

**HIV EXCEPTIONALISM AND THE SOUTH AFRICAN  
HIV AND AIDS EPIDEMIC:**

**PERSPECTIVES OF HEALTH CARE WORKERS IN  
PIETERMARITZBURG**

by

LINDA JOY STILL

submitted in part fulfilment of the requirements for  
the degree of

MASTER OF ARTS

in the subject

SOCIOLOGY (SOCIAL BEHAVIOUR STUDIES IN HIV/AIDS)

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: DR GE DU PLESSIS

CO-SUPERVISOR: MR L ROETS

OCTOBER 2008

## DECLARATION

---

I declare that **HIV EXCEPTIONALISM AND THE SOUTH AFRICAN HIV AND AIDS EPIDEMIC: PERSPECTIVES OF HEALTH CARE WORKERS IN PIETERMARITZBURG** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

**Linda Joy Still**

.....

Signature

.....

Date

## **ABSTRACT**

---

The limited success of HIV-testing facilities in South Africa means that many people are not accessing necessary antiretroviral treatment services. This study investigates the practical implications of HIV exceptionalism inherent in Voluntary Counselling and Testing (VCT). A semi-structured interview schedule was used to survey participants for their perspectives on barriers to HIV-testing uptake as well as the effects of exceptionalist practices at VCT clinics. Responses showed marked perceptions of gender differences in people's willingness to test and several important barriers including problems of access to services. Significantly, exceptionalism displayed in certain clinic procedures was thought to contribute to stigma, and attempts to normalise HIV practice in order to combat the effects of stigma were being informally implemented. Participants' views on routine opt-out testing were explored. The researcher recommended further investigation on how HIV testing and treatment policies can be normalised so as to reduce stigma and increase testing uptake.

### **Key words**

Ethics, HIV exceptionalism, Provider Initiated Testing and Counselling, rights, routine opt-out testing, stigma, Voluntary Counselling and Testing.

## ACKNOWLEDGEMENTS

---

My sincerest thanks go to my UNISA supervisors, Dr Gretchen du Plessis and Mr Leon Roets, for all their assistance, encouragement and support; to the Ethics Committee of the Department of Sociology at UNISA, for approval of the research proposal; to the KwaZulu-Natal Health Department and the uMgungundlovu Health District, for permission to conduct the study and for the provision of information; to the research participants, professional nurses and counsellors, who gave their valuable time to share perceptions and insights; to my special friends, Tim and Claire, for their encouragement as well as professional and practical assistance; to Bobbie, my sister, for much time spent in patient and insightful listening; to my family, for their endurance and sacrifice, and especially to my husband David, for his unfailing optimism, good humour and belief in me.

*“You shall know the truth,  
And the truth shall set you free.”*

*John 8.32*

<b>TABLE OF CONTENTS</b>	<b>PAGE</b>
DECLARATION .....	ii
ABSTRACT.....	iii
ACKNOWLEDGEMENTS .....	iv
TABLE OF CONTENTS.....	v
LIST OF ACRONYMS AND ABBREVIATIONS .....	x
LIST OF ACRONYMS AND ABBREVIATIONS (continued).....	xi
LIST OF FIGURES .....	xii
CHAPTER 1: INTRODUCTION.....	1
1.1 BACKGROUND INFORMATION.....	1
1.1.1 Chapter overview.....	2
1.1.2 Human rights concerns and HIV exceptionalism.....	3
1.1.3 Voluntary counselling and testing.....	5
1.1.4 Provider-initiated counselling and testing .....	6
1.1.5 Response to routine testing as advocated in PITC.....	9
1.2 THE RESEARCH PROBLEM .....	9
1.3 THE RESEARCH QUESTIONS AND OBJECTIVES .....	10
1.4 THESIS STATEMENT AND DECLARED BIAS .....	11
1.5 DELINEATION AND LIMITATIONS .....	11
1.6 DEFINITION OF KEY TERMS AND CONCEPTS.....	12
1.7 VCT CLINICS IN KWAZULU-NATAL.....	13
1.8 PROFESSIONAL NURSES .....	13
1.9 CASE STUDY OF TWO BROTHERS.....	14
1.10 SIGNIFICANCE OF THE STUDY .....	17
1.11 CHAPTER OVERVIEWS .....	18
1.11.1 Chapter 2: Literature review .....	18
1.11.2 Chapter 3: Methodology .....	19
1.11.3 Chapter 4: The research context .....	19
1.11.4 Chapter 5: Presentation and analysis of findings.....	19
1.11.5 Chapter 6: Conclusion and recommendations.....	20
1.12 CONCLUSION .....	20

**TABLE OF CONTENTS (continued) PAGE**

---

CHAPTER 2: LITERATURE REVIEW ..... 21

2.1 INTRODUCTION ..... 21

2.2 HUMAN RIGHTS AND THE BELMONT REPORT OF 1979..... 22

    2.2.1 Principles of the Belmont Report ..... 23

        2.2.1.1 Respect for Persons ..... 23

        2.2.1.2 Beneficence ..... 24

        2.2.1.3 Justice..... 25

    2.2.2 Application of the Belmont Report principles ..... 26

        2.2.2.1 Informed consent and confidentiality..... 26

        2.2.2.2 Assessment of risks and benefits..... 28

        2.2.2.3 Fair distribution of risks and benefits..... 29

    2.2.3 Principles in conflict..... 30

2.3 EMERGENCE OF HIV EXCEPTIONALISM..... 32

    2.3.1 Origins ..... 32

    2.3.2 HIV exceptionalism in the South African context ..... 34

2.4 THE DEBATE ABOUT EXCEPTIONALISM..... 36

    2.4.1 Benefits of HIV exceptionalism ..... 36

    2.4.2 Criticism of exceptionalism ..... 37

    2.4.3 Poor uptake of VCT in South Africa..... 39

    2.4.3 Defence of exceptionalism ..... 40

    2.4.4 Which rights matter most? ..... 41

    2.4.5 The costs of inaction..... 42

2.5 THE EXAMPLE OF BOTSWANA ..... 43

2.6 A SUGGESTED FRAMEWORK FOR AN ETHICAL ANALYSIS ..... 44

2.7 CONCLUSION ..... 45

CHAPTER 3: RESEARCH METHODOLOGY ..... 47

3.1 INTRODUCTION ..... 47

3.2 RESEARCH DESIGN ..... 47

    3.2.1 Delimitation of the study ..... 48

    3.2.2 Geographical area..... 49

<b>TABLE OF CONTENTS (continued)</b>	<b>PAGE</b>
3.2.3 Strengths and weaknesses .....	51
3.3 METHODOLOGY .....	51
3.3.1 Research instrument .....	52
3.3.2 Research population.....	54
3.3.3 Sampling procedure .....	54
3.3.4 Data collection.....	56
3.3.5 Data analysis and interpretation .....	59
3.3.6 Trustworthiness and rigour .....	60
3.3.7 Limitations .....	62
3.4 ETHICAL CONSIDERATIONS.....	62
3.4.1 Permission to conduct research .....	63
3.4.2 Informed consent.....	63
3.4.3 Confidentiality.....	65
3.4.4 Provision of debriefing, counselling and additional information .....	65
3.5 CONCLUSION .....	65
CHAPTER 4: THE RESEARCH CONTEXT.....	67
4.1 INTRODUCTION .....	67
4.2 THE INTERVIEW PROCESS .....	68
4.3 BIOGRAPHICAL INFORMATION ON THE INTERVIEWEES.....	70
4.3.1 Eva .....	70
4.3.2 Nancy .....	71
4.3.3 Gertrude .....	71
4.3.4 Miriam.....	72
4.3.5 Thomas .....	73
4.3.6 Dorothy.....	73
4.3.7 Elizabeth.....	74
4.3.8 Theresa .....	74
4.3.9 Lily .....	74
4.4 BACKGROUND INFORMATION ON CLINIC PROCEDURES .....	75
4.5 THEMES EMERGING FROM THE INTERVIEWS.....	78

<b>TABLE OF CONTENTS (continued)</b>	<b>PAGE</b>
4.5.1 Barriers to testing .....	78
4.5.2 Willingness to test.....	78
4.5.3 Attitudes to VCT and other testing models .....	79
4.5.4 Participants' observations and recommendations .....	79
4.6 CONCLUSION .....	79
<b>CHAPTER 5: PRESENTATION AND ANALYSIS OF FINDINGS</b>	<b>80</b>
5.1 INTRODUCTION .....	80
5.2 BARRIERS TO TESTING .....	81
5.2.1 Stigma.....	81
5.2.2 Other barriers to testing .....	85
5.3 WILLINGNESS TO TEST .....	91
5.3.1 Male reluctance and female willingness to test.....	92
5.3.2 Changing attitudes to testing .....	94
5.4 ATTITUDES TO VCT AND OTHER TESTING MODELS .....	97
5.4.1 Counselling and confidentiality.....	98
5.4.2 VCT and routine testing: observations on HIV exceptionalism ...	101
5.5 OBSERVATIONS REGARDING PATIENT BEHAVIOUR .....	108
5.5.1 "People are not the same" .....	108
5.5.2 The need to please .....	110
5.6 RESEARCH PARTICIPANTS' RECOMMENDATIONS .....	111
5.7 CONCLUSION .....	114
<b>CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS</b>	<b>116</b>
6.1 SUMMARY OF FINDINGS.....	116
6.1.1 Summary of major themes .....	116
6.1.2 Analysis of current testing model.....	118
6.2 RESEARCH CONCLUSIONS.....	120
6.3 RECOMMENDATIONS.....	121
6.4 SUMMARY OF CONTRIBUTIONS .....	122
6.5 SUGGESTIONS FOR FURTHER RESEARCH .....	123

<b>TABLE OF CONTENTS (continued)</b>	<b>PAGE</b>
6.6 CONCLUSION .....	123
LIST OF SOURCES .....	124
APPENDIX.....	138
UNISA LETTER OF ACCESS.....	138
UNISA ETHICS COMMITTEE APPROVAL .....	139
UMGUNGUNDLOVU HEALTH DISTRICT APPROVAL .....	140
UMGUNGUNDLOVU HEALTH DISTRICT PERMISSION TO VISIT CLINICS .....	141
PARTICIPANT CONSENT FORM .....	142
INTERVIEW SCHEDULE.....	143
CODING FRAMEWORK ANALYSIS LEVEL 2 .....	146

## LIST OF ACRONYMS AND ABBREVIATIONS

---

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral treatment
ARVs	Antiretroviral drugs
ATICC	AIDS Training, Information and Counselling Centre
CD4	“Helper” T-lymphocytes in human blood.
CHC	Community health centres
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
IRIN	Integrated Regional Information Networks
KZN	KwaZulu-Natal
MSF	Medecins Sans Frontieres
PHC	Primary health care
PITC	Provider-Initiated Testing and Counselling
SAIIA	South African Institute of International Affairs
SAMRC	South African Medical Research Council

## **LIST OF ACRONYMS AND ABBREVIATIONS (continued)**

---

SANC	South African Nursing Council
STI	Sexually transmitted infection
TAC	Treatment Action Campaign
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNO	United Nations Organisation
VCT	Voluntary HIV Counselling and Testing
WHO	World Health Organisation
WMA	World Medical Association

## LIST OF FIGURES

---

Figure 1: Map of uMgungundlovu Health District .....	50
--	----

# CHAPTER 1: INTRODUCTION

---

## 1.1 BACKGROUND INFORMATION

Some 5.35 million people in South Africa are currently infected with the Human Immunodeficiency Virus (HIV) and an estimated 1 500 new infections are added daily (Aidsmap 2007; Statistics South Africa 2008). South Africa has one of the worst HIV epidemics in the world, and it is rendered more critical by the problem of poor uptake of testing services, as reported in a recent survey by the Human Sciences Research Council (HSRC 2005). Although HIV testing services have been available in South Africa since the early 1990s (Birdsall *et al* 2004), and despite the provision of antiretroviral therapy (ART), only 2% of the population had tested in the year prior to the survey (Smart 2007). Medical practitioners in the field of HIV/AIDS report a tendency amongst patients to delay testing for HIV until the onset of symptomatic illness, with the result that those who do test sometimes die before they access treatment (Aidsmap 2006).

