoulders of women. The sheer amount of voluntary (“invisible”) labour that this requires is already disempowering.

> ***I was looking after my sister. She was sick and when she died the doctors at the hospital said that she had AIDS. Then I got tested. People said that I looked ill. I was sick like her. I used to wash her – I did not know about the bloods and everything. Nobody told us. Now my younger sister will have to look after me when I get too sick. We sisters we look after one another, because no one else is there to help when you get too bad.*** *[Gita]*
>
> ***I hear them talk about women’s rights and to stop women abuse and what not. There were people in a rally shouting about these things where I stay. But I can tell you that the women take care of orphans, old people and the sick. But we are invisible to the politicians. So many of the people I grew up with are becoming sick and dying. So they will be needing us women in the future. We used to have funerals on Saturdays. These days, we have funerals on Monday too…many, many funerals. And it’s even sadder that so much time and money is being spent on education and prevention, but we are suffering from this disease.*** *[Funani]*

Funani’s comment about the rally shows poignantly that women’s empowerment requires more than a voice and a vote. Like other women, she felt unable to transform the repressive circumstances of her everyday lived experience. Through the vote, South African women obtained formal citizen status, but in the lived realities of the research participants many still experienced problems of citizenship in practice and felt unable to exercise their rights and capacities to be representative and to have a voice.

Foucault (1980c:133) reminds us that, through *"the arts of government*" power contours both the nature of people's lived experience and people's ability to make sense of it, so that *"The problem is not changing people's consciousness – or what's in their minds – but the political, economic, institutional regime of the production of truth."* In this chapter is has been demonstrated how the policies of disease containment have exactly such a goal in mind, namely to refashion the woman living with HIV into a therapeutic agent accepting her fate and protecting others from contamination. This shields the unpalatable truth that poverty has been a profound feature of these women's lives and will continue to be so and that they are incapable of shouldering the burden of disease containment and caring for the sick and the vulnerable on their own.

In this section, three aspects of representation (or agency) were discussed, namely the research participants' lived experiences as consumers, as female partners including as people embodying femininity and as political agents. In all three these dimensions, the research participants demonstrated marginal positions and reported exclusion from effective and equitable participation. In the following section, intersubjective states are discussed.

5.5 INTERSUBJECTIVE STATES

Three interrelated issues are discussed in this section, namely the social support systems that the research participants relied on, their understanding of motherhood and caring for their children and dealing with stigma on an interpersonal level. In this section it is demonstrated that an HIV-positive diagnosis not only initiates a personal crisis for the woman living with HIV, but also initiates a social and financial crisis that reverberates through the family, domestic and community life of the people involved.

5.5.1 Social support systems: "*My mother is my rock*"

Support systems for the research participants took on different forms in that the formation of such systems varied widely and the nature of support systems was interpreted differently by the various respondents. Support systems included:

- Husbands, partners and boyfriends (for four of the research participants)
- Consanguine kin (mothers in two cases, sisters in two cases, a father for one of the research participants and a daughter for another)
- And conjugal kin (a sister-in-law for one of the participants).

Such systems offered support in terms of compassion, emotional encouragement, protecting them against outside forces of discrimination, providing physical shelter or housing, sharing scarce resources, being a treatment buddy and assisting with transport or household chores. These supportive functions often unfolded along distinct gender and inter-generational lines. Thus notions of support were deeply embedded within local sociocultural contexts. For example:

> ***When it comes to coping, I talk to my own mind most of the time. For helping me, my sister is close to me and I know that she will help me when I'm sick and cannot get up from bed. My father gives me money from his pension to travel to the clinic.*** *[Diane]*
>
> ***My mother is my rock. And you won't believe, my mother she is suffering from the Alzheimer's. She doesn't move around anymore, she is always in bed. She is so supportive, because she always opens the verses in the Bible – you know she leaves tissues inside the pages so that she knows the parts I like to hear so that she can find those verses again. She is always trying to make me happy.*** *[Lerato]*
>
> ***My mother takes care of me. She has come along for the counseling and will support me to take the medicine. She sets the alarm of her clock to tell me the time to take this medicine. She prays for me. She always helps me and my children. She will help***

> ***me with this as well**. [Funani]*

In their narrations, some of the research participants repeated the popular image of mothers and grandmothers as towers of strengths and “rocks” able to absorb and deal with illness and family crises. Such notions stem from an androcentric discourse that deems women to be naturally nurturing and the *de facto* caretakers, thereby silencing their invisible labour and multiple burdens. The following narration demonstrates the point:

> ***I have only disclosed to my mother. She helps me and my children. But I feel sorry for her. The other day my mother said to me: “Do you remember*** *[name of a person]****?” I said: “Yes, Mamma? Why do you ask me this? She is your sister’s child and we have known each other all our lives.” Then she said: “You must not think funny of*** *[name of the person]* ***when she comes here today. She and her child will stay with me now, because she needs my help”. I was wondering why my mother was saying these things to me. And I got a big fright when I saw that girl. She was so very thin and she just sat there and did not speak to anybody. She has HIV and TB and now my mother has two of us to worry about.*** *[Funani]*

As discussed under sub-heading 5.4.2, many of the research participants were socialised into caring and supportive roles in their families and communities, and having been forced to cultivate a support system of their own were regarded by some as a reversal of roles:

> ***I guess that there will come a time for me with this disease that I would need people at my house to help me, but it would be hard for me because I like being independent.*** *[Betty]*

> ***Some of my family wants me to go out more, but I like staying on my own. My health is my own business and I don’t really talk about it with people outside of the clinic. That way, people also***

> ***leave me alone. I do speak to the counsellors, but mostly I see this as my own business. This is how I would like it to be, because I do not like to be a bother to other people. If I become a burden, then it will be better for me to die.*** *[Tina]*

It can be seen from the verbatim quotations that the invasion of the disease and the subsequent loss of independence were fears that some of the women had to deal with. The loss of the ability to reciprocate with care and support because of the progressive, debilitating nature of the disease was an affront to long-held views on collectivist survival and interdependence in the family and community. To be resigned to one's fate and not to be a burden as in **Tina's** narrative above or to accept compounded burdens of care as in the case of **Funani's** mother earlier, are indicative of learned behaviour passed along over generations in which the devaluing and dehumanisation of women were normalised. In addition, some (like **Selinah** whose parents had dependency problems, **Lerato** whose mother suffered from Alzheimer's disease and **Gita** who had been her sister's primary caretaker until her death of AIDS-related illness) had had poor social support systems prior to their HIV-positive diagnoses, and lacked the confidence or skill to acquire a new support system. Again, the individualist bias in the biomedical treatment of HIV is revealed, since it focuses on individual coping and acceptance, obscuring the fact that these people are part of families and communities and have to deal with real and perceived stigma. The lack of a social support system was, for some of them, the reason for wanting to start a support group, for example:

> ***I was thinking that we can start a support group where I stay with women who live with this disease like me. Then we can help one another when things are bad for one and so on. We can help with the ID-documents….We can share for transport….We can get people to talk with us about treatments and what you can do when you are ill****. [Gita]*

Religion, a personal relationship with God, church groups and fellow worshippers also featured as issues in some of the research participants' support and coping systems and played an important role for some in conceptualising their HIV-infection into spiritual meaning. For example:

> ***The way that I cope is to pray and attend church. I like being with the people from my church, because they do not judge me. But my church is against the use of condoms, did you know that?*** *[Tina]*
>
> ***I'm a born-again Christian and I told myself that I will be healed. Because in the Bible Jesus says by my strength you are healed. So I'm fine, because I have never been admitted to hospital. What I suffer from now is those things that I suffered from when I was a young child like tonsillitis. My mind is always positive. When I was born, then God gave me all the days of my life and I will live those days that God has planned for me for my life. I won't die because of my status, see? To me to be HIV-positive it was a wake-up call and it was a blessing in disguise.*** *[Lerato]*
>
> ***Me I pray to God and I ask Him to guide me. I accept that I am HIV-positive now. This is who I am now and God loves me.*** *[Funani]*
>
> ***I believe in God and I take strength from my religion. But you see on Sunday as well, there is something that is bothering me about church. The people they pray for people with the disease and they think that it will be cured. I think that is a problem, because at the clinic they say that there is no cure for this. People need support and hope, but false hope can kill your spirit.*** *[Lora]*

These narrations reveal some of the felt tensions between self-renunciation in complete obedience to the church's teachings and secular self-mastery in order to accept the fatality of the disease and to be in control to prevent further spread of the disease. At the same time however, for some, spiritual belief enabled them to reconceptualise themselves not as dying victims but as living individuals.

Securing a support system for the woman living with HIV is contingent upon disclosing her status. The personal experience of disclosure as a confessional is discussed in greater detail under sub-heading 5.6.3 in this chapter. Having reflected on the central role played by mothers in the support systems of some of the research participants, the next section focuses on their own perceptions of motherhood.

5.5.2 Conceptions of motherhood: *"These are women's troubles"*

Issues of care-giving were discussed above and mothering can be regarded as a special type of care-giving for women. Notions of mothering are deeply imbued with ideational and cultural meanings. Choices, decisions and experiences around mothering are circumscribed biologically, culturally and socially. The HIV-prevention discourse is at odds with the taken-for-granted discourses of mothering. Before HIV entered their lives, many of the research participants regarded mothering as a natural extension of female personhood[13]. After their HIV-diagnoses, motherhood (including conception, antenatal care, childbirth, birth care, postnatal care and breastfeeding) along with so many aspects of their lives became constituted primarily as medical events in their lives. As opposed to "natural" mothers these women became "contaminating" mothers.

> ***This thing of HIV will make it hard for women to be women. When I was a young girl, this is what you know how your life will be – to get married and have babies. Yes, you know there was illness around then too. Young children got sick and so on. But this HIV and AIDS is a different thing to worry about.*** *[Diane]*

> ***I will have another child soon, but I will talk with the doctor about it first. It is not the right thing to do – to just fall pregnant just like that. So it's better if you know your status and the status of your partner, so if you make a baby you both of you must sit down with the doctor and inform that doctor that you want to have a baby. Then that doctor will give you options, you know? And the doctor will check all those things – viral load and CD4-counts. It is different now with my condition, I cannot just fall pregnant.*** *[Lerato]*

For some of the participants, having a healthy child as an HIV-positive woman became a marker for being a responsible woman. The caring, concerned mother preventing the vertical transmission of the infection to her child became emblematic of the ideal embodiment of the conscientious, rational therapeutic woman living with HIV. **Selinah** and **Tina**, two of the research participants who discovered their HIV-positive statuses during antenatal testing, gave the following accounts:

> ***This is a good thing that the government is doing with the ARVs for pregnant women. I want to say really that it is OK to have a baby and use medicine to prevent that baby from getting the virus. I did it and it was not bad to take that medicine. This is what we women can do for our children – to take that medicine so that they don't get the same virus. It is not the children's fault that there is this thing of HIV. So they should not be the ones to be suffering. But you know, the trouble we are really having as women is that bringing up a child is too expensive. That is the main problem. These are women's troubles, this thing of taking care of the children and the men run away from the problems.*** *[Selinah]*
>
> ***I have no problems with the*** *[ARV and VCT]* ***services, they are really OK. I like talking to the doctors and nurses about my child and they can see that he is doing well. When they say that he is well, I feel proud and I think that I am a good mother. I was scared, because at the hospital where he was born some of the people were talking that the medicine*** *[Nevirapine]* ***is like a poison for your baby. But I took that medicine and I did everything that the nurses told me to do with my baby.*** *[Tina]*

The essentialist categorisation of child-care as exclusively "women's troubles" is indicative of patriarchal ideology and a normalisation of this burden placed on women. In VCT and ARV-services patriarchal ideology and biomedical hegemony combine to increase some of the women's anxieties in terms of demonstrating their abilities to be “good” mothers. As an extension of this, **Tina** had used Nevirapine during her pregnancy, but feared the possibility that her child’s HIV-seronegative diagnosis had somehow been a false result and that the virus would return. This dreaded “return of the virus” was interpreted by her not as a possible failure in testing and/or treatment but rather as a signal that she as a mother was not responsible enough to keep her child alive:

> ***I am so worried about my child all the time. I worry that the virus will come back and kill him and that people would say that I could not take care of him. Sometimes I worry so much I cannot sleep. I sit and look at him all the time. When we were children we got sick and then we got better - without medicine even. But with this it is different – when he gets sick now I must take him to the doctors and it costs money and every time I think the doctors they are thinking by themselves that it is the virus returning in him but they are not telling me.***

Breastfeeding – the ultimate enactment of mothering through which the procreative female body commits to the care and nursing of another (the child) – was regarded by the research respondents as both a maternal gift and as a form of female labour. Before HIV-AIDS entered the picture, breastfeeding conferred immunising advantage. Yet HIV and the infection-control focus of public health interventions also restricted decision-making autonomy in this sphere of mothering and the participants saw this as another loss suffered by HIV-positive women. Within the disease containment rhetoric, breastfeeding is feasible, desirable and advantageous only if done according to medical instruction. For the research participants this threw doubt on taken-for-granted norms and rituals in infant feeding practices. Bottle-feeding was regarded as a sign of possible HIV-infection and was hidden. **Mbali** and **Selinah** had different experiences with breastfeeding. **Mbali** followed medical advice, but felt confused about traditional infant feeding practices and feared the stigma associated with bottle-feeding. **Selinah**, by contrast, regarded her own contamination by the HIV-infection and her extreme poverty as precluding her from safely breastfeeding her baby and her narration demonstrates how HIV-AIDS disrupted taken-for-granted images of breast-milk as pure and medicinally beneficial[14]. In both the narrations it is clear that infant feeding is a sociocultural practice.