Several reasons have been identified for people's reluctance to be tested, including a false sense of security related to HIV infection (HSRC 2005), psychosocial barriers such as stigma and feelings of fatalism (Van Dyk & Van Dyk 2003b) and service-related barriers (Van Dyk & Van Dyk 2003a). Half of the respondents who tested positive in the HSRC survey (2005) indicated prior to testing that they did not believe that they were at risk. This false sense of security means that over two million HIV-positive people in South Africa are unaware of their serostatus and do not even think they need to be tested (HSRC 2005).

Stigma and discrimination play a significant role in low uptake of testing (Buchanan 2005). Historical factors have led to an association between HIV and marginalised groups such as gays, prostitutes and injecting drug users (Skinner & Mfecane 2004). Partly because of this link, a diagnosis of "HIV

positive” carries a significant stigma and in many instances may lead to discrimination, rejection and even abuse, particularly for women (Nolen 2007). Fear of such prejudiced reactions is a major cause of poor uptake of testing services. The association with ostracised groups also contributes to the inaccurate perception of personal risk, as people who do not identify with these groups believe themselves not to be in danger of infection.

A number of service-related barriers to testing were identified in a study of Voluntary Counselling and Testing (VCT) services in South Africa (Van Dyk & Van Dyk 2003b). Indeed there is concern amongst experts (Aidsmap 2006) that features of the current approach to HIV testing, namely VCT, may be unintentionally contributing to poor uptake by inadvertently adding to the existing stigma through procedures which can be described as “exceptionalist” (Cameron 2006; De Cock *et al* 2002). In response to poor uptake of VCT in many African countries, the World Health Organisation (WHO) issued guidelines in 2007 for an expanded testing approach referred to as Provider-initiated Testing and Counselling (PITC), or “routine opt-out testing” (WHO 2007). In line with this, South Africa’s new National Strategic HIV and AIDS Plan for 2007 to 2011 recommends that HIV testing be offered routinely to people visiting health services (Aidsmap 2007). However, there is still a significant gap between recommended strategy and the current implementation of testing.

### **1.1.1 Chapter overview**

This chapter presents a perspective on the development of the VCT model against the backdrop of human rights concerns, and introduces the concept of HIV exceptionalism. Central characteristics of the VCT model are described, as well as the main features of PITC or routine opt-out testing. This provides the context for the formulation of the research problem. Background information is given on the clinics and nurses in the uMgungundlovu Health District where the research was undertaken. A case study describing the experiences of two brothers living in the Pietermaritzburg area is added to

illustrate some of the difficulties which beset current testing practice. The chapter ends with an outline of the remainder of the dissertation.

### **1.1.2 Human rights concerns and HIV exceptionalism**

Since the early days of the HIV epidemic, constructive response has been grounded in a foundation of human rights concerns (Bayer & Fairchild 2006; Danziger 1996). Health care workers and researchers employed in the field of HIV testing are required to uphold basic human rights to equality, life, privacy and health care which are enshrined in several human rights instruments including the South African Bill of Rights (Constitution of the Republic of South Africa 1996). The basic ethical principles of respect for persons, beneficence and justice as outlined in the Belmont Report of 1979 (US National Institutes of Health 1979) are expressions of these rights, and provide a useful framework of analysis for examination of HIV testing procedures. These principles are explored in greater depth in the literature review which can be found in the second chapter of this dissertation.

When the HIV and AIDS epidemic first appeared during the 1980s amongst members of the gay community and injecting drug users there were serious risks associated with being identified as HIV-positive in the United States because of discrimination against people with AIDS in areas of housing, employment, insurance and medical care (Wolf *et al* 2007). There were also few benefits of knowing one's status, since no treatment was available. Public health officials were nevertheless concerned that testing should be encouraged in the hope that it would reduce transmission rates. However they feared what might happen if standard public health procedures were enforced (De Cock *et al* 2002). Such policies, which include targeted testing, surveillance and partner notification, if applied to people already stigmatised, were likely to drive the epidemic underground (Bayer & Fairchild 2006; De Cock *et al* 2002).

In addition, human rights activists were outspoken on behalf of groups which suffered discrimination, particularly the gay community, and insisted on the inclusion of specific informed consent and confidentiality procedures in any approach to testing (De Cock *et al* 2002). This differs from the common practice of medical consent which recognises verbal, non-specific consent for many procedures (Wolf *et al* 2007). The outcome of this perceived conflict between public health officials and human rights activists was the recommendation that testing for HIV should only be undertaken after counselling and with specific consent, that delivery of test results should be accompanied by additional counselling, that test results should be treated with a higher level of confidentiality than is common with medical information and that people should have the option of testing at separate sites to maintain anonymity (Wolf *et al* 2007).

HIV/AIDS was thus accorded special or “exceptional” status, and this came to be known as “HIV exceptionalism”. The term refers to the tendency to treat HIV and AIDS differently from other sexually transmitted or fatal infectious diseases (Bayer & Fairchild 2006; De Cock *et al* 2002). Out of this exceptionalist approach the current model of HIV testing, namely Voluntary Counselling and Testing or VCT, was developed. VCT with its particular emphasis on voluntarism, confidentiality and individual rights embodies an exceptionalist response and stands in contrast to the standard, medical response to infectious diseases (De Cock *et al* 2002; Wolf *et al* 2007).

Adoption of the VCT model seemed an obvious route to follow in South Africa, where the onset of the HIV and AIDS epidemic coincided with the process of democratisation (Thornton 2008). VCT is characterised by a strong voluntarist basis, with the decisions to be tested, to disclose serostatus, and to access treatment all being made voluntarily at the initiative of the individual (Danziger 1996; Richter 2006). In the context of a country moving away from coercive measures it was natural to adopt an approach which emphasised personal freedom.

Experts in the field of HIV and historians of the epidemic (De Cock *et al* 2002; Seidel 1996; Thornton 2008) have argued, however, that following the example of the developed countries mentioned earlier was inappropriate in the African context where the epidemiology of HIV/AIDS is different to the rest of the world (De Cock *et al* 2002; Iliffe 2006). South Africa, it is contended, would have done better to find an African response like the informal, communication-based approach adopted in Uganda (Seidel 1996; Thornton 2008). The characteristics of the VCT and PITC (routine opt-out) models of testing are considered in the next section.

### **1.1.3 Voluntary counselling and testing**

VCT emphasises that testing should be voluntary (Aidsbuzz.org 2008b). To ensure voluntarism, VCT requires that testing is “client-initiated”, meaning that testing is done at the initiative of the client only. This is a safeguard against testing becoming mandatory or compulsory, which is a major concern from a human rights point of view (Kippax 2005). VCT places a high degree of importance on counselling as part of the informed consent process and insists on a confidential setting for testing and treatment (KwaZulu-Natal Health Department 2007).

With post-test counselling and ongoing treatment VCT aims to maximise the possible benefits and minimise the risks of knowing one’s status, through adopting a “positive” attitude to living with HIV (KZN Health Department 2007). VCT was designed to protect human rights, and has the following characteristic features, sometimes referred to as the “Three Cs” for consent, counselling and confidentiality (Csete & Elliott 2006):

1. Informed client consent;
2. Comprehensive pre- and post-test counselling;
3. Confidentiality.

The emphasis on choice and free will implicit in the VCT model is intended as a protection against stigma and discrimination. It gives individuals

responsibility for making their own decisions about difficult health issues. In so doing, however, it enables people to delay finding out the truth about their status. Often it is only when severe illness or pregnancy forces further investigation that the reality becomes known. Kanya *et al* (2008) report that 90% of HIV infected people worldwide do not know their status, despite two decades of VCT availability. Many experts in HIV testing (Bayer & Fairchild 2006; Cameron 2006; De Cock *et al* 2002; Richter 2006) believe that VCT has not been performed adequately, and may in fact be discouraging testing. They advocate for implementation of a routine opt-out approach.

#### **1.1.4 Provider-initiated counselling and testing**

Guidelines for Provider-Initiated Testing and Counselling, or PITC (WHO 2007) were published by UNAIDS and WHO in 2007. This development is in response to the seriously low uptake of VCT in most African countries to date, where surveys show that a median of 10% of women and 12% of men have been tested and received their results (WHO 2007:5). One of the drafter's of the United Nation's original 1985 testing policy, David Miller, said of the recommended shift to a routine approach (South African Institute of International Affairs 2004:4): *"What made us change our position is the fact that VCT wasn't working."*

PITC is proposed by UNAIDS and WHO not as an alternative to VCT, but rather as an expansion of it (Richter 2006). It differs from VCT in one important respect, namely, that instead of testing being done only at the initiative of the client or patient, testing is initiated routinely by standard clinic practice. Patients are informed of this, and of their right to refuse testing. The onus is then on patients to opt out of testing if that is their choice. This is referred to as an informed "right of refusal" (Richter 2006; WHO 2007). Patients who do not exercise this opt-out right are deemed to have given implicit consent.

An important aspect of the rationale for PITC is the concern that currently many people who present at health care settings showing clinical symptoms

of HIV infection are not being offered an HIV test, in line with the VCT commitment to testing being *client*-initiated (WHO 2007). This is demoralising and ethically difficult for health care workers who find themselves in a position where they are not truly free to follow the course of clinical action which seems most beneficial to the patient (Leitch 2003). Important opportunities for intervention are being lost (Bassett *et al* 2007; UNAIDS 2007).

PITC comprises two main testing strategies, outlined below (Richter 2006:20-22):

### **1) Diagnostic testing:**

As with other illnesses the doctor or nurse is guided by the presence of medical symptoms and undertakes any testing deemed necessary to lead to a diagnosis. The process involves confidentiality and informed consent, as well as limited pre-test and comprehensive post-test counselling.

### **2) Routine testing with the right to decline:**

Patients attending health care facilities are routinely tested for HIV. There is no discrimination based on clinical symptoms. Patients are informed of the testing policy and of their right to decline testing. They are also assured that declining an HIV test will in no way prejudice their ability to access medical care in future. This model is one of informed “*right of refusal*”, and consent is assumed unless the patient expressly objects. It is also known as an “opt-out” approach.

The WHO guidelines recommend that the application of these strategies should be determined by the prevalence of HIV in the population, and identify three different epidemic levels (WHO 2007:6-7):

- **Low-level HIV epidemic**, where HIV infection may have been present for many years but where it has never spread significantly to a

subpopulation group; infections are largely restricted to specific groups known to engage in high-risk behaviour;

- **Concentrated epidemic**, where HIV infection rates have reached a significant level within at least one subpopulation group, but where the evidence suggests that this group does not have active networks to the general population;
- **HIV epidemic**, where sexual networks within the general population allow the spread of HIV infection independently of subpopulation groups.

The guidelines recommend that for situations of low-level and concentrated epidemics an approach of *diagnostic testing* be implemented. HIV testing and counselling should not be routine, but should be recommended to all people attending health care facilities who present clinical or diagnostic symptoms which suggest an underlying HIV infection (Richter 2006; UNAIDS 2007).

It is recommended that in situations where the epidemic is generalised, as is the case in sub-Saharan Africa, an approach of *routine testing with the right to decline* should be adopted. HIV testing and counselling should be presented as “*part of the normal standard of care provided to the patient*”, regardless of the presence or absence of any HIV-linked symptoms, and regardless of the patient’s expressed reason for attending the facility (UNAIDS 2007:7).

The UNAIDS guidelines make some important provisions to the recommendation of routine testing. Firstly, WHO and UNAIDS distance themselves from coercive or mandatory testing and call for comprehensive training of medical personnel to ensure that routine testing always includes the right to decline. Secondly, what is termed an “enabling environment” is regarded as essential for successful implementation of PITC. This means that HIV testing and counselling should be offered in conjunction with a “*package of HIV-related prevention, treatment, care and support services*” (WHO

2007:8), which include interactive pre- and post-test counselling, access to antiretroviral therapy, access to interventions to prevent mother-to-child transmission and a social and legal framework which offers basic community support. This “package” is not yet universally available, and the WHO guidelines acknowledge that a phased implementation of PITC may be necessary based on constraints of resources and capacity (WHO 2007).

### **1.1.5 Response to routine testing as advocated in PITC**

PITC signals a move away from the exceptionalism of HIV which is inherent in VCT (SAIIA 2004). Some human rights activists see this move as a threat to the rights-based approach which has come to characterise testing policy (Buchanan 2005; Csete & Elliott 2006; Kippax 2005). Others welcome PITC as part of the process of normalising HIV which they regard as essential to improving testing rates (Basett *et al* 2007; Kanya *et al* 2008). Dr Francois Venter, head of the South African Clinicians Society, and Zackie Achmat of the Treatment Action Campaign (TAC), both voiced approval for an approach which would help to normalise the management of HIV/AIDS in order to reduce associated stigma (Integrated Regional Information Networks 2007; News 24.com). There is, however, an ongoing debate over the shift toward PITC (Aidsmap 2007), and this is explored in Chapter 2 of this dissertation.

## **1.2 THE RESEARCH PROBLEM**

The problem which this study seeks to investigate is whether, in the view of the research participants, HIV testing rates are being negatively affected by the exceptionalism inherent in the VCT approach, and whether PITC could offer improved rates of testing without compromising human rights. Exceptionalism is currently manifested in the requirements of voluntary informed consent, pre- and post-test counselling and strict confidentiality. In addition, many VCT clinics have attempted to minimise effects of stigma and discrimination by adopting measures which involve the separation of HIV patient facilities from those of general patients. The PITC approach seeks to

normalise HIV and AIDS, bringing management and treatment in line with other infectious diseases.

### **1.3 THE RESEARCH QUESTIONS AND OBJECTIVES**

The purpose of this study is to provide insight into the experiences of senior nurses who work in the field of HIV testing. In so doing, the research explores their attitudes to the exceptionalism inherent within VCT. It asks whether the twin goals of increasing testing uptake and decreasing stigma might be better served by the normalisation of HIV and AIDS through a routine opt-out testing model as advocated by PITC. Finally, it seeks to present the findings in such a way as to offer insights which might prove useful in informing decision-making pertaining to HIV-testing policy.

In the context of face-to-face interviews with nine research participants, the study investigates the following research questions:

1. What do the interviewees see as the major barriers to testing for HIV in the communities which they serve?
2. In the opinion of the interviewees, how do people feel about the special approach to HIV testing, which requires both pre- and post-test counselling?
3. How do the interviewees think attitudes to testing might change if an HIV test was offered routinely to all patients attending a primary health care facility?
4. What perceptions do the interviewees hold regarding the introduction of PITC or routine opt-out testing? Could this increase uptake of HIV testing without compromising human rights?

## **1.4 THESIS STATEMENT AND DECLARED BIAS**

The following thesis statement expresses the researcher's position at the start of the research project:

*The exceptionalism inherent within VCT practice at clinics in South Africa is unintentionally increasing stigma and decreasing willingness to test.*

The researcher wishes at the outset to acknowledge a bias in favour of a routine opt-out approach. This is rooted in her experience as a personnel manager for a small business which in the past few years has lost a number of valued employees to HIV and AIDS. The researcher observed a marked tendency on the part of these employees to delay seeking testing or treatment, despite the availability of these services and a supportive employer-employee relationship. Some of these employees attended clinics regularly for minor health matters, but did not get tested for HIV until they had become very ill with AIDS-related disease. These experiences served to shape the researcher's viewpoint and led to the formulation of the thesis statement.

## **1.5 DELINEATION AND LIMITATIONS**

This is not a comprehensive investigation of HIV testing models. It is exploratory research, revealing the perceptions of a sample group of nine participants on the implications of VCT, and the potential implications of PITC, within their clinics. Mandatory testing and compulsory testing are not considered in this study, except for being defined so as to exclude them. The researcher has not attempted a thorough examination of how well VCT is working generally, but has merely reported on aspects of VCT practice at the

selected clinics. As this is not quantitative research, the findings cannot be generalised to the wider population.

## **1.6 DEFINITION OF KEY TERMS AND CONCEPTS**

The following terms require clarification. Based on their usage in the literature they can be defined as follows:

**1.6.1 Compulsory testing:** This refers to testing in which there is no voluntary or informed consent element. It is done at the initiative of a person or party other than the one being tested, and sometimes without the knowledge of that person (Canadian HIV/AIDS Legal Network 2005).

**1.6.2 HIV exceptionalism:** This refers to the tendency to treat HIV and AIDS differently from other sexually transmitted or fatal infectious diseases (Bayer & Fairchild 2006; De Cock *et al* 2002). It emphasises strict clinical confidentiality, informed consent and anonymised surveillance systems (De Cock & Johnson 1998).

**1.6.3 Mandatory testing:** This refers to testing required as a pre-condition for some benefit, such as immigration, blood or organ donation, or employment in the armed services (Canadian HIV/AIDS Legal Network 2005).

**1.6.4 Normalisation of HIV/AIDS:** This refers to treating HIV/AIDS in line with procedures common to other infectious diseases, for which early diagnosis is essential to appropriate prevention and management policies; it acknowledges the need for informed consent and respect for confidentiality (De Cock and Johnson 1998).

**1.6.5 Voluntary testing and counselling (VCT):** This is a model of HIV testing which emphasis the elements of pre- and post-test counselling, informed consent and confidentiality of test results (Aidsbuzz.org 2008b).

**1.6.6 Provider-initiated testing and counselling (PITC):** This recommends diagnostic testing in areas of low-level HIV epidemic, and routine opt-out testing in areas of concentrated epidemic. It includes limited or implied consent (right to decline), counselling and confidentiality (WHO 2007; Wolf *et al* 2007).

## **1.7 VCT CLINICS IN KWAZULU-NATAL**

Public health service in KwaZulu-Natal, as in the rest of South Africa, is tiered with some clinics being administered by the provincial health department and others by local government. Primary health care centres (PHCs) offer first level health care services. Community health centres (CHCs) are the next level, offering all the services of PHCs but in addition providing 24-hour maternity, emergency care and casualty, and a short stay ward. Patients who require higher level care are referred to a district or regional hospital (KZN Health Department 2008a).

The uMgungundlovu district where Pietermaritzburg is located has four CHCs, 23 provincial clinics, 17 local government clinics and 17 mobile clinics. VCT services are available at all PHCs and CHCs. Initiation of antiretroviral treatment (ART) is done at accredited CHCs, of which there are currently nine in the uMgungundlovu district, as well as at district and regional hospitals (KZN Health Department 2008b).

## **1.8 PROFESSIONAL NURSES**

The South African Nursing Council (SANC 2009) recognises three categories of nurses in South Africa. A “nursing auxiliary” is a nurse who has completed a one-year course of study, an “enrolled nurse” is one who has completed two years of study, and a “professional nurse” (also known as a registered nurse) has completed a four-year course of study. The training of a professional nurse includes courses in general nursing, midwifery, psychiatry and

community nursing. The Nursing Act of 2005 (Act No. 33 of 2005) requires that all professional nurses in practice be registered with the South African Nursing Council (SANC) (Nursing Act 2005).

The SANC stipulates a four-year training programme at an accredited institution, but also makes provision for nurses with basic training to upgrade their qualifications via a bridging programme (SANC 2007a). Universities which have a Department of Nursing offer degree programmes, and colleges which are affiliated to a university offer accredited diploma programmes (Kortenbaut 1997). The South African Nursing Council (SANC) reported a ratio of 47:1 for population per qualified nurses at the end of 2007 (SANC 2007b).

All PHC facilities in the uMgungundlovu district have at least two professional nurses. These nurses hold a diploma in general nursing, midwifery, community and psychiatry, as well a diploma in primary health care, which includes HIV/AIDS counselling, HIV/AIDS clinical management and integrated management of HIV/AIDS, sexually transmitted infections (STI) and tuberculosis (TB) (KZN Health Department 2008b).

## **1.9 CASE STUDY OF TWO BROTHERS**

The following case study tells the true story of Nathi and Vusi (not their real names), two brothers from a Pietermaritzburg family known to the researcher. The events in the story took place during the course of this research project, and serve to illustrate several of the issues affecting HIV testing rates.

### **Nathi's story**

Nathi, aged 38, worked in Durban but went home to Pietermaritzburg from time to time to see his family. In June 2008 Nathi became ill and on a visit home he decided to have himself tested for TB. A family member urged him to test for HIV at the same time, which he did. He attended a clinic in

Pietermaritzburg and tested positive for both TB and HIV. Since he worked in Durban he decided to visit a clinic there to have his CD4 count taken, thinking this would be more convenient for ongoing treatment. However, before the CD4 count results were returned his health deteriorated further and he had to go back to his home in Pietermaritzburg. He had already begun TB treatment but was unable to continue working, and his health worsened over the next few weeks.

One morning when his condition had become critical, Nathi's family took him to a local Pietermaritzburg clinic. They explained to staff at the clinic that he had tested positive and that his CD4 count results were available at a Durban clinic. However, the local clinic staff said they did not have a telephone number for the Durban clinic. At this point the researcher, known to the family, was asked to help. The researcher successfully acquired the telephone number of the Durban clinic, and then phoned the local Pietermaritzburg clinic to give staff there the telephone number. This clinic was one which the researcher had visited in the course of her research approximately five weeks earlier. She explained to a staff member that she wanted to give them contact details to assist in getting CD4 count results already available at a Durban clinic for a patient who was sitting in the local clinic at that moment. However, the staff member, although apparently interested and concerned, explained that CD4 count results could only be sent from one clinic to another by fax, not verbally, and that their fax machine was broken. She thought it was unlikely that the results could be sent to another fax number (where the researcher worked) due to constraints of confidentiality.

Later that day Nathi was admitted to hospital, where he died in the early hours of the following day. He had known he was HIV positive for less than three months, and had not yet begun ART. He left an 18-month old daughter, whose young mother informed the family shortly before Nathi's death that she had known she was HIV positive for two years. Her previous boyfriend had died in 2005 of AIDS-related illness.

## **Vusi's story**

Vusi is Nathi's brother. When Nathi became ill and was taken to the Pietermaritzburg clinic, Vusi had also returned to the family home too ill to work. He had been tested in May and was informed that his CD4 count was 264. Clinic staff advised him to return for another test six months later. He also tested positive for TB and was started on TB treatment. At the time that Nathi was taken to the clinic shortly before his death, the family judged Vusi to be the more critically ill of the two brothers. They did not expect him to live, although they hoped Nathi might still receive medical intervention in time to save his life. After Nathi died, hopes that Vusi might recover were further diminished. Family members became preoccupied in making Nathi's funeral arrangements. Vusi's condition continued to worsen, and he was unable to stand or care for himself in any way. His breathing was difficult and laboured. His throat was sore and swollen and the family struggled to get him to eat anything.

A week after Nathi's death at the urging of a sister who is well-informed about HIV and AIDS, the family decided to take Vusi to the clinic. Vusi could not walk the distance from the home to where a taxi could collect him, and he was being looked after by his elderly mother who was unable to carry him there. A third brother was summoned home to assist, and Vusi was taken to the same clinic which had had the broken fax machine. However, Vusi's mother and brother did not understand that the clinic had separate facilities for VCT and ARV located in a park home trailer outside of the main clinic. They took Vusi to the main clinic. There he was put on a drip, given some tablets and sent home.