> ***When I was diagnosed*** *[as HIV-positive]* ***they*** *[public health care personnel]* ***told me that you can breastfeed or get formula milk from the clinic. You must choose only one of these and stick to it: you choose breast or formula. Before, when my sister had her baby, I went with her to the clinic and the nurses there they were so happy that we black women breastfeed our babies. They used to say that this is good, it is healthy. You know, in the past you breastfeed for a year or so and then you start feeding the baby little small bits of pap so that makes him strong. They always told us at the clinic that 'breast is best'. People look funny at a black woman with baby bottles. We did not run to buy the dummy and the bottle when you had a baby, because there was your breast. This is what a woman gives to her baby – her breast and her milk. Even the mother, it helps her to be healthy after the birth. And in that time of breastfeeding the woman abstains from sex also. They talk at home amongst themselves now, you see. People see there is a woman with bottles and they say to themselves that woman she is HIV-positive. You see it's not our culture. So I myself I breastfed my baby also and you see there is no problem now.*** *[Mbali]*

> ***I did not breastfeed my baby. My health was too bad after the birth. I think I did not have enough milk for him. My body was fighting this infection. So I got the milk formula from the clinic. It was a worry about the water and so on. Also, I came to the clinic many times so that I did not run out*** *[of formula].* ***But it is OK now, because my child is eating now. That time*** *[referring to when the baby was small and bottle-fed]****, I kept to myself, so people did not know. When anybody asked why you don't breastfeed, I just say that there was a problem with my breast. I think it was better with the food and things they give at the clinic, because we are very poor and the things they gave us at the dietician helped us a lot.***

> *[Selinah]*

Under sub-heading 5.5.1 the role of mothers in the social support systems of women-living-with-HIV were discussed. Maternality and its meanings therefore do not stop when children are grown-up or when women pass the age of reproduction. On the contrary, notions of maternal practice continue throughout the life cycle. In fact, HIV-AIDS shape this landscape as well as many elderly women and grandmothers are forced to become primary care-givers to children orphaned by AIDS. Mothering therefore extended to thoughts on how to care for children once the HIV-positive mother passes away. **Lerato** decided to set goals for herself to help her retain a positive outlook and these goals were linked to events in the lives of her children. Her notions of mothering reached past her children's ages of dependence.

> ***Then*** *[referring to a period approximately 6 months after her HIV-positive diagnosis]* ***I started to know the reasons why I want to live, you know. I started to say:"I won't die until my first child is 21". I set goals for myself and for my children and it's happening every day. Then my latest goal – I told myself that I want to see the opening of the World Cup 2010 with my children. We will be watching that first match and we will watch it in the stadium as a family. I won't be watching at home in front of the TV – I will be there with my children. I will set money aside for this. And then my other important goal is that I want to pick my youngest child*** *[referring to her 5-year old]* ***up from school when she starts school. When she starts, I will take leave for a week and pick her up from school every day until she is used to school.***

Betty decided not to have another child of her own and was concerned about children left orphaned due to HIV-AIDS. Her narrative introduced another dimension of the embodied maternal that is neglected in the HIV-therapy discourse, namely that of adoptive mothers.

> ***I don't know how it would have been without the virus and I don't think on that at all. I just think how to live now and how to take***

> ***care of my family. I want to be a good mother to my child and to my sister's child. I know that I am ill and I think the best I can do for now is to take care of these children while I still can. You know I think that every person must decide for herself what to do, but I myself would not have another baby of my own. I would suggest that people adopt the children out there who need a family. You know there are many children who need taking care of.***

Betty also felt empathy for those women with HIV who were not mothers but desired a child. From her narration, and from the other remarks quoted in this section, it can be seen that the transformation of a woman into a mother is a process of exceptional normative and cultural richness and significance.

> ***You know what; I think that a person's heart always hurts for that thing that you think you cannot get. So if you have never been pregnant, or never had a child of your own, then as a woman this will be the thing that you want most of all. You will want to be a mother. So I am not going to judge someone and say you must not have a child because you have HIV. People must decide for themselves. Nobody has the right to tell a woman that she cannot be a mother.***

Thus mothering as a specific kind of female embodiment was revealed in the narrations as:

- Subjected to biomedical control, structural constraints, cultural rules, tenets of social acceptability and stigma
- A medium through which social relations are reproduced and caring of the vulnerable is enacted[15]
- A signifier inscribed with cultural meanings, through which identity is produced and according to which benchmarks for "good" or "bad" mothering can be set.

In all of these above-mentioned aspects, the research participants as women-living-with-HIV failed to experience what Habermas (1996:426) refers to as *"the equal* *right to an autonomous private life"* as the hegemonic power of biomedical control invaded their lives. In their narrations, the research participants spoke of how mothering, nurturing and breastfeeding were lauded as things that women do and how HIV-AIDS and the disease containment directive of public health have repudiated these taken-for-granted aspects of embodied living. Prior to HIV-AIDS, child-rearing, nurturing and lactation were already invisible aspects of labour done by women (or women's troubles in a "natural" sexual division of labour). With the advent of HIV-AIDS, maternal bodies and the practices related to them became problematised and subjected to biomedical control and surveillance in order to prevent further spread of HIV-infection.

Mothering and giving and accepting support are practices that are experienced intersubjectively with and in relation to significant others. In the last section dealing with intersubjective states, the issue of stigma is discussed.

5.5.3 Dealing with stigma: *"People can talk, I don't care"*

Upon receiving an HIV-positive diagnosis (discussed at the start of this chapter) the research participants already became aware that they were labelled with a potentially stigmatising marker. At various junctures in this chapter, the issue of stigma has been mentioned and it seems that many of the research participants' narrations and actions dealt with responses to real or perceived stigma. Examples of stratagems adopted against stigmatisation already referred to were:

- Restricting one's social contacts only to other HIV-positive people
- Deliberately restricting the number of close friends
- Perceiving the treatment afforded them by nurses as discriminatory
- Dressing appropriately and concealing the markers of disease on the body
- Hiding ARV-medication, brought along to the clinics and hospital for routine pill-counting with the counsellors, in many different shopping bags to disguise the true contents
- Not accessing a social disability grant to avoid further stigmatisation
- Walking fast and performing "good health"
- Going to beer halls and "passing for normal"

- Performing the role of the responsible mother
- Breastfeeding an infant or concealing bottle-feeding.

Goffman's (1963:4 & 41) binary distinction in terms of the discredited and the discreditable spoiled identity is useful to examine the problems of stigma that the research participants had to deal with. Discredited people have greater difficulty in managing stigma since their spoiled identities are apparent. Transplanting this notion to living with HIV, a discredited woman living with HIV can be one who belongs to a perceived high risk group, has clear symptoms of advanced HIV-infection (or even a mother that bottle-feeds her infant) or who has disclosed her seropositive status widely. If a person is discredited already, much of that person's struggles in managing stigma revolve around controlling tensions in interactions. A discreditable person, by contrast, is a person whose stigma is not apparent and in the case of a woman living with HIV would include those individuals with enough command over symbolic capital[2] (and who are asymptomatic) to keep their sero-positive statuses hidden (or to engage in information management). Due to the emphasis on disclosure in order to get a treatment buddy and to protect others from possible infection, the research participants did not have full control over stigma management. Disclosure is discussed in greater detail under sub-heading 5.6.3 in this chapter.

Management of stigma also related to two issues, namely managing felt stigma and managing enacted stigma (Scambler & Hopkins 1986). Felt stigma refers to internalised stigma and its emotive and behavioural manifestations in the form of fear, shame, guilt, withdrawal and self-stigma. Enacted stigma is externally imposed social opprobrium and takes the form of abandonment, discriminatory practices, compulsory testing, quarantine and violence. **Gita**, for example, regarded the nurses' attitudes as enacted stigmatisation and related it not only to her HIV-positive status, but also to the fact that she was unemployed, had TB and lived in an informal settlement. However, when asked about her own experiences of stigma and how she coped, she replied: "***People can talk, I don't care."*** Her actions belied this nonchalant attitude, as her children, aged 17, 15 and 12 stayed with a relative in the Winterveld and she explained this domestic arrangement as an attempt to protect her children against stigma:

> ***My children stay with my auntie in the Winterveld. They do not know that I am ill. They do not have to know, because it is better that way…. They are children…what could they do? They will not understand and people will talk about them as the children of a mother with HIV. They don't need that so it's better if I stay away from them even if I miss them. You see, people can say bad things about me and I don't care. But for my children, I can protect them so that people do not say bad things about them.***

Whereas few of the research participants were able to recall actual instances of enacted stigma (apart from **Gita's** perception of discrimination by nurses and her perception that she would not find employment due to her TB as well as reports by some of the research participants that they were abandoned by a husband, partner or some friends), much of their narrations were about anticipated stigma, for example:

> ***I have disclosed only to my sister, my child and my father and they all support me. They pray for me and they do not allow other people to say bad things about me because they know me. They knew me before I had this virus and they know that I am a responsible person who never would have damaged my own health. They know where this thing has come from and they understand that I am fighting this disease every day of my life. But there are days that I feel so very sad about this.*** *[Diane]*

> ***As for stigma, there are some of my friends who don't visit with me anymore. But in the area where I live, many people are affected by this disease and it's not so strange anymore. But still, I don't talk about this here and there and everywhere. Also, I keep my medicine away from other people in my house. I keep it in my bedroom in a cupboard, because as you can see there are many bottles with medicines. Now people would wonder about it. So many pills will tell then that I am too ill. I don't like hiding things,***

but for now it is the best thing to do. *[Lora]*

Some of my friends left me, but I have also changed to join a different group of friends. I think a lot has changed since two or three years ago. The government did a lot since then. The stigma is not so bad anymore and there is medication now. *[Lerato]*

I am no longer ashamed, because it's not written on my forehead that I have HIV and people see me doing well…No, I don't feel that people stigmatise me. I also show people that I can live a full life with this disease…. You see – I take it this way: I can die out there in the traffic one day and then I would not have died from the virus, but from an accident. People would not know me by my status after I have died, but by what I have done. *[Betty]*

I don't see so many of my friends anymore. Some of my family members are afraid of touching me. But people should know that just because I was tested first, does not mean that I had the virus first. My husband was very unfaithful to me and this is where it came from. The shame belongs to him. *[Funani]*

In some places, yes there is still this thing of stigma. It was much worse in the early days. People were afraid of people with HIV and thought that you can get it by being in the same room with them. Now I feel that people talk about it more. *[Poppy]*

I do not have many friends, so I keep to myself and people have no reason to talk about me. My parents wanted nothing to do with me even before my trouble with HIV. *[Selinah]*

I stay out of other people's way. Then they have no reason to talk about me. *[Tina]*

I don't talk about this to everybody. I used to cry a lot, but now I

> ***am OK.*** *[Mbali]*

Stigma management for the research participants took the following forms:

- Selective disclosure of an HIV-seropositive status to close confidants
- Actively resisting stigma by confronting other people's stereotypes and offering accounts of the circumstances surrounding their infection in order to position themselves as innocent victims
- Self-stigmatising behaviour
- Turning the seropositive status disclosure into a moral task and thereby earning moral credit (this point is discussed further under sub-heading 5.6.2).