Later Vusi's sister called the family from her place of employment for an update, only to realise that Vusi had not received the proper attention. A telephone call to the clinic confirmed that Vusi had not been seen in the ARV unit. Two more days passed before the family was able to mobilise resources again to get Vusi back to the clinic. This time, with Vusi's sister having taken leave from work so as to be present to assist and advise, they took Vusi to the

ARV unit where he was seen by a doctor and put on co-trimoxazole, an antibiotic commonly used to control opportunistic infections for HIV positive patients (Aidsmap 2008). He was told to return for a CD4 count once he had completed two months' TB treatment. He remains critically ill.

This case study illustrates the tendency to delay testing, and the serious consequences which are associated with a late diagnosis (Tolsi 2007). Routine testing might have saved Nathi's life and improved Vusi's chances by alerting them to their positive serostatus several months earlier. The story demonstrates that clinics may be virtually inaccessible to people whose health has deteriorated too far to allow them to use public transport.

The case study also raises questions about clinic communications systems. Clinics should be equipped to contact each other easily by telephone and fax. It should not be necessary for a member of the public to look up the telephone number of one clinic for another. Nor should a working fax machine be regarded as a luxury for a clinic. In the case of a fax machine being temporarily out of order, it should be permissible to communicate CD4 count results verbally.

Finally, the separation of HIV testing and treatment facilities from standard clinic facilities is confusing to patients and may lead to inadequate intervention. As will be discussed in detail later in the dissertation, it may also contribute to the stigma surrounding HIV.

## **1.10 SIGNIFICANCE OF THE STUDY**

While HIV exceptionalism has been much debated at a theoretical level, this study offers insight into its practical outworking within a clinic setting. Professional nurses employed in the South African VCT context are uniquely poised to offer comment on the question of poor testing uptake. A study by Van Dyk and Van Dyk (2003a:9) concluded that nurses in South Africa already carry a heavy burden in the HIV epidemic, but will be expected to

*“form the backbone of VCT services.”* It is hoped that by giving professional nurses an opportunity to share their insights, this study might not only offer a contribution to the debate on HIV testing policy in South Africa but also acknowledge the valuable role which nurses play in dealing with the HIV epidemic.

On a theoretical level this study examines features of VCT and PITC from a human rights viewpoint. Analysis of the research participants’ perspectives aims to offer comment on whether HIV exceptionalism may be compromising the effectiveness of VCT.

Finally, in Chapter 2 a set of questions derived from the principles of the Belmont Report of 1979 (Zimmerman 1997) is suggested for use in assessing whether a particular model of HIV testing is ethically sound. These questions are applied to the research material generated by this study, but their foundation in human rights makes them more widely applicable.

## **1.11 CHAPTER OVERVIEWS**

In the next section a brief overview is provided of each of the following chapters in order to familiarise the reader with the structure of the dissertation.

### **1.11.1 Chapter 2: Literature review**

Chapter 2 considers the literature on the debate over HIV testing models, focussing on VCT and PITC. It explores the main concerns of human rights activists in relation to HIV testing, and shows why HIV exceptionalism developed. Using a human rights foundation it suggests a framework for analysis of any HIV testing model and sets the background for the research questions.

### **1.11.2 Chapter 3: Methodology**

In Chapter 3 the rationale behind the research design is articulated. The instruments and techniques used for data-gathering and analysis are described, and the procedures undertaken in order to satisfy ethical requirements for a study of this nature are detailed. Nine research participants, including seven professional nurses and two counsellors (one trained and one informal), were interviewed to elicit attitudes on exceptionalist practices within VCT clinics. The study made use of a qualitative, exploratory design.

### **1.11.3 Chapter 4: The research context**

In Chapter 4 the VCT clinics which were visited for purposes of conducting interviews and the characteristics of the research participants are described. Standard clinic procedures of VCT and ART are discussed to enable a better understanding of the milieu of HIV testing and treatment practice. This sets the context for reporting the research findings in the following chapter.

### **1.11.4 Chapter 5: Presentation and analysis of findings**

The interview material is presented in Chapter 5 according to the major themes and sub-themes which emerged during data analysis. Perceived barriers to HIV testing as well as gender-related factors which influence willingness to test are discussed. The effects of stigma and discrimination are considered. Research participants' attitudes to exceptionalist practices currently in operation at VCT clinics are explored. Additional comments made by interviewees are offered to shed light on the question of why some people choose to test and others do not.

### **1.11.5 Chapter 6: Conclusion and recommendations**

Chapter 6 offers the researcher's conclusions regarding the impact of exceptionalism on testing rates as portrayed by the research participants' responses. Based on these conclusions certain recommendations are made regarding HIV policy.

### **1.12 CONCLUSION**

In this chapter, the problems pertaining to HIV testing, with particular reference to HIV exceptionalism, have been introduced. Background information has been provided on the problem of poor testing uptake, as well as the two models considered in this study, namely VCT and PITC. The research problem and the objectives for the study have been named. In the next chapter a detailed review of relevant literature will further acquaint the reader with the concerns surrounding the HIV testing debate.

## **CHAPTER 2: LITERATURE REVIEW**

---

### **2.1 INTRODUCTION**

The emergence of the HIV/AIDS epidemic in countries like France and the United States took place in a context already sensitised to human rights concerns. Both countries had complex histories involving the struggle to define and protect human rights, and these countries had in the 18<sup>th</sup> century produced declarations which became fundamental precursors to international human rights instruments (Human Rights Web 1997). Common to these and later human rights documents such as the Universal Declaration of Human Rights (United Nations Organisation 1948), the African Charter on Human and People's Rights (African Commission on Human & People's Rights 1981) and the South African Bill of Rights (Constitution of the Republic of South Africa 1996) is the assertion of the basic equality of all people before the law, which guards against unfair discrimination.

Notwithstanding this history of attention to human rights, some appalling human rights atrocities were committed during the course of the last century for purposes of research in both Europe and the United States. These resulted in the formulation of three important documents codifying the basic ethical considerations necessary for protection of human rights in research. The Belmont Report of 1979 was the latest of these documents (Zimmerman 2001). Although compiled to provide protection in the context of research settings, the principles of this report are derived from and correspond closely to basic human rights as outlined in various rights documents, including the South African Bill of Rights of 1996 and the African Charter on Human and People's Rights of 1981. The right to health, the right to privacy and the right to equality before the law are enshrined in international human rights instruments, and it is from these rights that the ethical principles are derived.

In this chapter the principles of the Belmont Report are outlined and their relevance to the HIV testing debate is illustrated. The origins and rationale of HIV exceptionalism are then described, and it is demonstrated that the tenets of the Belmont Report underpin the VCT model of testing. The debate over HIV exceptionalism is considered from both sides and the introduction of routine opt-out testing in Botswana is used as a case study. Finally, a framework for analysis of testing models based on the Belmont Report principles is suggested.

## **2.2 HUMAN RIGHTS AND THE BELMONT REPORT OF 1979**

The Belmont Report of 1979 followed the international adoption of two earlier codes written to guide physicians and scientists in the ethical conduct of human research. The Nuremberg Code of 1947 (Zimmerman 1997) was formulated when the atrocities committed by Nazi researchers came to light after World War II. This recognised that the voluntary informed consent of any human subject involved in research is an essential human rights requirement (Family Health International 2007). In 1964 the Declaration of Helsinki was developed by the World Medical Association (WMA). This document added to and improved on the provisions of the Nuremberg Code, in particular highlighting the principle that the well-being of a human research participant takes precedence over the interests of science and of society (Family Health International 2007; WMA 2004).

The United States was not a signatory of the Helsinki Declaration, but it had been the primary sponsor of the Nuremberg Code in 1947 (Zimmerman 1997). Yet the United States government chose to ignore the principles outlined in these documents, and sponsored unethical research with humans in the infamous Tuskegee study. This took place between 1932 and 1972 in the United States and involved, for the purposes of research, the deliberate denial of treatment and information by the United States Public Health Service to black men suffering effects of long-term syphilis infection (Fairchild & Bayer

1999). The Belmont Report was compiled in response to the exposure of these serious human rights abuses. It set forth three universally recognised principles, namely respect for persons, beneficence and justice, to be discussed in the next section.

The Belmont Report was published in 1979 and would have been fresh in the consciousness of human rights activists when HIV and AIDS appeared in the early 1980s. The principles articulated in the Report came to influence the response to HIV/AIDS and to shape the development of the resulting VCT testing model. The well-known “three Cs” of VCT, namely consent, confidentiality and counselling (Csete & Elliott 2006), are underpinned by the universally-recognised principles of human rights articulated in the Belmont Declaration of 1979.

### **2.2.1 Principles of the Belmont Report**

The Belmont Report identified three ethical standards for any research involving human participants, discussed below (US National Institutes of Health 1979). While not making use of the same terminology, these principles are grounded in the rights to health, privacy and equal protection and equality before the law, fundamental rights recognised in both the African Charter on Human and People’s Rights of 1981 and the South African Bill of Rights of 1996.

#### **2.2.1.1 Respect for Persons**

The principle known as “respect for persons” has two components. The first is the recognition of the autonomy of the individual (South African Medical Research Council 2006), which means that competent individuals have the right to make their own choices and decisions about matters that affect them. For example, a researcher may only include a person in a research study on a voluntary basis, with that person’s prior knowledge and consent. Similarly a health care professional may not test a patient for HIV without his or her knowledge and consent. In South Africa, informed consent of the individual

prior to testing is a legal requirement except in cases of anonymous epidemiological screening programmes by health authorities (Van Dyk 2005).

The second component of the principle follows on from this, and states that if an individual is not capable of adequately assessing the factors around which he or she must make a choice or take a decision, he or she is entitled to protection. Examples of such persons are children, the mentally handicapped or those who are incapacitated by illness. Less obvious but not less important are those for whom cultural factors or lack of education place them in a position of being unable to understand and freely choose what is being offered (either participation in research, or treatment options). Respect for these people must be guaranteed despite their incapacity, and researchers and health care workers are required to act in their best interests (US National Institutes of Health 1979).

#### **2.2.1.2 Beneficence**

The principle of beneficence means that the researcher or health care worker must act in the best interests of the participant or patient, and that the well being of the participant or patient must be protected (Family Health International 2007). It encompasses the two concepts of doing no harm and maximising possible benefits while minimising possible risks (Zimmerman 2001).

The South African Medical Research Council's ethics policy distinguishes between these as two separate principles of biomedical ethics, namely: beneficence, which refers to the benefit to the research participant, and non-maleficence which means an absence of harm to the research participant (SAMRC2006). Ethical dilemmas arise when a particular course of action offers benefits to participants but also poses the risk of harm. The principle of beneficence directs that in such a case the benefits should outweigh the risks (Zimmerman 1997).

As with respect for persons, beneficence is a principle rather than a set of guidelines. It requires that the best interests of another person be sought. However, this leaves open to interpretation the judgment of what is “good” or “better” for another person, and this is where conflicts may occur, particularly in a multi-cultural context such as the South African one.

### **2.2.1.3 Justice**

The principle of justice refers to the impartial selection of research participants and the fair distribution of the benefits and risks of research (Zimmerman 2001). It directs that one group within society should not benefit at the expense of another, and access to treatment and intervention should be available equally to all sectors. The principle of justice corresponds to the rights of non-discrimination, equal protection and equality before the law, which appear in Article 1 of the South African Bill of Rights (Constitution of the Republic of South Africa 1996).

Gray *et al* (1995) identify some major ethical dilemmas for HIV/AIDS researchers in the developing world, to which the principle of justice provides guidance. Developing countries often combine features of a generalised HIV epidemic with poorly developed regulatory systems which poses a risk of exploitation, as unscrupulous researchers may be attracted to situations where subjects are readily available but are not well informed of their rights. Researchers may also argue that in settings of generalised HIV epidemics the situation is so severe that normal regulations protecting individuals should be suspended since “*they are going to die anyway*” (Gray *et al* 1995:24). Alternatively the severity of the epidemic means that experimental vaccines are less likely to be “wasted” in these settings than in more developed populations (Gray *et al* 1995). Such examples illustrate the need for careful consideration of and adherence to ethical standards. The next section demonstrates in greater detail what these principles mean in practice.