Most of the research participants were selective in their disclosures. **Diane** and **Funani** tried to actively resist transmission stigma by making sure that people knew that their husbands' were the infective partners. **Mbali**, **Lerato**, **Funani**, **Selinah** and **Tina** followed self-imposed social avoidance. **Mbali's** self-stigmatisation constrained her to only date sero-positive men. Like many of the other research participants, **Gita's** felt stigma encompassed a painful inner struggle in which her personhood and her seropositive status completely fused. Unable to hide her status due to her rapidly deteriorating health, **Gita** instead opted for protecting her children against stigma. As the discredited, **Gita** decided to manage tensions in social interactions. This kind of stigma builds on the internalised self-hatred of women so that even their acts of resistance and contestation are eventually turned against the self. In **Gita's** case, she dropped out of her treatment regime and refused to resume it. Despite her bad health, she continued to drink alcohol and smoke, countering that: ***"These things will not kill me, the AIDS will kill me."***

Actual, enacted stigma appeared to be less prominent in the research participants' narrations than anticipated stigma and self-stigma. **Diane**, **Lora**, **Lerato** and **Poppy** felt that stigmatisation of people living with HIV had lessened over the years, yet their behaviours were still oriented towards eliminating or minimising the effects of stigmatisation on their lives. This implies that dealing with anticipated stigma remained a life-long struggle in the illness careers of the research participants and that reaching a stage of complete self-acceptance was a naïve idea promulgated by therapy. Coping with a stigmatised identity in real life was far more complex.

Moreover, self-stigma fuelled reactions such as poor self-esteem, chronic sorrow and self-imposed active social avoidance. Social and self-stigma are the distressing products of the powerful biomedical hegemonic framing of HIV-infection as the self-induced result of the immoral behaviour of risk groups. In the next section, the research participants' own decision-making, biographical reconstructions and contestations are discussed.

5.6 INDIVIDUAL DECISION-MAKING: *"I WANT TO LEARN HOW TO LIVE WITH THIS VIRUS"*

In this final section of analysis and interpretation of the narratives of the research participants, the focus is on individual decision-making. In this section, the women's ideas about future childbearing, on reconstructing a new self and on resisting the hegemony of biomedical discourses are discussed.

5.6.1 Number of children ever born and future fertility preferences

Reproductive interventions, processes and decisions happen in and through the bodies of women. The ethical contours of reproductive events include social and material institutions of parenting which implies a weighing-up of risks and benefits associated with having a child. For the woman living with HIV, the risks may be even greater. In the narrations, a pregnancy for a woman with a known HIV-positive status was often depicted as a dangerous undertaking. Even those research participants who desired future childbearing were not completely confident about the efficacy of risk reduction strategies (see the quoted responses from **Lerato** and **Mbali** below).

In Table 5.1 below, the actual and desired number of children of the research participants and the reasons they quoted for their decisions to have another pregnancy are given. Both the actual and the desired number of children show low fertility aspirations for the research participants.

Decisions about future pregnancies divided the research participants in two groups, namely those who wanted to keep their childbearing options open, and those who definitely wanted no more children. Only three of the women wanted another child: **Betty** wanted to adopt a child, **Mbali** did not want her daughter to be an only child and **Lerato** wanted to please her partner's desire for a child. As far as **Betty** was concerned, her desire for another child did not include a pregnancy of her own. Her need for another child was not borne out of a reproductive need, but rather came from the responsibility she felt towards her late sister to bring up her child *"like she would have wanted to."* **Betty** therefore represents a different case for reproductive needs of women living with HIV. As discussed earlier on in this chapter, however, she had problems in translating her need for a non-reversible method of contraception into action.

Table 5.1: Actual and desired number of children of the research participants and their main reasons for their decisions on future childbearing

Pseudonym	Actual number of children	Wants another baby	Desired number of children	Reason
Diane	1	No	1	*"God gave me one child and that is what I should have."*
Tina	1	No	1	*"It is so much trouble looking after this one…"*
Mbali	1	Yes	2	*"I don't want my daughter to grow up alone…"*
Betty	1	Yes, but the second child will be adopted	2	*"Child care is expensive…"* and *"I want to adopt my sister's child…"*
Selinah	1	Don't know	Undecided	*"We are too poor..."*
Poppy	2	No	2	*"I will never allow another man into our lives."*
Gita	3	No	3	*"Three children are enough."*
Lerato	3	Yes	4	*"My new partner wants me to have a baby with him…"*
Lora	4	No	2	*"Child-rearing is so expensive."*
Funani	4	Don't know	Undecided	*"A pregnancy will harm my health…"*

Mbali described her future childbearing options as follows:

> ***Maybe I will have another child one of these days, but it depends***

> ***on my partner's health status as well. I don't want my daughter to grow up alone, so yes I think it will be good to have another child in the house. But I am worried – you see I don't know how safe it would be to have another child with my status. When I know that my daughter is healthy, then it would also influence my decision to have another child, since they can look after one another. A child alone in this world is not safe… My boyfriend is very supportive. We will make the decision together. He will be angry if I got pregnant without talking to him about it first…. I haven't discussed this with the doctor or the nurse, because I want them to first see that I am doing well and that the HSV is under control. They stress all the time that we should use condoms and I don't want to talk about it now. When we decide to try to get pregnant, I will bring my boyfriend along so that we can talk with the doctor together. Here in this hospital the staff is much better about this. When I used to go to*** *[name of a clinic]* ***the nurses were so strict about telling women that they should not fall pregnant when they are HIV-positive. But you see now I am still young and I will think about having another baby at some time. Anyway, people will ask why I am still young with only one child.***

Mbali's narrative reveals her perceptions about public health care practitioners' dismay at the prospect of a woman wanting to have another pregnancy or more children whilst dealing with a compromised immune system, poor nutritional status, homelessness, unemployment and other dependent children to take care of. At the same time, her decisions were shaped by her health concerns and concerns about her partner's health. In addition, **Mbali's** decision to keep her childbearing-options open was also influenced by her concern for her child to have a sibling to offer support. Finally, anticipated stigma against a young woman with only one child also featured in her considerations for another pregnancy. Decision-making about future childbearing for a woman living with HIV is therefore not influenced by one factor only, but by many complex considerations.

Lerato's thoughts about a future pregnancy were greatly influenced by her need to entertain her current partner's wishes. Her partner's expectations outweighed her confidence in her own opinion and her own health fears. It demonstrates a difficulty to break with normative gendered assumptions and expectations about women as reproducers. The resulted stress was narrated by **Lerato** as feelings of guilt for going against these expectations.

> ***Actually I am not sure. My new partner wants me to have a baby with him. He said I used ARVs with my last baby and there were no complications. My daughter tested positive at birth, but after some time she tested negative. My partner says this means we can also have a healthy baby – he wants a child of his own with me. But I don't know… I don't know what another pregnancy will mean for me. But I have been in this relationship for two years now and it is a very good relationship. That is why I am thinking it is the right thing to do now - to have another child within the next two years with this man. I will feel guilty if I don't have a baby with him. Due to this condition that I have, I do not want to postpone a pregnancy any longer. The age is also running – I don't want a baby when I'm 45. My boyfriend really wants to have another child.***

Two of the research participants were undecided about future childbearing, but decided to keep their options open. **Selinah's** hesitation was due to her extreme poverty, as she described:

> ***No, I don't want another baby soon. We are too poor. Maybe I'll have one later if we*** *[referring to her live-in boyfriend]* ***get married. Right now, life is a struggle for us financially and another baby will make things even harder for us…. Actually, we have not been talking about that*** *[another pregnancy]* ***at all. We are worried every day about rent and food.***

Funani, a mother of four, also did not want to rule out the possibility of another pregnancy in her future:

> ***When I was still with my husband, I wanted to fall pregnant again, but I have been experiencing gynecological problems. But now with this virus, I feel scared you know? I do not want to die. Yes, you can use ARVs when you are pregnant. Then you have this baby and you look at it and you see it is so cute and fat. It is healthy. But what about you – what about your health and this disease? What did the pregnancy take out of you? We, ourselves, we'd like to have babies, but we are scared for our health… I don't want to think about a pregnancy now – actually I am not sure. I want to learn how to live with this disease. A pregnancy will harm my health…***

Concerns about the deleterious effects of pregnancy on the health of an HIV-positive mother were expressed in some of the narratives. This reveals the tension between gendered norms that stress nurturing and putting the needs of others (like male partners' needs for children) first on the one hand and individualist concerns to prioritise one's own health on the other hand.

Five of the research participants did not want any more children. The reasons varied between fertility as God's will, the burdens of childcare, not wanting to have another heterosexual relationship and economic considerations. Thus a positive HIV-status was not the sole determinant of reproductive decisions made by the research participants, for example:

> ***God gave me my one boy and that is OK for me now….My boy is doing OK and he has a job and I am very proud of him.*** *[Diane]*

> ***It is so much trouble looking after this one. He had many health problems when he was a baby and I don't want to go through that again.*** *[Tina]*

> ***I will never allow another man into our lives and, anyway, I have all the children I want.*** *[Poppy]*

> ***Three children are enough. It is too expensive to have many children. I am too sick to fall pregnant again.*** *[Gita]*

> ***Life is so expensive.*** *[Lora]*

The reasons for wanting or not wanting future pregnancies were therefore varied and complex, indicating that the reproductive health needs of women living with HIV are equally varied and complex. Although not all the respondents were in stable heterosexual relationships at the time of the interviews, it was only **Betty** who expressed the wish to obtain a sterilisation to rule out future pregnancies. The other research participants had to be either supremely confident in their own abilities to plan (or avoid) a next pregnancy according to their or their partners' health and economic statuses or they might have misperceived their own risks of falling pregnant again. The four women, who wanted to keep future childbearing options open, placed currency in their ability to reproduce. Keeping their options open meant that they were possible repositories of childbearing capital. In this way, some women living with HIV may actively collude with patriarchal expectations as part of bargaining (or as part of corporeal investment) in the face of tenuous economic situations. In the next section the question of whether women living with HIV can become agents (as opposed to passive receptors) in symbolic capital[2] accumulation strategies is examined.

5.6.2 Using the "woman living with HIV"-identity: Biographical reconstruction

Part of the biographical reconstruction of the woman living with HIV is to come to terms with the diagnosis, to access and control information about the disease and to manage stigma. These issues all relate to normalising the diagnosis and the label of being HIV-positive. A central activity in this reconstruction was the disclosure of this HIV-status or -label to significant others in the research participants' lives.

For the purposes of treatment, the HIV-positive statuses of all the research participants were known to the public health personnel. The ten participants also “disclosed” their statuses to the researcher as part of their participation in the study. In general, the act of disclosing was fraught with the danger of rejection, yet held the key to unlocking social support and strategies for living. Decisions about disclosure, however, were seen as highly personal. All the research respondents reported that they were fearful of losing relationships and support due to disclosure, for example:

> ***I waited three months before I told anybody****. [Lora]*
>
> ***I was so scared to tell my family about this and thought about it a long time****. [Diane]*
>
> ***My boyfriend knows that I am sick and he knows about the TB, but I have not told him about the HIV even if I think he must know. I am waiting to tell him, because I know that after a while he would not want to carry on with using condoms anymore****. [Gita]*
>
> ***I think that I was in denial after the diagnosis, because it took me a long time to admit it to myself and to be able to tell other people. I only tell family who I think can handle it.*** *[Mbali]*
>
> ***After the diagnosis, I was angry, sad and scared. Then I went to the psychologist and we talked a lot. I have accepted this as a part of my life now. I am able to disclose to people I trust. I only disclose to people I know will accept me. Now I have friends who are also HIV-positive and who have also disclosed to me****. [Betty]*
>
> ***It took me a year to disclose to my children. I felt so scared that they might not accept me.*** *[Poppy]*
>
> ***A person who is HIV-positive should have control over who they decide to tell.*** *[Tina]*

Disclosure was usually to close family members that were able to offer support (3 research participants), to husbands or partners (2 research participants), to mothers

(3 research participants) and to friends and support group members (all of the research participants). Only two of the research participants disclosed their statuses to their children. Moreover, only one of the participants disclosed only to support group members and to no one else. It was not only deciding on who to disclose to that was regarded as difficult, but also how to disclose. **Lerato** received help in disclosing her status to her children:

> ***I told myself that I would not hide this from my children. Then what I did, I did not tell them myself. I was working at NAPWA*** *[National Association of People Living with HIV]****. I talked to my director and told him that I want to disclose to my children, what must I do? He said to me: "Don't worry, I'll make a date with you, I will come to your place and counsel your children first. Then, if I see that your child is ready to know your status, then we will disclose to them". He did that, he went to my place twice. The first time was only to talk to them about the information of HIV and AIDS. The second time, we disclosed to my children. Then they accepted me, they don't have a problem. The first and the second child they are boys and they are supporting me. Really - especially the first one – he doesn't want anything bad to happen to me. When I'm ill, he'll ask me: "What can I do for you? Did you see the doctor?" Things like that. He would say: "Mommy I will bring things to you. You must not sleep the whole day and feel overwrought. You must you wake up, and move around, you must take things slowly". Then he'll prepare food for me – you know all those things.***

For some, disclosure in the support group was seen as a positive experience and as a safer option than disclosure to family members, for example:

> ***It is much easier to tell somebody who is also HIV-positive and not a relative. Relatives always want to find out how you got infected and they would ask too many questions. Also with relatives, if you tell just one person then soon everybody will***

> ***know. With the support group there, they don't want to know how you got HIV and they don't see it as their business and they don't judge you. Myself I got my support person from that group and it is better than having to deal with family.*** *[Selinah]*

Children were not always seen as competent audiences for their parents' disclosures, for example:

> ***I think that my daughter she is too young to understand. But I am planning to disclose to her a little later on.*** *[Mbali]*
>
> ***I will not tell my children. They do not need to know this.*** *[Gita]*
>
> ***I have not yet disclosed to my children****. [Funani]*

The disclosure experiences were seen as autobiographical, as compelling the person to narrativelty recreate a self. It was also regarded as a confessional, in the sense that the HIV-positive labelling somehow acted as a mechanism to unlock a "true" or more authentic self – a self forced out in the open by the construction of the ideal therapeutic woman living with HIV favoured by biomedical intervention.

> ***One lady came to our support group and introduced us to memory books. I was confused first – I did not know what to write or how to write a memory book. Then she showed us and I started to write. It makes me understand myself, because previously I did not understand who I was. I only started thinking about me when I became HIV-positive and had to learn how to deal with my own health.*** *[Lerato]*
>
> ***I like telling people now, because I help them by sharing my experiences with them. I also feel less stressed about it when I can talk about it. This was new to me – all this talking about myself.*** *[Poppy]*

> ***I was thinking about my life before the HIV and I really don't know. Maybe because I found out about the HIV when I was pregnant, I am a better mother, because I worry about my baby more.*** *[Selinah]*

> ***I have made my peace with this virus. Now I want to tell other people so that they can learn how to live with it as well.*** *[Diane]*

In this sense, Foucault's (1997:281) words seem poignantly apt: *"Why must the care of the self occur only through the concern for truth?"* For Foucault (2001:144) the obsession with truth-telling in technologies of the self implies *"endowing the individual with the preparation and the moral equipment that will permit him* [sic] *to fully confront the world in an ethical and rational manner."* This is clearly the case with the insistence on the therapeutic value of disclosure as a step closer to establishing the ideal woman living with HIV who has the kind of self-mastery to become moral, rational combatants in the war against the spread of further HIV-infections.

On the other hand Foucault (1988:42) points out that the confessional in Christian religion is deeply paradoxical, as it *"rubs out the sin and yet reveals the sinner."* Because of the powerful presence of perceived stigma ("revealing the sinner") in their lives, all of the research participants actively embarked on identity work to bring about congruence between how they saw themselves (in general and as extensions of their former selves prior to the diagnosis) and how they perceived others saw them (reflected appraisals). As has been demonstrated throughout this chapter, HIV-AIDS as an illness is steeped in gendered meanings; yet coping with the illness required breaking with some of the gendered expectations. Most of the research participants found it difficult to acquire the self-interestedness required to cope with the illness, for example:

> ***I have to make sure that I don't get stressed. Seriously I did have stress for a long time and I was on anti-depressants. So I told myself that I don't like to feel this way. Because I used to get stressed about minor things – then I told myself that stress is not***

> ***good for me with this virus. I don't want this virus to stress me either. So now I take things easy and this is hard for me, because I used to be different. Nowadays - let's say that you do something and I don't like it – I will tell you straight out there and then that I don't like that thing that you are doing. I had to learn to speak up for myself and this was a new thing for me.*** *[Tina]*

> ***First, when I came here to the hospital, I was always in a hurry. Some of the people here you will see they complain about waiting. But now I say we wait everywhere – you wait at the shop, you wait at the taxi rank. Now, I don't mind to wait. I don't see this as wasting my time anymore. Before I felt so guilty to take a whole day for myself, but now I see that I must care for my own health.*** *[Diane]*

Whitehead (2006:1024) quotes three themes in the biographical reconstruction for people living with chronic illness, namely restitution, chaos and quest. In restitution, there is a quest to return to a former self - or for what Carricaburu and Pierret (1995) refer to as biographical reinforcement. For most of the research participants, there was a loss of a former self prior to the HIV-positive diagnosis. These former selves were strong and performed gender-based activities (for example **Lora** who mourned the loss of being the one to do things for her children). A return to a former self was impossible for the research participants, although some performed activities to help them "pass for normal".

Chaos, according to Whitehead (2006:1024) is where the person is unable to make sense of the illness. Examples of such chaos have also been given in this chapter, where women ask the "why did this happen to me"-questions (for example **Funani**), suffered under severe self-stigmatisation (for example **Mbali's** self-inflicted restrictions in terms of meeting only other HIV-positive people) and dealt with fear, anger and sorrow. **Lora** mentioned how medicalised her life had become. Because there is no possibility of restitution to a former self, she remained stuck in a sick role that had no end in sight:

> ***I have been living with this since 2005. When I think back over the two years, all I see is doctors and clinics and medicine and nothing else. I think this is my life now – pills and pills and pills.***

Gita also spoke of experiencing sorrow:

> ***Oh, I feel very sad that I am so sick. I used to drink many beers. But I smoke, I should not smoke with the TB…but I am sick.***

Finally, under the theme of quest, Whitehead (2006:1023) sees the person developing a new sense of self that draws on the experience of suffering. **Tina**, for example, did not fit this description, but rather seemed to have abandoned the task of identity reconstruction completely. She described her life following the HIV-positive diagnosis as follows:

> ***I don't think my life is really different with the virus. I think that this is how my life was supposed to be. I did not make any big changes in my life due to my status.***

Being part of a support group enabled the research participants to recast themselves as caretakers and nurturers and to reconstruct their gendered identities with the support of their peers. The notions of "helping" or "giving back" were often used to describe a new sense of being. These ideas were even given as reasons for agreeing to participate in the study. Moreover, disclosure and helping were cast as moral tasks that demonstrated individual and communal responsibility and could potentially bring the person living with HIV as a possible transgressor/disease vector back into the fold of "normal people". For example:

> ***Generally for myself I get as much information. I learn something new every day. I watch TV like Siyayinqoba. I always update myself by going to talks. Then, if there is something I don't understand, I will sit down with the doctor and discuss. But I don't keep that information just for myself. I tell the other women at the support group so I always update them with information. This is***

> ***what I can do to help other women who also are HIV-positive.*** *[Lerato]*

> ***It is OK for me to talk to you about these things, because I think it would help that people know about my life. To hear what happened to me at the clinics. Then it would not have been about my illness and my troubles only. I will be helping. Hey... I don't know…We talk amongst ourselves. At the hospital, there is no time to discuss with other people. I have read some of your books here*** *[referring to pamphlets by the Department of Health left at the meeting place]* ***and I talk to the people who ask me about living with HIV. I think I can help them in a support group.*** *[Gita]*

Poppy saw her sero-positive status and the fact that she coped with living with HIV as having currency to qualify her as a counsellor:

> ***I think this was meant to happen to me so that I can help other people. When I help other people, I feel happy and strong. I feel that this is what I can do that no one else can do as well as me because I have been living with HIV since 1994.***

After failing to secure a position as a lay counsellor, she applied for a position as a receptionist with a private company. The position was a half-day contract post, but the company accepted her HIV-positive status. This was her response to this change in her life:

> ***You know what, I see that before I was stigmatising myself. I thought that I could only work as an AIDS counsellor. Now I see that there are other things that I can do as well that has nothing to do with my status. This was an eye-opened for me.***

Poppy arguably lived the longest with her diagnosis, making it entirely plausible that she could have reached these insights into a reconstructed self over time. The narrations and the researcher's experiences with some of these women in the support group after the major data-gathering phase was completed, however, revealed that themes of restitution, chaos and quest should not be regarded as hierarchical or linear steps in the biographical reconstruction or illness trajectory of people living with chronic disease. The loss of a former self, the chaotic nature of living with a serious and stigmatised condition and the search for a new self that emerges from the suffering but is able to integrate with “normals” were recurrent themes in the support group discussions. In the end it was impossible to quantify how many of the research participants have reached acceptance of their statuses or whether any one of them developed an identity pride as being an HIV-positive woman. In the next and final section of the discussion of the data, the question whether agency can be activated to contest or reject objectification is examined.

5.6.3 Bringing agency back in: Contestation and rejection of objectification

The research participants evaluated, negotiated, resisted, ignored and renewed their identities as women living with HIV. For many of them, rejecting objectification meant a first-time break with repeated gendered performances.

Contestation took the form of:

- Quitting a treatment regime or dumping pills
- Questioning the therapeutic insistence on compliance
- Complaining about bringing a “treatment buddy” along
- Criticising the practice of pill counting
- Bemoaning unsympathetic treatment or being dehumanised, objectified, stereotyped or judged
- Complaining about nurses acting in self-interest to show their commitment to *Masakane* without embracing the spirit of it.

These complaints were mentioned in the interviews and aired and discussed at support group meetings. The treatment received at public health facilities were, however, not seen as fundamentally unjust or disempowering, but rather as a symptom of the “naturally given” order of an inbuilt inequality.

> ***For now we must just put up with this - the pill counting, the waiting and so on. This is better than having no ARVs.*** *[Diane]*

> ***We are poor people without medical aids. We cannot really change the public health service. So it is better that we grumble here and when we go back to the doctors we smile and nod. Then they mark on their forms that you are adjusting and they leave you alone.*** *[Lora]*

Gita's complaints about the nurses seeing her as "lazy" stem from a normative expectation that nurses should be caring, sympathetic and non-judgemental. For example:

> ***We don't get counselling. What counselling? You cannot counsel someone and then shout after them. The nurses talk about Masakane and Bato Pele. Masakane is only for the newspapers and television. They treat us like animals – like children standing for hours in the hot sun waiting for medication. They say we must drink it in front of them – they want to see us drinking the pills. They say we are lazy and should find jobs. They shout at us. This is not what a nurse should be – she should care for the sick.***

Bemoaning "the way things are" also extended to the research participants' understandings of their relationships with male partners. Men absconding, having sexual liaisons that endangered the reproductive health of spouses or refusing testing were regarded as symptoms of gender inequality and disadvantage. For example:

> ***We cannot change the men just because we have HIV. The government must insist that the husbands get tested. We cannot do this by ourselves, it will be dangerous***. *[Funani]*

The research participants tended to undervalue their own role to act and present decisive, self-informed knowledge. In this way, some women were implicated in the oppression of other women and maintained a stake in the continuation of the *status quo*. The support group formed as an outcome of the study remained beset by problems of money, irregular attendance and power struggles.

Bryan Turner (1993:2) defines citizenship as "*that set of practices (juridical, political, economic and cultural) which define a person as a competent member of society, and which as a consequence shape the flow of resources to persons and social groups."* The stories and observations presented in this chapter demonstrate how these aspects of citizenship are constrained by biomedical hegemony, structural bases of power and intersubjective relations and individual decision-making power.

There is a difference between being recalcitrant (in the form of disobeying the authority of the public health care advice or bemoaning a situation) and actual resistance. When confronted with the powerful authority of biomedicine that holds sway over lifesaving treatments and social disability grants, the voices of contestation were silenced. By remaining fixed in recalcitrant contestation, the research participants penetrated some of the structural barriers to actual empowered reproductive health care for women living with HIV but nevertheless adopted the very attitudes and behaviours that condemned them to a life inhibited by biomedical hegemony.