## **2.2.2 Application of the Belmont Report principles**

Each of the theoretical principles described in the Belmont Report of 1979 has corresponding practical measures to ensure that procedures are ethically correct. These are considered below.

### **2.2.2.1 Informed consent and confidentiality**

The principle of respect for persons is embodied in the informed consent process (US National Institutes of Health 1979). The first step in this process is the disclosure of all relevant information, including the purpose and procedures of research, possible harmful effects, possible benefits, alternative courses of action, and measures taken to ensure confidentiality (Gray *et al* 1995:38). The emphasis is on making certain that the research participant, or medical patient, is fully informed with regard to the nature of the research, the testing procedure or the treatment about to be undertaken.

The second and third steps are to ensure comprehension and voluntariness (US National Institutes of Health 1979). In some instances this may involve written consent forms which the individual reads before agreeing to participate, but in many cases this would prove an inappropriate means of ensuring comprehension and the method should be tailored to the specific setting in question. In a culturally complex country such as South Africa, for example, this step would require a counsellor fluent in the individual's language and with a good understanding of the cultural matters which might have an impact on his or her sense of freedom in making a truly informed choice.

The informed consent process is a very important practical application of the principle of respect for persons. However as Gray *et al* (1995:62) point out, no set of guidelines can replace basic ethical common sense: *"Informed consent formalities are a necessary but not sufficient means of safeguarding*

*the interests of participants. Informed consent procedures must necessarily go beyond mere formalities if those interests are to be protected adequately.”*

Incorporated in the process of informed consent, and yet standing on its own as one of the cornerstones of ethical research and practice, is the principle of confidentiality (Family Health International 2007). Confidentiality refers to the management of privileged or confidential information imparted by a client or patient to a professional caregiver within a situation of trust (Patania 1998). It stems from the “right to privacy” regarded as a universal human right and embedded in Section 14 of the South African Bill of Rights which states: *“Everyone has the right to privacy, which includes the right not to have the privacy of their communications infringed.”*

Confidentiality is a central aspect of professional relationships in the fields of medicine, psychology, psychiatry and social work (Boyd 1992; Patania 1998). Through the creation of an atmosphere of trust between a professional caregiver and the client, the client is able to communicate information of a private and intimate nature in the belief that this information will be protected and will not be allowed to pass to a third party without his knowledge and consent. Confidentiality carries an ethical as well as a legal obligation on the part of the professional (Patania 1998).

The principle of confidentiality is regarded as *essential* but not *absolute* (UNAIDS 2000:11). Amongst experts in socio-medical ethics it is commonly recognised that there are some important exceptions to the rule (Family Health International 2007; Gray *et al* 1995; Patania 1998), although not all agree which situations call for the exception. In general, however, researchers and health care professionals concur that there may be a moral obligation to break confidentiality in the case of a third party who is known to be at risk of harm at the hands of the client or patient. This is known as the “Tarasoff principle” or “duty to protect” (Patania 1998:251). It is nonetheless seen as a last resort, to be used only after all other avenues have been pursued.

Within the HIV/AIDS context, confidentiality applies to knowledge of an individual's serostatus, and requires that an individual's informed consent be obtained before communication of this knowledge to others (UNAIDS 2000:30). The process of informed consent must ensure that the individual understands the degree of confidentiality being offered, whether in a research study, an HIV testing procedure or a particular treatment approach. This involves making the person aware of any possible limitations to confidentiality (Family Health International 2007). For example, will test results be shared with other staff members? What course of action will be followed if a person tests positive but declines to inform sexual partner(s) of his or her status, even after counselling?

As will be seen later in the chapter, in the South African HIV/AIDS context there is not universal agreement as to how the principle of confidentiality should be implemented. Some argue that offering a strict guarantee of confidentiality is the only way to protect HIV positive people from the stigma and discrimination which are currently so devastating (Human Rights Watch 2007). Others argue, conversely, that confidentiality is frequently manifest as secrecy, which is harmful (UNAIDS 2000:11). Confidentiality is seen as one of several ethical principles which need to be kept in balance. When it is applied inappropriately an atmosphere of secrecy may be created which, it is argued, exacerbates stigma and discrimination (Cameron 2006; Natrass 2004; Seidel 1996).

#### **2.2.2.2 Assessment of risks and benefits**

The application of the principle of beneficence requires a systematic analysis of the risks and benefits associated with a particular research study or health care intervention (Gray *et al* 1995; US National Institutes of Health 1979). This is relevant to the question of whether an individual chooses to disclose his or her serostatus. The potential benefits of disclosure of a positive test result (for example access to treatment and support from friends and family members) must be balanced against the risks (possible rejection by friends and family and possible discrimination in the workplace).

Assessment of risks and benefits can also be applied in measuring the appropriateness and efficacy of an HIV testing model. The principle of beneficence requires that risks and benefits should be balanced. *“In general, risks to the subject should be outweighed by the sum of anticipated benefits to the subject and to society”* (Zimmerman 1997:4). HIV testing services should therefore be structured in such a way that any risks posed to patients in making use of them are more than balanced by the benefits offered.

### **2.2.2.3 Fair distribution of risks and benefits**

The application of the principle of justice requires the fair distribution of risks and benefits at the levels of both individual and society, and states: *“An injustice occurs when a benefit to which a person is entitled is denied without good reason or when an excessive burden is imposed”* (Zimmerman 1997:3).

With respect to the question of HIV testing models, application of the principle of justice suggests that the benefits of testing, i.e. access to treatment and support, should be equally accessible to all individuals. No one should be denied the advantages offered by testing and treatment, nor should the process of accessing such testing and treatment impose on the recipients an excessive burden.

An illustration of one area within the HIV/AIDS context where the principle of justice is not adhered to is that of paediatric research and treatment. Because AIDS in children is not a significant problem in the developed world, it attracts little attention or funding for research (Nolen 2007). Testing procedures and medicines specifically for children are not readily available. Yet in African countries, children make up a significant percentage of the HIV positive population. For example, of the 2.6 million children living with HIV worldwide, 90% are Africans (Nolen 2007).

South Africa is one of the few countries in the world with a rising infant mortality rate due to the HIV/AIDS epidemic (Kahn 2007). Because of their

immature immune systems, children who are HIV positive are less able to cope with the impact of opportunistic illnesses and half of all HIV-infected children die before they reach their second birthdays. Children are at a disadvantage in the areas of both testing and treatment. Tests suitable for babies (up to the age of 18 months) are far more expensive than those used for adults (\$120 compared with \$2). Paediatric ARVs have only recently become available and generally require refrigeration, an unavailable luxury in poorer homes. Paediatric ARVs are also exorbitantly priced, costing between five and twelve times more than the same treatment for adults (Nolen 2007:204).

Prejudice in the way the benefits of research are distributed in the field of paediatrics is just one example of how the principle of justice has been breached in HIV/AIDS testing and treatment. Later in the chapter the question will be asked whether the current testing approach adequately adheres to this important principle.

### **2.2.3 Principles in conflict**

Application of the principles identified in the Belmont Report of 1979 can in practice lead to serious disagreements amongst health experts and human rights activists who perceive their goals to be mutually exclusive. In this regard Boyd (1992:173) mentions: *“The moral reasons for maintaining or breaching medical confidentiality have not been changed by the advent of AIDS. HIV infection, however, has the potential not only to create a medical pandemic, but also to provoke social prejudice. This makes it especially important to protect patients with HIV infection or AIDS from casual or unintentional breaches of confidentiality. At the same time, the need to control the spread of infection makes it vital that maintaining confidentiality should serve the common good as well as that of the individual patient. In some cases these goals may be, or may be perceived to be, in conflict.”*

The two requirements of serving the common good as well as that of the individual lead to many ethical dilemmas in the area of HIV testing. This tension is manifest in questions such as:

- Whether HIV/AIDS should be made a notifiable disease. In South Africa this is an old debate that was recently reopened at the African National Congress Conference in June 2007 (African National Congress 2007).
- What the moral imperatives are surrounding the benefits and risks of disclosure versus non-disclosure of HIV serostatus. This is another area of ongoing dispute with strong arguments on each side (UNAIDS 2000; USAID Synergy Project 2003),
- Which model of HIV testing best serves the interests of both the individual and public health, a question at the centre of this research and pivotal to the discussion on HIV exceptionalism (Richter 2006; WHO 2007).

These questions embody a dissonance between the principles of respect for persons, beneficence and justice, as the protection of confidentiality for one individual may result in an unfair burden being placed on other individuals through becoming infected unnecessarily with HIV. Health care practitioners find themselves faced with a moral dilemma when put in the position of having to allow people to remain ignorant of their status when their symptoms suggest they are infected with HIV, and when treatment is available (Leitch 2003).

In this part of the chapter the three basic principles of ethics expounded in the Belmont Report of 1979 and founded in universally recognised human rights have been reviewed and illustrated. The concepts and language of these rights are essential to the development of an understanding of the origins and rationale of HIV exceptionalism, which will be discussed in the next section.

## **2.3 EMERGENCE OF HIV EXCEPTIONALISM**

The origins and rationale of HIV exceptionalism are discussed in this section. Benefits which have accrued from an exceptionalist approach are acknowledged, and the debate around exceptionalism in the literature is explored and considered with special attention to the practical implications for HIV testing as manifest in distinctions between VCT and routine opt-out testing.

### **2.3.1 Origins**

AIDS emerged in the United States in the 1980s as a disease amongst gays and injecting drug users. The stigma and discrimination associated with a positive diagnosis were intense, and public attitudes were unsympathetic (De Cock *et al* 2002). There were several reasons for this. Firstly, its association with members of already stigmatised groups meant that infection with HIV inherited the negative social attitudes already held about those groups (Skinner & Mfecane 2004). Secondly, little was known about the disease, how it was transmitted or how to treat it (De Cock *et al* 2002). This ignorance bred fear and hatred, which were directed toward HIV positive people in these already stigmatised groups.

The shocking disclosure of the Tuskegee study, which gave rise to the Belmont Report of 1979 (Zimmerman 1997), was a recent event as the HIV/AIDS epidemic came to light, and awareness of human rights in medical contexts was heightened. Application of a traditional public health approach to manage the HIV/AIDS would have involved mandatory testing, notification, contact tracing, quarantine and directly observed therapy (Kippax 2005). Because of the link with groups already vulnerable and stigmatised yet with highly articulate activist members (De Cock *et al* 2002), there were compelling reasons not to apply this standard model of disease management. Firstly, health care professionals were motivated by concern for their patients'

wellbeing and correctly foresaw how the introduction of coercive measures would curtail patients' access to medical assistance (Cameron 2006). Fear of being identified through testing and the subsequent discrimination would keep people from seeking medical help. Secondly, no cure or treatment was available. Widespread testing in the absence of any form of treatment was thought to offer little value (SAIIA 2004) and appeared unnecessarily punitive (Cameron 2006).

Thirdly, it was evident to health care professionals as well as public health officials that there was a great risk of driving the epidemic underground if coercive measures were enforced (Bayer & Fairchild 2006). This would be harmful to HIV positive patients themselves but would also increase the possibility of spreading the epidemic to others in the risk categories. Finally, the epidemic was not thought to pose a significant danger to the general population because its concentration amongst minorities as well as its primary mode of transmission through sexual contact made it easy to avoid (Iliffe 2006).

By the late 1980s discussion of HIV and AIDS began to involve human rights concepts (De Cock *et al* 2002:68), as it became evident that epidemiological differences in the pandemic were linked to vulnerability arising from conditions of gender and poverty. Public health officials and advocates of human rights came to be seen as opponents in the debate on rights versus disease containment. De Cock *et al* (2002) refer to an "unusual coalition" which developed amongst the gay community, medical and health care practitioners and proponents of civil liberties to avoid the adoption of public health prevention measures which might increase discrimination against already stigmatised groups. This alliance effectively placed a shroud of secrecy and anonymity over the diagnostic process and led to an "exceptionalist perspective" (Bayer & Fairchild 2006:648).