5.7 CONCLUSION

In this chapter, stories and observations were given and analysed to demonstrate how biomedical hegemony, sociocultural constructions and material constraints shape the reproductive health of women living with HIV. The aims of this study were not only to critically examine the notion of female empowerment of women living with HIV, but to also uncover the experiences of such women. It can be deduced from the data that women living with HIV and dependent on public health care suffered from poor access to social capital[2] and lack of sexual autonomy. This, in turn, made them vulnerable to compounded health problems and decreased their ability to voice their own opinions about treatment and support.

In conclusion the findings from this chapter would suggest a need for an empowerment approach that better contends with the multiple needs of women living with HIV. A description of such an approach is suggested in the next chapter which also encompasses a summary of the findings and an examination of the contributions, strengths and limitations of the study.

ENDNOTES FOR CHAPTER 5

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[1] Research suggests a link between early sexual debut and cervical cancer (see Gatune & Nyamongo 2005).

[2] Symbolic capital and social capital are discussed in Chapter 2.

[3] In a recent article by bioethical experts (one of them working in Johannesburg), it is stated: *"…we seek to demonstrate that a mandatory approach to testing and treatment has the potential to significantly reduce perinatal transmission of HIV and defend the view that mandatory testing is morally required if a number of conditions can be met….If such programs are to be introduced continuing medical care, including highly active antiretroviral therapy, must be provided and pregnant women must have reasonable alternatives to compulsory testing and treatment. We propose that a liberal regime entailing abortion rights up to the point of fetal viability would satisfy these requirements"* (Schuklenk & Kleinsmidt 2007:1179). Mandatory antenatal testing cannot be seen as a benevolent intervention in the course of the HIV-AIDS epidemic when it is enforced in the absence of real empowerment of women and in the presence of a dual health care system (an under-resourced public one and a private one accessible to those with a preponderance of economic and cultural capital that enables them to refuse mandatory testing or to control disclosure). See also Grove, Kelly and Liu (1997) for a discussion.

[4] Broyles *et al* (2006:190) make the important observation that the very notion of adherence is imbedded in biomedical authority in which non-adherence or non-compliance is in respect of a failure to obey the health care provider's will and not a refusal to act according to one's own will, choices or preferences.

[5] Items on such questionnaires include:

- The name and file number of the patient
- Her academic qualifications, marital status and living conditions
- Her knowledge of HIV, AIDS, TB, ARV, CD-4 counts and viral loads
- Whether the patient is pregnant
- The types of ARV-regimens and their potential benefits
- Personal coping styles, stress and anxiety
- Alcohol use, illegal ("street") drug use and smoking
- Whether she has a criminal record
- Psychiatric problems, intellectual ability and emotional stability
- Side-effects
- Disclosure, caregivers and treatment buddies
- Condom use

- Stigma
- Using reminders to take medication at the correct intervals
- Financial burdens and employment status.

[6] ARV-treatment regimes for HIV-patients with TB are discussed in Chapter 1.

[7] During fieldwork, both male and female prisoners were observed to visit the selected VCT and ARV sites (and at least on two occasions the reason was to receive PEP after attacks during incarceration). Male HIV-positive prisoners can potentially infect their female partners after release and fail to disclose their statuses. In counselling sessions, careful statistics are taken of the number of visits each patient kept and of all related compliance behaviour. The prisoners were not regarded as dangerous people *per se*, but rather as non-ideal candidates for moulding into virtuous, compliant patients. They were seen as people who have already failed and therefore as beyond redemption and likely to disappear from treatment once they were released from incarceration.

[8] The poor are not vectors of disease in the HIV-AIDS epidemic. Instead, the experience of living with HIV is different for a poor person. As Mufune (2003:45) rightly points out: *“the association of HIV/AIDS with poverty is over-emphasised. For example, one of the most affected countries is Botswana, yet the economy of Botswana has been among the fastest growing in the world for the last two decades. Moreover in all the southern African countries HIV/AIDS is at least as widespread among the educated and well-off as among the poor.”*

[9] The nature of these changes were in the form of less or no sexual intimacy for some, fights about HIV-testing with a male partner, and for one participant, a renewed closeness in the relationship.

[10] In this regard, Araia (2003: 50), commenting on AIDS in Africa, makes and interesting observation*:” In addition to being influenced by historical location and time and by linked lives, agency is also related to individual characteristics such as education, temperament, intelligence and so on. For many young people in Africa agency is created and recreated in trying to break with tradition and the past in search of their future. Eventually, it is changes in the agency state that will determine the course of the epidemic.”*

[11] Re-infection with a different strain of HIV can lessen the effectiveness of ARV-treatments and also increases the possibility of becoming treatment-resistant. Re-infection (or superinfection) with HIV is discussed in Chapter 4.

[12] This is not the only chasm to cross for a woman living with HIV as far as the body is concerned. From the quoted narratives, it can be seen that the research participants also struggled with the difference between their lived experiences as bodies-with-HIV and with the representational use of the body as a symbol of femininity within their everyday contexts.

[13] Woodward (1997:12) proposes that “essentialist” identities - such as motherhood - are acutely desirable to marginalised women.

[14] Sandra Steingraber (1997) argues that environmental pollution renders breast-milk unsafe for mothers and infants in both developed and developing countries. Untreated TB, hepatitis and various other diseases in the mother are other contraindications for breastfeeding. Moreover, malnutrition and substance abuse by the lactating mother make breast-milk hazardous for infants. Van Esterik (2002) suggests that current discourses tend to blame the breastfeeding mother as a toxic source instead of situating lactating mothers as the targets of economic, social, environmental and cultural forces that impact on their health.

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[15] The embodied maternal thus includes women who are trying to conceive, pregnant women, birthing women, adoptive mothers, lactating mothers, bottle-feeding mothers, women who donate gametes or breast-milk to other women, women who care for infants, children and adult children and elderly maternal bodies who are key figures in women's support systems. The bias of disease containment privileges some of these embodiments and silences others. Moreover, the continued importance of mothering over the life-course is an important discovery from the narratives. It differs from the recent work by Sarah Wilson (2007) amongst British mothers with HIV who perceive a cut-off date of about 16 years for children as the age at which their mothering responsibilities stop.

CHAPTER 6

CONCLUSION

6.1 INTRODUCTION

In the previous chapter, data from research interviews and observation were given and analysed with the intent of uncovering systems of power and subordination as suggested in the model for critical ethnographic work by Carspecken (1996). In this final chapter, the research findings are summarised in terms of systems of power and conclusions are made about the aims and central thesis of the study.

It is the contention of the researcher that the aims of the study have been met. The study demonstrated how the active disempowerment of women in South Africa has contributed to the context of risk in reproductive health (Chapters 4 and 5). Moreover, lack of women’s empowerment in South Africa, far from being an obstacle in fertility transition, actively created a context conducive to poor reproductive health. The central aim of the study was to investigate women’s perspectives and experiences of HIV-positive statuses and how that impacted on their decisions and actions regarding future pregnancies, reproductive health, autonomy and empowerment. This aim was met by offering verbatim quotations from in-depth interviews and by contrasting what is experienced or "lived" with what is publicly prescribed for “living positively” with HIV. In so doing it was possible to uncover if and to what extend, HIV-positive women participated in reifying hegemonic biomedical views of their own lives.

In this chapter, the contribution of the study as an emancipatory project is also evaluated and implications for policy and practice are suggested. The researcher also attempted to expand the notion of female empowerment within the discipline of social demography. In response to this aim, an expanded notion of women’s empowerment is proposed in the final section of this chapter.

6.2 SYSTEMS OF POWER AS REVEALED IN THE FINDINGS

The goal of this study was to move beyond description to uncover power relations that inhibit empowered decision-making by HIV-positive women in the area of reproductive health. Using critical ethnography permitted a valuing of the research participants as women living with HIV and facilitated the discovery of oppressive structures of power. The thesis of this work was to critically examine the notion of female empowerment of women living with HIV as it is framed by social constraints and enablements. The following discussion is a response to this thesis as emerging from the data and the analysis.

The data presented in Chapters 4 and 5 reveal how HIV differentially burdens women. In Chapter 4 the historiography of reproductive health issues in South Africa demonstrated the contours of disempowerment of women; leading to what Solomon Benatar (2006:120) refers to as *“both apartheid and HIV/AIDS as manifestations of exploitation.”* In Chapter 5, the research participants’ narrations were shown as being permeated with anticipated stigma that hindered a collective drawing on these women’s stakes as women living with HIV. Common themes that emerged were gendered “ways of being” such as fighting off the stigmatising image of women as vectors of disease and of HIV-positive women as being “bad” mothers.

Catherine MacKinnon (1987:16-17) points out that *"One genius of the system we live under is that the strategies it requires to survive from day to day are exactly the opposite of what is required to change it…. Until the cost of this is collectively experienced as unacceptable by those who have drawn the best of men's options for women, and glimpsed as changeable by those who have drawn the worst, we will continue to live–if it can be called living–under its aegis"*. For the research participants the “collectively experienced” features of their lives were treatment compliance, conforming to heterosexual and heterosexist expectations and taking up the burdens of uncompensated labour for the sick and vulnerable. Power was also discursively part of the structures of knowledge and technological practice so that VCT and ARV therapies became disciplinary apparatuses in the medicalisation of the official South African fight against HIV-AIDS. Moreover, power revealed itself in the culture-authorising articulation of infant feeding practices and marital procreation as socioculturally-prescribed "natural" things that were disrupted by HIV-AIDS.

Power differentials ***between*** women, however, were revealed as existing on multiple levels and sites, such as between:

- Public health care providers versus recipients of such services
- Those accessing social disability grants versus those resisting such practices
- Those residing in informal settlements versus those who lived in formal settlements
- Those who conformed to a heterosexual framing of womanhood as defined by domesticity and those who chose a different sexual agency[1]
- Those with discredited spoiled identities versus those with discreditable spoiled identities.

The participation of the research participants as citizens through spheres of civil society was restricted. In fact, following their diagnosis as HIV-positive, all of the research participants became subjected to very direct state-led biomedical control. Due to their poverty, they were excluded from certain consumer practices. As political agents, they did little more than vote[2] during local elections and complain (in the safety of private meetings) about perceived public health service inadequacies and the regulatory discourses of counselling. The notion of empowered health consumers free to choose and take responsibility for their own health as envisaged in the "own responsibility"-rhetoric (see the discussion in Chapter 1 under subheading 1.4 and Chapter 2 under sub-heading 2.2.4) thus obfuscates the constraints that women living with HIV and accessing public health care face.

As women in the reproductive ages, the research participants faced the paradox of fulfilling their reproductive responsibilities but in a biomedically prescribed and regulated way. They exhibited low fertility preferences however, and their HIV-statuses were not the only or main considerations in their future reproductive decision-making. Attendance of support group meetings was irregular as other burdens encroached on the women's lives. Access to goods and resources, command of symbolic capital to control the disclosure of a stigmatised status and abilities to perform as "normals" or negotiate safer sex differed between the research participants.

Biomedical hegemony and disease containment rhetoric undermined the empowerment of women by perpetuating women's subordination through an overemphasis on women's responsibilities in curtailing new infections and caring for the sick and vulnerable. The research participants were not empowered with knowledge about how to deal with side-effects, condom failures and the reluctance of husbands and male partners to be tested for HIV. Whereas disease curtailment and care are certainly points to consider, the empowerment of women does not imply that women living with HIV should be considered as therapy-activated soldiers in the fight against the epidemic[3]. Instead, empowering women living with HIV requires making visible their multiple invisible burdens and labour.

The ideal therapeutic woman living with HIV as created within the discourse of public disease containment and treatment adherence is a woman emptied out of all her subjectivity, biography, social connectivity, emotionality and sexual expression. Therefore a comprehensive notion of empowerment must embrace the biological embodiment of femininity by paying attention to women's bodies, the resources needed by women and the social support required for those affected and infected with HIV.

The theoretical framing and chosen methodology of this study implied a value-commitment to moving reproductive decision-making for women who are HIV-positive from a pre-concluded tale of destiny to a tale of empowered agency. Theories about empowerment assisted in thinking through the narratives and observations in the data-gathering, data-analysis and interpretation phases of the study. Important concepts used in this regard were symbolic capital, hegemony, power, discourse and women's empowerment. In keeping with a critical orientation, the emancipatory success of the research project is evaluated in the next section.

6.3 THE EMANCIPATORY SUCCESS OF THE RESEARCH PROJECT

In Chapter 3, the reasons for selecting a critical ethnography were deliberated. The chosen methodology implied a commitment to maintaining particular research values. This means that the accountability of the researcher not only rests on the quality of the research product that is delivered, but that the research process itself should conform to the value of emancipation.

The primary record (in Chapter 4) revealed how the history and reality of invidious female subjugation in reproductive health exacerbated paternalism of care disguised as beneficence. This subjugation was exposed in the narrations and in the observations of ARV and VCT care giving at public health sites. The research participants' voices as women living with HIV were silenced and made subordinate to the knowledge of biomedical experts. Women living with HIV and refusing treatment, falling pregnant, smoking, drinking or wanting a sterilisation at a young age and low parity were constructed in the biomedical discourse as people perverting some deeper, more rational and more authentic desire for a better way of being. ARV and VCT therapy endorsed a discourse of health ir/responsibility that made women fearful of openly discussing reproductive, contraceptive and sexual issues. This ir/responsibility was gendered as female since the women were supplied with male condoms whereas female condoms and microbicides were not made available. In addition, there were no direct efforts made to help women to involve their male partners in testing. As reported in the previous chapter, some of the research respondents found this absolution of men problematic and as discursively inscribing and legitimising men's less important responsibility for safer sex. As **Funani**[4] remarked during a support group meeting:

> ***Taking Nevirapine is for women only. Only the women take it to prevent her baby from getting HIV, but what about the father of that baby? Who will know if he is HIV-positive or not? He has to do nothing to protect that baby. So the men think it is only the women's responsibility.*** *[Fieldnotes, support group meeting]*

Androcentric and biomedical hegemony combine to prescribe to women how to live with HIV according to a standard of ***a***bstinence, ***b***eing faithful and ***c***ondomising[5] that seem more affiliated with male sexual behaviour (in homosexual and heterosexual relationships) than to the lived experiences of women. **Poppy**[4], for example, read these codes of conduct for safer sex as being the norm first set for men and to which women will have to conform to survive in the time of the HIV-AIDS-epidemic and transferred them to a homosexual relationship. Moreover, much of the therapy and treatment (condom use, treatment buddies, pill counting as a form of directly observed therapy for ARV-treatment and adherence counselling) were in respect of an imagined, future possibility of sexual encounters, non-adherence or pill dumping which did not always bear any relation to the lives or needs of the research participants. The research participants' immediate felt needs were for material assistance, dealing with men, managing child care, coping with the side-effects of treatments, having greater choices in contraceptive options and handling anticipated stigma. They enacted, resisted and lived with HIV in different ways, incorporating some of the biomedically prescribed posturing as women living positively and blending it with stigma-negating performances and gender-prescribed ways of dressing, walking and acting.

The question that arises is who will act as the "interpreters" of the needs of women living with HIV and dependent upon public health care services? A related question is whether support groups can become sufficiently politicised to take on the role of interpreter. Can support groups eventually become protagonists of the state and of civil society? These two questions are answered below by first elaborating on the notion of democracy through human interdependence and then by reporting on the research participants' experiences of the support group.

Young (2000:132-33) argues that democracy can be strengthened by pluralising the modes and sites of representation and by improving the connection between representation and the participation of citizens in the public spheres of civil society. Public responsibility, in turn, is based on the capacity of individuals to recognise their problems as being collective. This goes hand in hand with political socialisation and mobilisation. For women living with HIV, this means making the private public. Moreover, it means rethinking the rhetoric of autonomy by stressing human interdependence as a reality that holds transformative implications for political ideology and for practice. Support groups can function as spaces for such transformative interdependency, or they can become what Foucault (1998) calls "*crisis heterotopias*". Hospices caring for dying AIDS-patients and community organisations caring for those who were ostracised by their families and communities due to the HIV-AIDS crisis all have the potential of removing from general sight those affected and infected by HIV into crisis heterotopias. With these ideas as background, the experiences of the research participants with the support group were investigated next.

In the support group, women were able to connect through the sharing of lived experiences of women living with HIV in Gauteng and accessing public health care services. This was the start of networking and women-to-women advocacy. In the support group, they retold the tales of their infection, of how they dealt with the diagnosis, treatment, disclosure and stigma and exchanged ideas on how to live with HIV. They shared the making of memory books and assisted one another to adopt self-care. Some of the talk in the group was about maintaining a positive body image through caring for one's hair, skin and nails thereby reaffirming the embodiedness of living with HIV and the quest for women to reassemble their bodies and selves in gendered ways. Support group members also spoke about spiritual, emotional and religious coping strategies. A semblance of group cohesiveness was forged, forming a type of political economy of exchange within the social field of the support group. In the following section, brief summaries of the ten research participants' experiences with the support group are given to demonstrate the point of networking.

> **Lerato**[4] assumed a leadership position in the support group and had a profound influence on the group. She was able to bring along speakers to address the group. Having gained confidence in leadership, she assisted in the formation of another group.
>
> **Funani**[4] found the support group to be a safe place to vent her feelings of anger against her husband, whom she blamed for her infection. In later meetings, she was able to move beyond these feelings of anger and suggest strategies to involve men in counselling, testing and treatment.

Gita[4] joined the group searching for belonging and understanding. Her attendance at the support group meetings, however, was irregular. Having decided not to continue with ARV treatments, she eventually disappeared and was unreachable for further discussions.

Mbali[4] was the information-gatherer in the group. This gave her an established role in the group, but she remained steadfast in her conviction that she can only find acceptance from fellow HIV-positive people.

Poppy's[4] past experience as a lay HIV-AIDS counsellor meant that the group was able to benefit from her experiences of support group work. She did not disclose the status of her gay relationship to the group. She eventually stopped attending meetings.

Tina[4] did not attend all the meetings, but reported that she found the support group beneficial. She brought along other young mothers living with HIV to the support group.

Selinah[4], as the youngest of the research participants, found it difficult to establish a role in the support group. She valued being able to talk to the group members and intimated that she only ever disclosed her status to her partner and the group members.

Diane's[4] health deteriorated to such an extent that it prevented her from attending the support group meetings. Some of the support group members visited her at her home.

Betty[4] was able to finalise the adoption of her deceased sister's daughter. She remained an enthusiastic member of the support group and supported **Lerato's**[4] efforts with the formation of other support groups.

Lora[4]**,** the oldest of the research participants, reported that she felt an outsider to the group. However, despite her self-stigmatisation, she was a regular attendee at meetings. Lora said:

> ***All these young ones cope well with their illness and treatment, but I keep on suffering. I don't see them with the swelling like I get. Sometimes I think I should stay away so that they don't feel sad when they look at me and see that I am getting worse****. [Notes on a telephone conversation with the research participant]*

Although a more detailed exploration of the research participants' experiences in the support group falls outside the main data-gathering of the study, it provides a valuable post-script to comment on the outcomes of the research engagement and to further evaluate the notion of women's empowerment. As discussed in Chapter 2, empowerment can be seen as a process or as an outcome (Charmes & Wieringa 2003; Gage 2000; Kabeer 1999; Sen & Batliwala 2000). As a process, empowerment can be measured in terms of the degree and type of participation that women enjoyed in emancipatory processes and also whether they were left feeling empowered by such participation. For the research participants, involvement in the support group offered opportunities for process empowerment via the development of leadership capabilities, gaining acceptance amongst their peers, building confidence in speaking out and starting to define collective goals. Participation validated their experiences and promoted positive self-perception. Thus for some of the participants, partaking in the study gave rise to personal reclaiming of agency. Although these can be valuable components in personal feelings of empowerment, the formation of a collective voice was hampered by irregular attendance, the interference of community leaders and horizontal violence (see the discussion in Chapter 5).

As an outcome, empowerment can be measured in terms of changes taking place in the allocation of resources and in overturning exploitation, marginalisation, powerlessness and enacted and symbolic violence (Charmes & Wieringa 2003; Kabeer 1999). These long term goals of empowerment were not yet achieved in the support group. There was no evidence of activism or of a collective social consciousness emerging from the group. A new notion of empowerment should therefore regard agency as dynamic, process-oriented and not as a static, all-or-nothing-state as implied with the ideal therapeutic woman living with HIV.

6.4 QUESTIONING AND CRITIQUING TAKEN-FOR-GRANTED ASSUMPTIONS ABOUT WOMEN LIVING WITH HIV

The narrative vignettes provided in the previous chapter enable a questioning and critiquing of the taken-for-granted assumptions of being women living with HIV and accessing public health care. Moreover, it helps to construct situated agents enabled and constrained by biomedical hegemony, institutional power and material vulnerability. Some of these taken-for-granted assumptions that were uncovered, problematised and ***refuted*** in Chapter 5 were, that the research participants as women living with HIV:

- All perceived their sexual relationships as putting them at increased risk for infection
- Were able to control and negotiate safer sexual practices and condom use without problems
- Regarded their HIV-statuses as the only or the most prominent consideration in future fertility preferences and decision-making
- Were situated in or were able to create social support systems that could render the necessary material, emotional and other stanchion required
- Saw mothering as confined to their own biological children or to culturally-dictated ages of independence of children
- Willingly accepted embarking on ARV-regimens as a normal part of an HIV-positive illness career and saw ARV-taking as a mechanical process open to biomedical auditing
- And using ARV-regimes were potential defaulters, recalcitrant, careless, deceptive, unmotivated or irresponsible
- Dealt with stigma and came to terms with the diagnosis in predictable, hierarchical, linear processes with complete acceptance as the end goal.

HIV-AIDS thus makes the analysis of lived experience by attending to gender and feminist concerns no longer optional, but imperative. In this respect Hellsten (2006:267-279) points out that the promotion of women's empowerment means reconciling claims to communitarian/universalistic rights (such as the right to be protected against infectious disease), individualist/relativist rights (such as the right of the individual to choose treatment options) and feminist rights (which regard both communitarianism and individualism as capable of violating women's rights and bodily integrity). This study demonstrated that issues such as informed consent for antenatal testing, adherence to ARV-treatment regimes, infant feeding practices and reproductive decision-making for women living with HIV are shaped by individual needs, social circumstances, cultural contexts and material resources. In all four of these issues (testing, treatment, infant feeding and reproductive choice) the research participants experienced tensions between biomedical and sociocultural prescriptions (see Chapter 5, especially subheading 5.4.2). The future success of VCT and ARV treatment therefore depends on paying attention to these tensions and finding creative solutions to them without ignoring the rights and empowerment of women.

Critiquing, however, is not enough for a critical study, as it does not involve praxis (Madison 2005:54). Rather, it is the first step and can be seen as the means to emancipatory efforts (as opposed to the end). Critiquing enables the challenging of discourses and practices such as technocratic methods of control. Treatment and adherence therapy was shown in the narrations and observations as practices that valorised female passivity to adopt a particular performativity as a therapeutic agent whilst also championing female conscription into the brave war against new infections. Such practices normalised men's refusals to be tested for HIV and women's silent compliance into becoming the invisible informal care-givers of those infected and affected by HIV-AIDS (see Chapter 5). In the next section, incremental liberation as a step following on critiquing is discussed.

6.5 INCREMENTAL LIBERATION

Incremental liberation refers to the improvement of individuals' ability to free themselves from certain forms of oppression. This second step, following on critiquing, focuses on the social relations of the emancipatory effort and gives attention to inequalities of power (Carspecken 1996:8).

From the evidence presented in Chapter 5 it is clear that problems of living with HIV cannot be solved through the mechanical application of rights, but rather by making the application of care responsive to the embeddedness and relationality of living with HIV as a woman. Mechanical problem-solving obscures the multiple positions and contexts in which women living with HIV exist. Such positions and contexts taint women's decision-making not by rendering their choices irrational, but by constraining the rational choices available to them.

The research participants expressed that their own self-concept was diminished because they measured themselves against the yardstick of "good therapeutic agents" and found themselves deficient (see the discussion on self-stigmatisation in Chapter 5 and subheading 5.6.2 in particular). In voicing their problems in living with HIV, accessing services and dealing with anticipated stigma, they re-evaluated their own agency. All of the research participants were willing to participate in a support group. This shows that the study had some success in terms of creating awareness from a critical and feminist perspective.