The term "HIV exceptionalism" was first used in 1991 by Ronald Bayer to refer to the special or unusual way in which HIV/AIDS was treated in comparison with other sexually transmitted or lethal infectious diseases (De Cock *et al*

2002). He noted that the exceptionalist approach was applied in areas of HIV testing, surveillance and contact investigation. Whereas in the case of infectious diseases such as syphilis or hepatitis B, consent for testing is regarded as implicitly assumed when a patient presents for a medical consultation, for HIV and AIDS there was always an emphasis on the importance of counselling, confidentiality and the informed consent process. These “three Cs” (Csete & Elliott 2006) which are foundational to the current HIV testing policy of VCT are rooted in the principle of respect for persons.

However, the definition of HIV exceptionalism given below hints at the problems of polarity between public health authorities and human rights activists which have existed since the earliest days of HIV and AIDS:

**HIV exceptionalism.** Public health. *A stance in which health care policies favour the rights for privacy of HIV-infected individuals over concerns for public safety.* (McGraw-Hill Concise Dictionary of Modern Medicine 2002)

The perceived conflict between public health and human rights led to the development in industrialized countries of an exceptionalist approach to HIV. This stance toward HIV infection was not seriously contested in countries which were more heavily affected with HIV, and so exceptionalism became the global standard (De Cock *et al* 2002; Iliffe 2006). In the following section the way in which HIV exceptionalism was transferred to the South African setting is explored.

### **2.3.2 HIV exceptionalism in the South African context**

HIV exceptionalism emerged in the United States out of concern that coercive public health measures, applied to HIV/AIDS within the minority gay and drug communities, would lead to stigma and discrimination and thus drive the epidemic underground (De Cock *et al* 2002). The VCT model was developed in the mid-1980s in response to these concerns (SAIIA 2004), and was adopted in South Africa, for use in what would later be recognised as a very

different context (Ilfie 2006; Thornton 2008). In fact, adoption in Africa of the disease-management strategies designed by Western countries for their own much smaller epidemics has been described as “*one of the most striking modern examples of globalisation*” (Ilfie 2006:65).

The reasons VCT was implemented in South Africa are several and varied. Firstly, as South Africa’s own HIV epidemic began, the country was in the process of leaving behind a history of repression and human rights abuses. It made sense to introduce testing measures that emphasized individual freedom and moved away from coercion. Many of the same people who had fought for political freedom took up the cause of protecting people infected with HIV or living with AIDS. For example in 1992 the HIV and AIDS Charter was drawn up by a group of political activists and was founded on the Freedom Charter (Thornton 2008). This served to entrench a politicised approach to AIDS which encouraged exceptionalism and “*prevented the possibility that AIDS might be seen as a disease like any other,*” something which Mandela pleaded for (Thornton 2008:123). In the same year the WHO passed a resolution that no public health rationale existed for limiting individual freedoms through mandatory testing (Ilfie 2006).

Secondly, South Africa’s new leaders compared the country to the developed west, rather than to countries to the north (Thornton 2008). Uganda’s response to the HIV/AIDS crisis was decentralised and informal, and yet remains an arguably instructive example of a country which sought appropriate solutions to the emerging health crisis (Epstein 2007; Ilfie 2006; Thornton 2008). South Africa, by contrast, was influenced by international health organisations who introduced VCT in the country roughly a decade after it had emerged in the US (SAIIA 2004).

Thirdly, when VCT was introduced to South Africa, no treatment was yet available. It was thought that widespread testing for HIV in a medical context served little purpose (SAIIA 2004). Thus, the early testing sites were largely in non-medical settings. AIDS Training, Information and Counselling Centres (ATICCs) offered counselling and testing services (Birdsall *et al* 2004), but

overworked clinics and hospitals battled to meet the counselling requirements of VCT (SAIIA 2004). This separation of HIV testing from other medical services persists today even at VCT clinics, as will be seen in later chapters.

In the next section the literature on the ongoing debate over exceptionalism will be reviewed, with particular reference to the South African context.

## **2.4 THE DEBATE ABOUT EXCEPTIONALISM**

HIV exceptionalism has critics and defenders and both sides have debated their positions convincingly. Their arguments are outlined below, but attention is first given to the undeniable benefits which have resulted from the exceptionalist position. These have been identified in the literature by several of the strongest critics of exceptionalism, notably Cameron (2006), De Cock & Johnson (1998) and Frieden *et al* (2005).

### **2.4.1 Benefits of HIV exceptionalism**

Significant advantages have resulted from the exceptionalist approach to HIV and AIDS. De Cock and Johnson (1998) write of the enhanced autonomy and confidence of patients as they have taken choices about their own health that were previously made for them by medical professionals. They remark on the improved communication between patients and doctors and increased respect for principles of informed consent and confidentiality. Taking stock of these gains, Cameron (2006) asserts that the exceptionalism of HIV and AIDS has had a beneficial influence on what is now regarded as normal for all diseases.

The exceptionalist approach has also meant that HIV/AIDS has attracted considerable resources for research and funding (Frieden *et al* 2005). The focus on the epidemic as unique, special and apart from other medical conditions has meant that funding for HIV prevention and AIDS treatment is

frequently prioritised, instead of having to compete for attention with other causes (England 2008; Frieden *et al* 2005).

Despite these obvious gains, HIV exceptionalism attracts considerable criticism. Some detractors assert that exceptionalism never was the correct response to the HIV epidemic or has outgrown its usefulness now that treatment is available (Bayer & Fairchild 2006; Halpern 2005), while others argue that exceptionalism represents a Western approach and is inappropriate and unsuitable in the African context (Iliffe 2006; Thornton 2008).

#### **2.4.2 Criticism of exceptionalism**

Critics of HIV exceptionalism argue that it has deep inconsistencies and inadvertently hurts the very people it is trying to protect (Bayer & Fairchild 2006; Cameron 2006; Danziger 1996; De Cock *et al* 2002). They claim it is not well-adapted to the African HIV context, which is characterised by a generalised heterosexual epidemic and quite unlike the setting which first gave rise to exceptionalism (De Cock *et al* 2002; Iliffe 2006; Thornton 2008). They believe exceptionalist practices are responsible at least in part for poor testing uptake (Frieden *et al* 2005), and argue that strict exceptionalist practices should give way to an approach of routine opt-out testing in order to save lives by making treatment more widely available (Kamya *et al* 2008).

Several authors have identified an inherent contradiction within HIV exceptionalism (Cameron 2006; Danziger 1996; De Cock *et al* 2002). They point to the unusual treatment of HIV and AIDS as a strong factor in enhancing rather than reducing stigma. The very practices which are implemented to protect patients from stigma and discrimination (strict adherence to voluntarism, informed consent and pre-and post-test counselling) may inadvertently increase stigma by drawing unwanted attention to patients. This inconsistency, whereby a human rights point of view actually *undermines* human rights, is discussed in detail by De Cock *et al* (2002: 68-71). They demonstrate that a reluctance to address HIV and AIDS as a public

health and infectious disease issue increases vulnerability to HIV both at an individual level and at the level of society. They argue for the infected person's right to privacy to be weighed against the rights of the uninfected not to be infected. They also draw attention to the rights of the infected person to be diagnosed in time to receive treatment.

Danziger (1996) noted as early as 1996 a growing recognition of inherent weakness in a strictly voluntarist approach. She argued that by denoting measures which were essential to health "elective" or voluntary, the most vulnerable sectors of society were disadvantaged. Women in some cultures, for example, may not be in a position to negotiate the use of condoms. Similarly, the very voluntariness of VCT may be in question for some, as is discussed in Chapter 5 of this dissertation.

Edwin Cameron, one of the founders of the HIV and AIDS Charter of 1992 (Thornton 2008), was originally in favour of an exceptionalist approach which he regarded as providing essential protection from the effects of external stigma and discrimination. However, more recently he has argued that the basic rationale for the exceptionalist approach has been eroded as conditions have changed. In situations where treatment is available, *"the exceptionalisation of HIV, designed to protect from needless discrimination, may constitute a barrier to diagnosis and treatment"* (Cameron 2006:7). In his view, ongoing exceptionalist practices contribute to and reinforce the *"internal dimension of stigma"* (Cameron 2006:5). This has significant implications for testing uptake since stigma is a major barrier to testing (Leitch 2003; Skinner & Mfecane 2004). As UN Secretary-General Ban Ki Moon has said (AVERT.org 2008c): *"Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world."*

### 2.4.3 Poor uptake of VCT in South Africa

Cameron (2006:8) argues that testing protocols such as those for VCT, although intended for the protection of patients, “*may be colluding with the patient’s inner fear and denial, with all too often fatal consequences*”. He sees this as compromising the principle of beneficence, which requires the health care provider to give accurate, early diagnosis of a treatable condition to the patient. Others have also voiced their concerns that VCT has not fulfilled its promise to make testing truly accessible, or is in fact to blame for the current low levels of testing. Frieden *et al* (2005:2397) warn that “25 years into the epidemic, progress is stalled”. These authors and others (Kamya *et al* 2008) urge a reconsideration of the current testing model. They call for a normalisation of the understanding of the epidemic and a move to a routine opt-out testing approach.

Dr Francois Venter, president of the SA HIV Clinicians Society, recently urged an approach of confidential mandatory testing based on his experience that most patients learned of their HIV infection only on their deathbeds (News 24.com 2006). Dr Venter asserted that ignorance, in this case regarding serostatus, could not be regarded as a human right. A similar statement was heard from a completely different quarter when Titus Kgatoke, secretary of an Ndebele initiation school near Johannesburg, was quoted as saying “*HIV testing in our ingoma is a prerequisite. You need to know your status, it is not negotiable*” (Flanagan 2006).

A number of service-related barriers as well as psychosocial barriers have been identified as posing problems for VCT in South Africa (Van Dyk & Van Dyk 2003a; Van Dyk & Van Dyk 2003b). Psychosocial barriers highlighted in the research include poor counselling services, lack of confidentiality, lack of follow-up services, problems of access, lack of incentive to test and fears that knowledge of HIV status might hasten death (Van Dyk & Van Dyk 2003a). Participants in this study said they would prefer to visit a VCT centre where they would not be known. An associated investigation identified uncertainties related to confidentiality, disclosure and rejection as posing obstacles to

people's use of VCT services (Van Dyk & Van Dyk 2003b). Such fears are exactly what the VCT approach is designed to mitigate, and it is a matter of concern that these apprehensions are not being adequately dealt with, suggesting a fault either in design or implementation of VCT services.

Research conducted at the outpatient department of McCord Hospital near Durban showed that many HIV-infected patients who make contact with health care services are not being referred by doctors for testing, or are not following through with the referral (Bassett *et al* 2007). Routine testing was introduced on an experimental basis for a 12-week test period following a 14-week "standard of care" period. The numbers of patients who accepted testing and the numbers of new cases of HIV infection identified during the "standard of care" period and the test period were measured and compared. The researchers concluded that a routine voluntary approach to HIV testing led to significantly higher rates of detection of HIV positive patients, and recommended that a routine opt-out strategy be practised more widely (Bassett *et al* 2007).

#### **2.4.3 Defence of exceptionalism**

The rationale for expanding or modifying VCT to include a routine opt-out testing approach is the fact that poor uptake of testing means that people do not access treatment in time (Bassett *et al* 2007; IRIN 2007; Richter 2006). Defenders of exceptionalism and a strict voluntarist approach to testing are aware of this concern (Csete & Elliott 2006) but claim exceptionalism is still warranted because the disease is not yet normalised. They say a routine approach incorporates potential for violation of human rights because of a diminished emphasis on informed consent (Rennie & Behets 2006).