Feminist scholarship challenges the premise that equality can be achieved without changing the existing institutional frameworks and the political culture that is dominated and defined by such frameworks (Hellsten 2006; Hewitt & Valverde 2000; Maynard 1998). The emancipatory process should culminate in setting up guidelines for action and policy. As applied to this study, it implies attempts to answer the question: In what ways can public health care be recreated to substantially improve the reproductive health of women living with HIV?

Suggestions for improvements as stemming from this study are listed below. These recommendations are discussed according to the range of analytical moments as identified in the analysis of data (see Chapter 5). The list of recommendations thus commences with suggestions regarding economic resources for people affected by and infected with HIV and policy reforms. Second, recommendations regarding social support and addressing stigma at an interpersonal level are discussed. Finally, recommendations relating to personal decision-making and biographical reconstructions are considered.

6.5.1 Recommendations pertaining to economic resources and policy reforms

1. Since grant programmes have the potential of fixing and producing forms of dependency and compliance that may harm women's health, **a wider base of social grant-giving** (including social disability, foster-care and child custody grants) **and an expansion of social safety nets for the poor should be investigated.** Addressing poverty should be seen as crucially important for strengthening human rights generally and reproductive health rights specifically. **Setting CD4-blood count limits to social disability grants denies many women the resources they need**.

2. Reshaping public health service delivery for women living with HIV depends on grassroots feminist activists (from support groups, for example) joining alliances with other women's organisations (such as *Amanitare*[6]) to build feminist policy networks and strong lobbies to demand reform that suits the lived realities of women living with HIV. Such grassroots organisations have a crucial role to play in **amassing bottom-up pressure (from community-based groups) for greater accountability and efficiency in public health services for people living with HIV** (see also Kabeer 1999). In the field of reproductive health civil society actors can contest government officials and corporate power (such as multinational pharmaceutical companies) over the content of public health and social welfare policies. Such activism "from below" can challenge technocratic, managerial responses to health problems. Moreover, grassroots activism can facilitate citizenship based on socioeconomic and human rights. This, in turn, re-establishes the

emancipatory values of democracy. **The avowal of deeper forms of democracy presents a powerful counter-hegemonic project to biomedical hegemony.**

3. **Men should be incrementally involved in reform tasks as partners in petitioning for better public health care facilities**. Perhaps the realisation that biomedical hegemony tends to subjugate all patients (male and female) might encourage men to support such efforts. Freeman (1982:63) argues that: *"The biggest challenge to developing future public policy affecting women [is] breaking the tradition that a woman's obligation and opportunities are largely defined by her family circumstances."* Men and women should be seen as equal rights bearers entitled to good public health care services without stigmatising women as the vectors for infection in the HIV-AIDS epidemic. The challenge is to involve men and to overcome their resistance to involvement in HIV prevention and reproductive health care. **The *Men as Partners Network (MAP)* should be encouraged to do promotional and educational work in South African communities** (Tshabalala 2005). The *Program H Alliance* in Latin America had some success in changing younger men's attitudes regarding condom use, HIV and STI-prevention, sharing in the home-based care burdens of women and in preventing sexual violence (Schueller, Finger & Barker 2005)

6.5.2 Recommendations pertaining to social support systems and stigma

1. Morbidity and mortality related to HIV-AIDS increase the care burden silently undertaken by women in their families and communities. **Research into the informal care-giving roles of women should be undertaken with the aim of making policy recommendations to assist such women and to recognise, appreciate and materially support their invisible work.**

2. **Epidemiological tracking of HIV-infections through antenatal testing of women at public health care facilities should be reconsidered in the light**

of its possible stigmatising effect on underprivileged women who do not possess enough symbolic capital to hide their HIV-statuses[7]. This practice reifies negative and erroneous constructions of risk groups. Mistaken beliefs about being at risk (or having ever been at risk) and tolerance of symptoms of ill health have been demonstrated in this study as impeding women's health seeking behaviour and testing for HIV. Mandatory testing is not recommended for the following reasons: First, it violates human rights and second, groups with enough command over symbolic capital will consistently escape testing thereby reifying risk group notions.

3. Support groups can assist their members with transportation to service delivery points, filling out forms for accessing grants and child-care for younger mothers. Such groups will require access to funding or donations to fulfil such functions and to become sustainable. **Private business should be encouraged and given incentives to support such grassroots initiatives**.

6.5.3 Recommendations pertaining to subjective identity as a woman living with HIV

1. In Chapter 2 England's (2000:55) notions of self-efficacy and entitlement were discussed. Self-efficacy for the woman living with HIV implies a belief that her considered actions will have the desired, intended effects. This can be achieved through concerted efforts to **expand the contraceptive choices available to women living with HIV** (irrespective of their ages and parity) and by paying attention to **emergency treatments for condom failure**. Greater attention should be given to **the development of microbicides that can prevent HIV- and STI-transmission** and to the availability of male and female condoms.

2. The use of ARV-therapies should be seen as a life-long practice. Working with the notion of self-efficacy, it is conceivable that HIV-positive women will use a combination of strategies in ARV-therapy. Such strategies might include tolerating the side-effects of ARV-medication, opting out of treatments,

skipping treatments, using traditional health practices or using supplements. The use of such strategies will depend on these women's own understandings of their bodies, their own illness progression, and the perceived efficacy of their treatments and the influences of significant other people in their lives. In order to move away from passive biomedical acquiescence towards self-directed, self-efficient illness behaviour **the ideological basis of compliance-obsessed biomedical auditing and directly observed therapy should be re-examined.** Such an examination could be a first step towards creating an ARV-care environment in which **the person-living-with-HIV is seen as the expert in living with the disease.**

3. According to England (2000:55) a sense of entitlement implies accepting that one deserves the same rewards that others receive for comparable actions. For women living with HIV this can be achieved **through IEC programmes that continue to address the issue of stigmatisation** and through enabling women's participation in support groups to help them voice their grievances, hopes and dreams. Furthermore, participation in such grassroots organisations should instil notions of political agency and citizenship.

4. Public IEC programmes directed at eradicating HIV-AIDS stigma should address the themes of **victimisation and transmission stigma**. Women should not be regarded as disease vectors or as passive victims because pity and guilt are not liberating notions. The findings of this study have demonstrated that the current problems of HIV-AIDS in South Africa are related to social injustice that had antecedents in the past and continued into the new democracy (see Chapters 4 and 5). The complexities of the situation mean that it is impossible to find a singular cause to blame for the rampant epidemic and that **to remediate inequalities in health means to eradicate the rhetoric of blame.**

6.6 PROBLEMS, DILEMMAS AND CONTRIBUTIONS OF THE STUDY

The small number of research participants makes generalisability according to positivist standards limited. The small number of interviewees, however, afforded the opportunity for in-depth interviews on more than one occasion with each woman and to observe their participation in a support group. This level of depth could not have been attained in a quantitative survey.

The narrations of the research participants as reported in Chapter 5 were not "*perfect counter-hegemonic stories"* or *"victory narrations"* (St. Pierre & Pillow 2000:3) but gave accounts of the constraints and enablements that shape the illness careers of women living with HIV and accessing public health services. In-depth interviewing encouraged a proliferation of voices and a subversion of monopolistic knowledge claims on how a woman should ideally live positively with HIV.

The historiography offered in the primary record (Chapter 4) enabled throwing the experiences of the research participants into broader historic relief, thereby making an understanding of the workings of hegemony possible. On a methodological level, this study is a demonstration of the contribution to be made by a micro-level, critical analysis to the body of knowledge about female reproductive health in the era of HIV-AIDS in South Africa.

The nature of the research topic meant that quandaries occurred in the fieldwork that had no easy solution. One problem was the elaborate steps that had to be taken to protect the research participants' identities in follow-up work and in the final write-up of the data. Other problems were finding meeting places for the support group, dealing with church leaders' repugnance against condoms and with a community leader that demanded payment for the researcher's presence in "his" residential area.

A particular ethical dilemma which came up in the study was **Gita's**[4] decision to stop her treatment regime. Feminism respects women's decisions to reject unwanted bodily intrusions and to refuse treatment. Moreover, feminists deconstruct the ways that women have been positioned in society and then reconstruct them by repudiating the positioning and the roles which have been socially constructed. Foucault (1982:216) suggests that *"maybe the target nowadays is not to discover what we are, but to refuse what we are."* **Poppy**[4] discovered this tellingly when she had found employment that did not directly draw on her HIV-positive status and discovered that repositioning her identity in this way was personally empowering. Yet **Gita's**[4] treatment refusal was a perturbing occurrence, posing a dilemma situated in the increasingly nebulous boundary between bodily autonomy and the benefits of biomedical intervention in serious illness. In critical research, the researcher's first concern is with the research participants. The questions which arose were:

- Was **Gita's**[4] decision an empowered one of active repositioning or a fatalistic surrendering?
- Did the researcher's ethical commitment oblige her to convince **Gita**[4] to resume treatment to postpone death?

Attending to the first question, it should be considered that any "choice" without access to knowledge is not a choice at all. In this respect, **Gita**[4] was invited to attend a meeting with a health professional at a community-based organisation that offers treatment for women living with HIV. She obliged and had a discussion about the possible consequences of her treatment interruption and resumption. Even after this intervention, she still decided not to continue with ARV treatment. As far as the second question posed above is concerned, the researcher decided to follow feminist ethics and respect **Gita's**[4] decision. The disease containment–cum-treatment adherence rhetoric aims at producing normalised, calculable and predictable individuals. This kind of instrumental rationality has been demonstrated in this study as capable of serving a perverse double function that makes the subject invisible and voiceless and at the same time advocates the full accountability of the isolated self. This kind of negative freedom is not empowering since it affirms a right to choice in a context devoid of actual choice, informed consent and unconstrained decision-making. The researcher's ethical commitment to **Gita**[4] was to do no harm through the research intervention, to offer information and to respect personal dignity. Her decision to stop her treatment was not an outcome of the research intervention, but a personal decision based on complex reasoning.

Not only does this ethical dilemma illustrate how the study was informed by theoretical considerations and ethical guidelines, but it also crystallises the centrality of the notion of choice in emancipatory research. This study makes a contribution towards informing the notion of women's empowerment in the following ways:

- It underscores how material, biomedical and sociocultural constraints frame women's lives in sickness and in health
- It recognises the interplay between the micro-level elements of situated experience, knowledge and preferences and the macro-level elements of sociocultural, biomedical and material influences on health and reproductive behaviour
- It analyses gender as a system of power that operates through the bodies of women as they are differentially situated in material and sociocultural fields and command and deploy symbolic capital differently
- It highlights women's multiple commitments as wives, lovers, mothers, care-givers, waged labourers and unwaged labourers that make it difficult for them to address their interdependent concerns in the area of health and to use such a collective consciousness to inform their politics
- It challenges a health promotion rhetoric that champions self-management (in *life choices*) and impedes an awareness of gender as an exercise of power (which shapes *life chances*)
- It confronts spurious claims of ir/rationality in the reproductive health choices of women and demonstrates how asymmetries of power between public health care service providers and service recipients have the potential of polarising issues of woman's empowerment in new and complex ways
- It acknowledges the bodies of women living with HIV as inscribed with social laws, morality and values in the Foucauldian sense as well as lived, corporeal, subjective bodies[8]
- It uncovers ways of being and living as a woman with HIV which forms a backdrop to understanding the constraints and enablements of women's capacities for self-determination.

In retrospect for the researcher, this study meant, beyond the obvious academic pursuits, a rediscovery of the self in relation to others. For a moment in time, the researcher was let into the lives of other women by virtue of their kind generosity and could experience how they contend or disidentify with objectified statuses; how they respond to contingencies/exigencies as they face decisions in their lives marked by HIV and uncertainty. In the process, the researcher discovered how difficult it is to speak for others and how this burdens the researcher to, as Geertz (1988:10) explains, find *“somewhere to stand in the text that is supposed to be at one and the same time an intimate view and a cool assessment.”* In the next section, an elaboration of the notion of the empowerment of women is suggested.

6.7 CONCLUSION: TOWARDS A NEW NOTION OF WOMEN’S EMPOWERMENT

This study drew on the model for women’s empowerment as conceptualised by Paula England (discussed in Chapter 2). Based on the findings, two dimensions are added to the England model, namely that of choice and collective action. Each of these two dimensions is discussed below.