Kippax (2005) warns that moving toward a traditional public health approach would be a mistake. She fears that routine opt-out testing would in effect become mandatory testing. Kaldor and Millwood (2005) frame questions about the effect of socio-cultural factors on the informed consent process, and ask whether people really would be free to opt in or to opt out. Rennie and

Behets (2006) argue that a model of routine testing could violate rights because many people in resource-poor settings do not have the liberty to say “no” or to opt out.

Authors Csete and Elliott (2006), writing for the Canadian HIV/AIDS Legal Network, acknowledge that poor testing uptake is a concern but warn that increased testing uptake should not be a goal in itself. They fear that knowledge of serostatus in the absence of well-developed medical and counselling support services could be more harmful than beneficial. They mention depression, suicide, abandonment and violence as possible negative outcomes (Csete & Elliott 2006:6). Buchanan (2005) similarly urges sensitivity in the approach to HIV testing, and warns against scaling up testing at the cost of human rights.

#### **2.4.4 Which rights matter most?**

Kamya *et al* (2008) point out that the right to opt out of testing is not the only right that matters. Additional rights to consider are the rights of people *not to be infected* by others, as well as people’s right to health which includes the right to receive care and treatment for opportunistic infections even in the absence of ARVs, something which a routine model would enable. Brewster (2007:60) predicts that in Britain: “*A court may soon find that the right to be born free of HIV infection outweighs all other considerations.*”

Csete and Elliott (2006:9), arguing for adherence to a strict voluntarist approach, assert that people should have the right to consent to a medical procedure which has “*great consequences in their lives*”. However, this position seems to overlook the fact that *not* choosing such a medical procedure can also have great consequences, for the individual concerned and also for sexual partners, children infected through mother-to-child-transmission, and family members and health care staff who must assist the infected individual when AIDS leads to severe illness and death (Kamya *et al* 2008; Nolen 2006; SAIIA 2004).

Csete and Elliott's (2006) insistence that people may not be able to handle the knowledge of their serostatus, and so should not be given too much encouragement to know their status is suggestive of paternalism, as illustrated in the following quote by a Zimbabwean doctor (Nolen 2006:3): "*You can't say that because a woman is poor and African, she is not capable of truly consenting to a test she is offered.*"

Metz (2005:405) presents a detailed defence of routine testing from a human rights point of view. Arguing from the principle of respect for persons Metz asserts that "*routine testing is morally justified because it is necessary to fulfil citizens' right to health care.*" He goes on to argue that routine testing is morally justified even in instances where treatment is not yet available, since it informs people of their serostatus and may help diminish transmission. He maintains that routine testing is "*likely to achieve these ends*", and that no other means could realize the same goals.

Finally, the debate about testing models is often cast as a choice between rights and coercion (Aidsbuzz.org 2008a). This is an unnecessary and false dichotomy according to Cameron (2006) and De Cock *et al* (2002) who argue that routine testing should be introduced not in spite of risks to human rights, but because of risks to human rights. Dr Eric Goemaere, medical co-ordinator for Medecins Sans Frontieres (MSF) in South Africa, in a recent interview about the integration of HIV and TB services at clinics in the Western Cape argued that the advantages of a routine, opt-out approach in this context far outweigh the potential disadvantages (MSF 2008).

#### **2.4.5 The costs of inaction**

A compelling reason for finding a strategy to encourage testing is the consequences of inaction. The United Nations predicted that unchecked the HIV epidemic would result in 20 million orphans in sub-Saharan Africa and a labour force diminished by some 35% by 2010 (SAIIA 2004). In terms of medical costs, HIV is cheaper and easier to treat when diagnosed early and before complications arising from opportunistic illness set in (IRIN 2008b).

Despite increased staffing costs, a routine approach has been found by studies in the United States to be cost-effective because early detection saves on health care expenditure (Frieden *et al* 2005; Medscape 2008).

## **2.5 THE EXAMPLE OF BOTSWANA**

In 2004 Botswana became the first African country to introduce a policy of routine opt-out testing (AVERT.org 2008a). This was in response to continued low uptake of testing and treatment even though anti-retroviral treatment had been made available since 2002 through the national health programme (Smart 2006b). Health care workers and experts in the field of HIV became convinced that stigma would be better combated by introduction of a routine approach rather than simply relying on education and provision of information (Smart 2006a). In addition, according to Ernest Darkoh, head of the retroviral programme (Leithead 2004:1): *“People were assuming that if they had seen a doctor, the doctor would have told them if they had AIDS. They presumed they had been tested.”*

A recent study by Weiser *et al* (2006) indicated that the routine approach in Botswana appears to be widely supported and is making a difference to stigmatising attitudes. Ongoing education and information campaigns remain a priority, but routine testing addresses the need for stigma-reducing efforts at a structural level (Smart 2006a). Similarly, Steen *et al* (2007) reported after two and a half years of routine testing in Botswana that a rapid scale up of testing had been accompanied by wide acceptance of the routine approach with no accounts of adverse effects.

In this model the burden for initiating testing is shifted from the patient to the health care provider and limited pre-test counselling is offered, with greater emphasis being placed on post-test counselling. Patients are provided with essential information on HIV, and informed of their right to refuse the test which is otherwise routine (Weiser *et al* 2006). Weiser *et al* (2006) report that a majority of their respondents indicated favourable attitudes toward routine

testing, as well as the perception that it led to decreased HIV/AIDS-related discrimination and increased testing uptake. In support of this Zembowicz (2008:2) suggests that: *“By transforming HIV testing into a common hospital procedure rather than a specialized service, the social stigma of infection is slowly dissolving.”*

Botswana provides a useful example of the process of normalisation of HIV through adopting a routine opt-out approach to testing. As more people are tested and learn their status, the levels of stigma in society are expected to decrease (Richter 2006). Former president, Festus Mogae, under whose leadership the country introduced routine testing, was recently awarded the Mo Ibrahim Prize for Achievement in African Leadership in recognition of his visionary contribution on the issue of HIV/AIDS (Dugger 2008).

## **2.6 A SUGGESTED FRAMEWORK FOR AN ETHICAL ANALYSIS**

Respect for persons means that the informed consent and protection of confidentiality must be allowed for in any ethics-based testing model. Furthermore, since testing is the entry point to treatment, the effectiveness of a testing model can be assessed by its ability to make ART accessible, in line with the principle of beneficence. The principle of justice requires that health care benefits should not be denied without good reason, nor should an excessive burden be associated with accessing them. If a particular model of HIV testing effectively discourages testing through use of stigmatising procedures, then it might be said to be in contravention of ethical requirements.

Based on the principles of the Belmont Report of 1979, the following three questions are suggested for use in this dissertation in assessing whether an HIV testing model is upholding basic human rights:

1. Does it rely on voluntary participation, and does it follow the informed consent process, by providing information in a manner which enables comprehension?
2. Does it balance risks and benefits, by providing a sufficient return on health-seeking behaviour to compensate for possible risks? Do the promised benefits outweigh the risk of harm?
3. Does it deny to any group of people the benefits to which they are entitled, or does it place on them an excessive burden?

These questions will be considered again in the final chapter once the findings of the research have been presented.

## **2.7 CONCLUSION**

This chapter has explored the context of the debate over HIV testing, illustrating that while in theory VCT adheres to basic ethical principles, in implementation there may be a conflict which is producing unintended negative consequences (Cameron 2006; De Cock *et al* 2002). Specifically, the measures which were designed to protect people from the effects of stigma may be inadvertently increasing stigma and thus acting as a barrier to testing uptake (Leitch 2003). Furthermore, at present many HIV infected people who make contact with the health system are not being tested for HIV, which means opportunities for intervention are lost (Bassett *et al* 2007).

For these reasons there is a growing acceptance of the need for “*re-conceptualisation of the requirements for consent*” (Bayer & Fairchild 2006:647). PITC, or routine opt-out testing, as outlined in the recommendations issued by the WHO (2007) is supported by many experts in the field of HIV (Basset *et al* 2007; Cameron 2006; Kanya *et al* 2008; MSF 2008) even though some human rights activists express concern over whether it may lead to rights abuses (Csete & Elliott 2006; Rennie & Behets 2006).

Botswana's example shows that implementation of a routine testing approach, alongside measures to ensure true informed consent and protection from discrimination (Richter 2006; Weiser *et al* 2006) can have a significant impact in normalising attitudes to HIV and encouraging testing uptake.

Through a review of the relevant literature this chapter has demonstrated the need for appropriately addressing the barriers which keep people in South Africa from accessing HIV testing and treatment services. In so doing it has provided a background to this study of the perceptions of nurses and counsellors regarding exceptionalism in current policy and practice.

## **CHAPTER 3: RESEARCH METHODOLOGY**

---

### **3.1 INTRODUCTION**

Despite the availability of ARVs, many people who are HIV positive do not access treatment in time to prevent serious illness or death. Since testing is regarded as the gateway to treatment (Nieburg *et al* 2005; Rennie & Behets 2006;) there is an urgent need to explore why people are reluctant to be tested, and to find ways to increase testing uptake and concomitant ARV initiation. Professional nurses employed at VCT clinics are in a unique position to provide comment on the reasons why people delay or avoid testing, as they are located between the patients and the larger health system. In this study, professional nurses were interviewed to explore their views on poor testing uptake, with the purpose of informing HIV testing policy.

This chapter describes the design and methodology employed in the study. The selected research design, sample type and sampling procedures and techniques for data collection and analysis are reviewed. Attention is given to the process of gaining permission to conduct the research. Ethical considerations and issues pertaining to the rigour and trustworthiness of the study are discussed, and consideration is given to strengths and weaknesses inherent in the design.

### **3.2 RESEARCH DESIGN**

A qualitative, exploratory research design was chosen to survey the perspectives of professional nurses employed in VCT clinics in Pietermaritzburg and surrounding districts. Qualitative research was a natural choice since the intention was to seek an explanation for a social phenomenon (Hancock 1998). Although the question of different testing approaches has been much debated at a theoretical level, little empirical

research has been conducted in South African clinics. For this reason exploratory research was appropriate.

Grounded theory offers a methodology well-suited to understanding the type of social phenomenon which is the focus of this research (Hancock 1998; Ryan & Bernard 2000). Two of the most common data-collection techniques described in grounded theory are interviews and observation (Hancock 1998; Pope *et al* 2000). This study made use of face-to-face interviews with participants in a small purposive sample, and engaged an interview schedule as the research instrument. The interview schedule was chosen in preference to a formal questionnaire because it offered more flexibility, which is a hallmark of qualitative research (Holloway 2003). Meeting the participants face-to-face gave the researcher an opportunity to view the clinic milieu first hand, and to witness the participants' working environment. This enabled a process of direct observations on the part of the researcher, which would have been absent from the study if a telephone interview or mailed questionnaire had been used instead.

The study made use of constant comparative analysis, an important feature of grounded theory which allows emergent data to guide the research process (Hancock 1998; Pope *et al* 2000). Finally, data analysis was accomplished by the classic grounded theory methods of theme analysis and the building of a codebook (Ryan & Bernard 2000).

### **3.2.1 Delimitation of the study**

The proposed units of observation in this study were professional nurses employed at primary health care clinics (PHC clinics) and community health centres (CHCs) in the uMgungundlovu district. The uMgungundlovu Health District administers seven municipalities in the Pietermaritzburg area where the research was conducted, and there are currently 240 professional nurses employed at provincial clinics within the district (KZN Health Department 2008b).

There were several reasons for choosing to interview professional nurses rather than doctors. Firstly, they are present at the clinic every day, whereas many clinics have a doctor only once a week. This meant the nurses were more easily accessible for interviews. Secondly, because of their regular presence at the clinics nurses would be in a better position to comment on the day-to-day clinic routines and practices of HIV testing and treatment, which are of relevance to the study. Thirdly, although their training places them at a different level to most of the patients who attend the clinics, it is likely that the professional nurses are more aware than doctors might be of the attitudes and feelings of members of the communities which the clinics serve. Professional nurses are thus well located to provide perspectives on the question of whether HIV exceptionalism is having an impact on testing uptake.