Earlier on in this chapter, the centrality of the notion of choice in emancipation was discussed. Choice implies that there are alternatives available to the person and that the person is knowledgeable about such alternatives (Kabeer 1999). Consciousness rising amongst women may therefore help them to understand the contours of their oppression, but may not enable them to act upon it in a transformative way because there are no viable alternatives. The result may be fatalistic or religious acceptance of suffering, anger and frustration. Choice for women living with HIV can be modelled at the collective level through the work done in support groups or at the individual level in the form of a role model (Charmes & Wieringa 2003:425). In economic, policy, judicial, intersubjective and personal decision-making spheres, choices can be expanded, embodied, modelled and copied in order to offer what Batilawa (1994:130) refers to as *“a growing repertoire of choices”*.

Just as “acceptance” in biographical reconstruction should not be seen as universally applicable, linear and automatic for all women living with HIV, so too empowerment of women should be regarded as complex, fragmented, beset with hazards and backlashes and composed of different activating moments depending on contextual and individual enabling and constraining factors. Women are likely to experience empowerment differently as a result of being differently positioned to receive and use different forms of capital. As a policy goal, the empowerment of women should remain an important step in dealing with social injustice and in redressing past inequalities. In the early years of the global HIV-AIDS epidemic, Allan Brandt (1988:168) said that *"AIDS will be a standard by which we may measure not only our medical and scientific skill, but also our capacity for justice and compassion".* The empowerment of women requires vision and political will, but is crucial in order to address the problems HIV-AIDS with justice and compassion.

Providing a greater variety of quality reproductive health services to women living with HIV is not automatically empowering in itself, but it creates a vantage point allowing for the formation of transformatory consciousness (i.e. collective action). Ferguson's (1986:217) notion of power is that it can be translated into empowerment as an ability to act with others to do together what one could not have done alone. The best stimulus for change in public health care services for women living with HIV can come from empowered women who concertedly stand up in pragmatic solidarity against oppression and demand new types of relationships with the apparatus of the state, service providers, employers and partners that are based on mutual respect, human dignity, equality and democracy. Via the formation of informal and formal alliances (with bilateral, multilateral and international organisations) to pursue joint action, a wider health consumer movement can be formed to shape services in ways more responsive to the needs and lived experiences of women living with HIV (Brown 1993; Gorna 1996; Horn 2006; Lather 1991; Moleon 2000).

In closing the study was an attempt to describe the lived experiences of women living with HIV and accessing public health care services from the perspective of the empowerment of women. What has been demonstrated in this study (see Chapter 5) is that power relations, yielded by biomedical hegemony, androcentric sociocultural practices, material deprivation, fear, discrimination and stigma mark and contour these lived experiences and potentially undermine such women's abilities to become empowered. Expansion of choices in various spheres or fields (such as employment, social welfare support, contraceptive use, social support systems) and collective action have been proposed as dimensions to be added to an empowerment-of-women approach to the problems of reproductive health in the age of HIV-AIDS.

HIV-AIDS claims lives and destroys individuals, families and communities. At the same time, however, this epidemic harbours liberatory potential to provide a platform for the transformation of gender relations and the encouragement of greater democratic participation. **To be most effective, prevention and treatment strategies should address injustice and inequality and restore human dignity.** This study provides a trajectory for research that attempts to enter and understand the lived experiences of women with HIV in order to contribute to a national conversation about stigma, empowerment, equality and physical and psychological health care-giving in the thirteenth year of South Africa's political democracy. Now is the time for women to seriously challenge the suitability of current public reproductive health care in South Africa and to in the words of Lather (1991:8) *"imagine otherwise."*

ENDNOTES FOR CHAPTER 6

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[1] The study did not find that the research participants were consistently incapable of effecting sexual agency, but rather that sexual agency for women living with HIV were restricted within androcentric and biomedical hegemonic discourses. In this respect, the study confirms Horn's (2006) arguments about sexual agency for women in Africa.

[2] Farmer and Campos (2006:272) in their analysis of bioethics pose the question: *"But what does it mean, for both bioethics and human rights, when a person living in poverty is able to vote, is protected from torture or from imprisonment without due process, but dies of untreated AIDS?"*

[3] To carry this war-metaphor further, to regard women as being sufficiently equipped in the public treatment therapy sessions (which is containment-driven) to become the change agents from the ground up can be likened to sending troops to the front armed with little more but some knowledge about danger and a will to protect themselves and their loved ones against it.

[4] This is a pseudonym. See Chapter 3 and 5 in which further background is given on each research participant.

[5] AIDS activists speak of a fourth dimension being added in the alphabetised slogan of ABC to include ***d***oing it yourself which refers to self-masturbation as a safer sex practice. This also seems more amenable to sexual relations other than heterosexual consensual unions or marriage in which sex and procreation are idealistically linked. [*Fieldnotes on a discussion at the Unit for Social Behavioural Studies in HIV and AIDS, UNISA]*

[6] *Amanitare*, formed in 2000, is the first pan-African network on sexual and reproductive health and rights (Horn 2006:10).

[7] Guido Pennings (2006:396) quotes reproductive tourism as an extreme example of how a bifurcation of rights in reproduction operates on a global scale. Affluent women travel from

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countries where certain reproductive technologies (such as gamete donation, sex-selection of foetuses or artificial impregnation of postmenopausal women) are prohibited, to countries like Belgium where such prohibitions do not exist. Whereas Pennings (2006:400) regards reproductive tourism as a moral safety valve that controls moral conflict, it should be apparent that women with a command over capital will thus be enabled to fulfill their reproductive needs whereas those who have less command over the capital available in the field of reproductive health and rights will not. Sperm washing and artificial insemination for HIV-serodiscordant couples as mentioned In Chapter 4 are further examples of this split in reproductive rights.

[8] In Chapter one it has been explained how HIV-statuses, AIDS and the patient's readiness to embark on ARV-treatment regimes are biomedically defined and measured as well as prescribed in terms of six psycho-social characteristics that imply inclinations for treatment. This study shows the irreducible difference between lived experience (both corporeal and psycho-social) and the biomedically prescribed ideal therapeutic agent that moves effortlessly through linear, taxonomic stages of disease acceptance, illness disclosure and responsibility. This unwritten contractual engagement between ARV-service providers and ARV-service recipients were honoured by some of the research participants and resisted and rejected by **Gita**.

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High court. Witwatersrand local division. In the matter of the State versus Jacob Gedleyihlekisa Zuma. 4/5/2006.

Minister of Health versus Treatment Action Campaign (No 2) 2002 (5) SA 721 (CC)

INFORMED CONSENT A

Background to the study, assurance of confidentiality and informed consent

Dear research participant,

Thank you very much for participating in this study. The goal of this study is to obtain detailed information on the reproductive health needs of women in a context of HIV/AIDS. This in-depth, qualitative study is intended to uncover experiences, problems and practical solutions in this regard. Your co-operation in this study can assist decision-makers to have better programs and services to address the reproductive health needs of South Africans living with HIV.

Please be informed of the following:

- This is a Doctoral-level study conducted by myself and with my own money (there is no outside sponsor);
- Your co-operation, whilst crucial, is voluntary;
- Your identity is protected and you will be given a false name in the final write-up of the interview. Your real name will never be mentioned in any presentation of the findings of this study and you will therefore remain anonymous;
- You are not required to sign anything. Instead, I will ask you to confirm your informed consent for the interview on the tape;
- This interview will be tape-recorded. I will transcribe the interview personally and no one else will have access to my raw data or the recordings. This means that your responses in the interview is treated as highly confidential;
- Your responses, along with those from other interviewees will be combined in the presentation of the findings to further protect your privacy;
- This data for this study is obtained from volunteer interviewees from different sites in Tshwane and outlying suburbs of Johannesburg;
- The interview will take about 40 minutes to 1 hour;
- Should you like to get a summary of the findings of this study, please tell me and I will give it to you as soon as it is available.

Again, thank your for your most valued co-operation.

G du Plessis

Gretchen du Plessis
Tel: 082-442-1528
Fax: 012-653-8302
E-mail: dplesge@unisa.ac.za or gretmar@mweb.co.za

INFORMED CONSENT FORM B

Background to the study, assurance of confidentiality and informed consent

Dear participant,

Our telephonic arrangements refer. Thank you very much for allowing this interview. The goal of this study is to obtain detailed information on the reproductive health needs of women in a context of HIV/AIDS. This in-depth, qualitative study is intended to uncover experiences, problems and practical solutions in this regard. Your co-operation in this study can assist decision-makers to have better programs and services to address the reproductive health needs of South Africans living with HIV.

Please be informed of the following:

- This is a Doctoral-level study conducted by myself and with my own money (there is no outside sponsor);
- Your co-operation, whilst crucial, is voluntary;
- Your identity is protected. Your real name and the name of your organisation will never be mentioned in any presentation of the findings of this study and you will therefore remain anonymous;
- This interview will be tape-recorded. I will transcribe the interview personally and no one else will have access to my raw data or the recordings. This means that your responses in the interview is treated as highly confidential;
- The main group of interviewees are women living with HIV and accessing VCT and ARV services at public health care facilities in Tshwane and surrounding areas;
- You were selected as a key interviewee due to the services you/your organisation render for women living with HIV
- The interview will take about 40 minutes to 1 hour;
- Should you like to get a summary of the findings of this study, please tell me and I will give it to you as soon as it is available.

Again, thank your for your most valued co-operation.

G du Plessis
Gretchen du Plessis
Tel: (012) 6538302
Mobile: 0824421528

DEPARTMENT OF HEALTH

Karel Schoeman Building
179A Skinner Street
9th Floor
Room 908
PRETORIA
0002

02 May 2007

Enquiries : Ms [redacted]
Telephone : (012) 303-[redacted]
Fax No : (012) 324-[redacted]

Gretchen du Plessis
Department of Sociology
P O Box 369
UNISA
0003

RE : PERMISSION TO CONDUCT INTERVIEWS WITH VOLUNTEERS AT THE VCT CLINIC AT THE TSHWANE DISTRICT HOSPITAL

I refer to your letter dated the 10th of April 2007 regarding the abovementioned matter.

Permission is hereby granted to you to conduct interview with volunteers at the VCT Clinic at the Tshwane District Hospital.

Kindly contact Dr [redacted], telephone number (012) 354-[redacted] make the necessary arrangements for the interviews.

Yours sincerely

MS [redacted]
DIRECTOR : TSHWANE/METSWEDING REGION

DATE : 02/05/2007.

GAUTENG PROVINCIAL GOVERNMENT

Department of Health
Lefapha la Maphelo
Departement van Gesondheid
Umnyango wezeMpilo

ENQ: [redacted]
TELEPHONE: 355-[redacted]
FASCIMILE: 355-[redacted]
[redacted]@gpg.gov.za

TO : **Ms Gretchen du Plessis: Department of Sociology - UNISA**

CC : **Ms [redacted] – Tshwane Metsweding Region**

FROM: **Ms [redacted]**

DATE : **10 May 2007**

RE : **Permission to conduct interviews with volunteers at the VCT Clinic at the Tshwane District Hospital**

I acknowledge with sincere appreciation your request to conduct interviews with volunteers at the VCT Clinic at the Tshwane District Hospital.

Kindly contact Ms [redacted] who is the Chief Director for Districts in the Tshwane Region. Her cell phone number is 082[redacted] for her guidance and advice. I wish you success in your studies and research. I will be happy to discuss the protocol and the benefits of the findings and outcome for the Gauteng Department of Health on the 18 May 2007 at 10:00 as per our confirmation.

Thank you

[redacted] 10/5/07.

Chief Directorate: HRD/EWP

Department of Health
Lefapha la Maphelo
Departement van Gesondheid
Umnyango wezeMpilo
TSHWANE-METSWEDING REGION
Office of the Chief Director: Mrs [redacted]
Tel: (012) 303[redacted]
Fax: (012) 303[redacted]
email: [redacted]@gauteng.gov.za

16 May 2007

TO WHOM IT MAY CONCERN:

PERMISSION TO UNDERTAKE A STUDY

TOPIC: REPRODUCTIVE DECISION MAKING IN THE ERA OF HIV AIDS

This letter serves to confirm that Gretchen du Plessis has been authorised to undertake the above study as per approval of the University of South Africa (UNISA).

The Gauteng Department of Health will be furnished with final research report before publication.

[redacted]

CHIEF DIRECTOR:
TSHWANE METSWEDING HEALTH REGION