For reasons discussed later on in the chapter, two additional participants falling outside of this delimitation were also interviewed. One was a trained VCT counsellor employed at one of the clinics, and the other was an informal workplace counsellor known to the researcher. Although they did not match the selection criteria, they expressed a willingness to be included in the research and their interview transcripts were thought to offer a meaningful contribution to the study. The qualitative nature of the research design and its orientation within grounded theory allow for such flexibility, as long as the inner coherence and consistency of the study is not compromised (Holloway 2003).

### **3.2.2 Geographical area**

Pietermaritzburg, the capital city of KwaZulu-Natal, is situated in the uMsunduzi municipality. uMsunduzi is the largest of seven municipalities or sub-districts administered by the uMgungundlovu Health District. Permission was granted by the district to conduct interviews at any of eleven PHC clinics or CHCs, five of which were within the uMsunduzi municipality and the other six each representing a smaller municipality. Interviews were conducted at seven of these health institutions, three of which were CHCs and the other four PHC clinics. Four of the institutions fell within the uMsunduzi

municipality, and the other three were in the municipalities of uMshwati, uMgeni and Mpopana. The seven clinics which were visited for purposes of

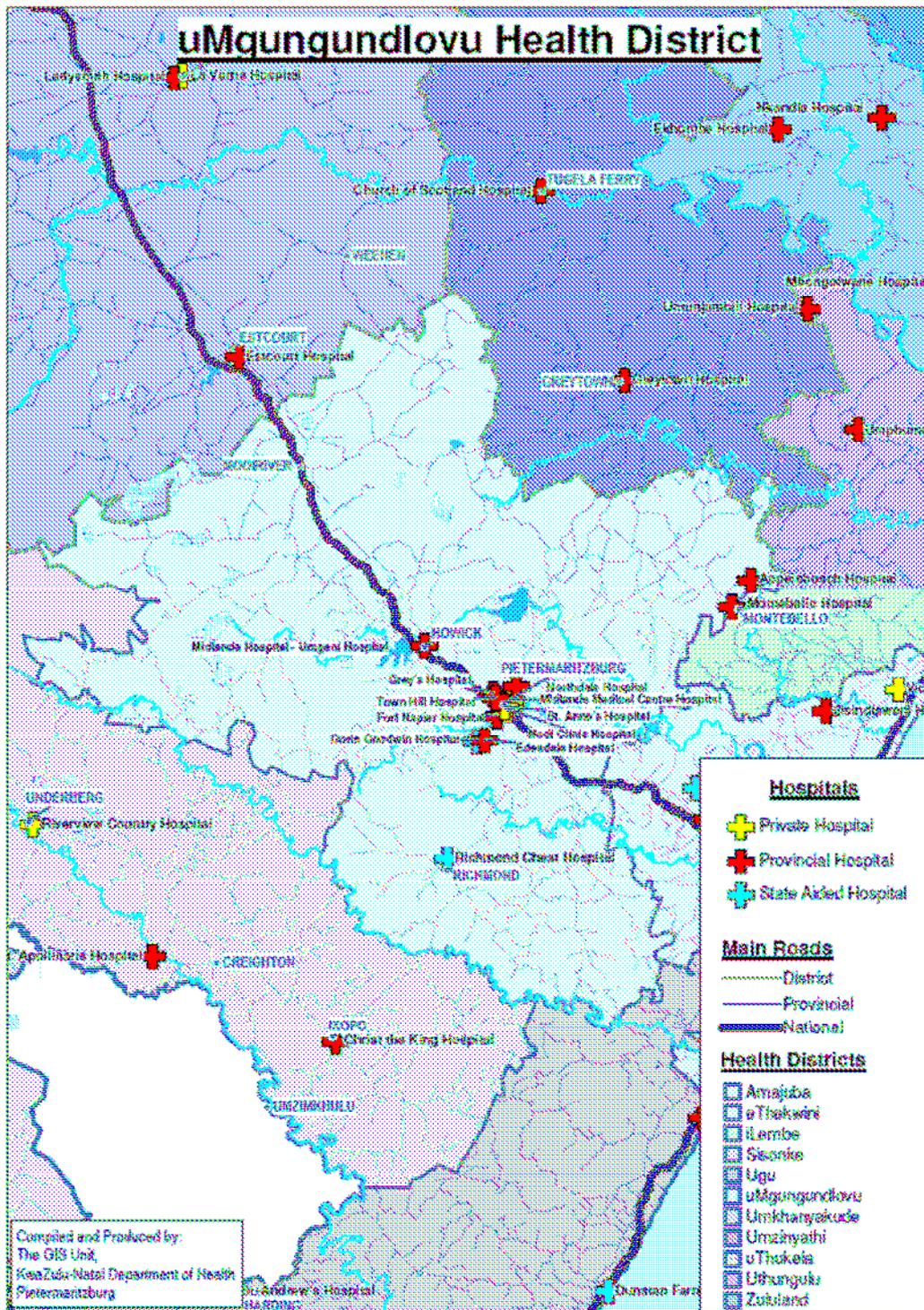


Figure 1: Map of uMgungundlovu Health District (KZN Health Department 2008c)

interviewing were not selected out of the eleven designated clinics on the basis of any particular criteria. Making contact with specified staff members at

certain clinics proved to be difficult, and so the clinics where the correct staff member could be reached more easily were those where appointments for interviews were made.

### **3.2.3 Strengths and weaknesses**

A major strength inherent in this research design was the flexibility offered by semi-structured interviews which enabled the researcher to elicit more in-depth responses than would have been possible otherwise. The face-to-face element meant the researcher was certain of who had answered the questions, which might not have been the case had written questionnaires been returned by post or e-mail (Hayden 2006).

A disadvantage of face-to-face interviews was that they were intrusive, interrupting the busy schedules of key personnel. On the part of the researcher, they proved costly in terms of time involvement and transport expenses.

The qualitative nature of the research is both a strength and a weakness. The richness and depth of information yielded by interview transcripts would have been impossible in a quantitative study. However, the findings of research of this type cannot be generalised to the wider population, and serve merely to inform further investigation.

## **3.3 METHODOLOGY**

This section describes the development of the research instrument, the selection of the population sample and the methods used for collection and analysis of the data. It also explains the researcher's attempts to ensure trustworthiness throughout the process of enquiry using reflection, peer debriefing and audit trail, which are accepted strategies for improving rigour in qualitative research (Barbour 2001).

### 3.3.1 Research instrument

The design of the research instrument was grounded in the extensive reading and preparation undertaken during the proposal-writing phase, and was developed by the researcher in consultation with her supervisor and with the assistance of an experienced research coordinator<sup>1</sup>. The original design underwent a number of revisions before it was accepted, and transcripts of the initial interviews were studied carefully to ascertain whether further modifications were necessary. These transcripts were presented to the supervisors for comment and it was agreed that the interview schedule appeared to be eliciting the required data.

The interview schedule comprised four main questions, each of which dealt with a number of specific focus areas which the researcher addressed by means of prompts. Open-ended questions were employed so as to promote discussion, and the schedule was engaged as a tool to explore perceptions rather than as a rigid list of questions. The interview schedule is included in the Appendix to this dissertation.

The four question areas addressed included:

- **Information on the standard procedures for HIV testing at the interviewee's clinic:**

Information sought in this section of the interview related to number of patients presenting for testing, number of counsellors, and average waiting time for patients and follow-up procedures. The purpose was to better inform the researcher of the testing, treatment and referral processes implemented by the clinics, and to form a picture of clinic capacity to handle these processes.

---

<sup>1</sup> The research co-ordinator at a Durban hospital.

- **Perceptions of the interviewee regarding major barriers to testing within that particular community:**

Here the researcher asked questions regarding access to the clinic's services, perceived "bottlenecks" in the health care system, issues of stigma and perceived gender differences in willingness to test. This was an exploration of practical problems which could contribute to low testing uptake, such as transport difficulties or lengthy queues for counselling. It also intended to reveal the operation of stigma in mitigating against testing, and in how this played out differently between males and females. Another part of this question dealt with perceptions of whether there were appropriate incentives which might increase willingness to test.

- **Perceptions of the interviewee regarding the exceptionalism implicit in VCT:**

Prompts offered to the interviewee explored attitudes to pre- and post-test counselling, issues of confidentiality and privacy, and normalisation of HIV testing procedures. The researcher wanted to establish whether the participants themselves identified any links between the special approach to HIV and AIDS implicit in VCT and the poor uptake of testing.

- **Perceptions of the interviewee regarding impact of routine offer of an HIV test on patient willingness to test:**

This section of the interview attempted to discover what participants thought the effect of a routine offer of testing, in line with the PITC guidelines, might have on patients' attitudes. It also tried to assess how participants felt about normalising HIV and AIDS protocols.

The researcher ended the interview by asking what the participant would like to see changed about VCT and the current approach to HIV testing. This was worded to elicit as wide a response as possible, using a phrase such as, "If you were the Minister of Health, or had power to change

anything you liked about HIV testing and treatment procedures, what would you do?"

### **3.3.2 Research population**

The study's population included all professional nurses employed in HIV testing or ART units at PHC clinics and CHCs in the uMgungundlovu district, to which the researcher had been granted access by the uMgungundlovu Health District Primary Health Care Co-ordinator. The researcher was given a letter of permission to make contact with eleven institutions within the district.

### **3.3.3 Sampling procedure**

Non-probability purposive sampling was used to select a group of participants on the basis of the following selection criteria:

- **They should be adult females over 30 years of age:**

Most professional nurses are female; however this criterion was included to provide homogeneity. The age specification was intended to ensure a basis of experience in the field.

- **They should be professional nurses:**

For reasons discussed earlier, professional nurses were seen to be uniquely positioned to provide perspectives on the research questions.

- **They should be employed at a VCT clinic in the Pietermaritzburg district:**

The link to VCT clinics is evident, as the question under investigation relates to testing uptake. VCT clinics are the context in which such testing is considered for purposes of this study.

Seven participants were chosen according to the selection criteria outlined above. Qualitative research sampling does not attempt to provide statistical representation (Pope *et al* 2000), so sample size is guided instead by judgment and experience (Sandelowski 1995). Small samples are often indicated because of the volume of data generated which requires a great deal of time to adequately process (Hancock 1998). The emphasis is on depth and richness of investigation in the form of field notes and interview transcripts. For this reason, the value of adding more participants must be weighed against the time needed to comprehensively process the material generated. In consultation with her supervisor, the researcher decided to conduct between five and seven interviews. Since interviews were transcribed immediately after each interview, it became apparent to the researcher during the interviewing process that seven interviews would produce a rich amount of data.

As the investigation progressed, two additional unplanned interviews were conducted with participants who did not fit the criteria but whose experience was deemed by the researcher to add value to the study. The inclusion of these participants did not represent a deliberate change in the sampling strategy, but rather embodied the flexibility inherent in qualitative research which allows for data coming to the researcher. The first additional participant, a VCT counsellor employed at one of the clinics, was introduced to the researcher by a professional nurse who, following her own interview, recommended further consultation with the counsellor. The other additional participant was an informal workplace counsellor known to the researcher, who learnt of the research being conducted and expressed an interest in being included. She discovered last year that she is HIV positive, and her own recent experience of the process of testing and initiation onto ART was thought to be of relevance to the study.

As has been noted, the researcher intended to conduct between five and seven interviews. Permission was granted by the Primary Health Care Coordinator to make contact with clinic managers at any of the eleven institutions identified. Clinic managers would then identify the person to be

interviewed, and set up an appointment for the researcher to visit the clinic. Depending on the perceived success of the scheduled interviews, in the view of the researcher, four to six additional interviews could be arranged if necessary. It was anticipated that difficulties might arise in some instances, such as appointments not being kept, or an interview being cut short due to a participant being needed elsewhere in the clinic. These predicted difficulties did not, in fact occur, and all of the original seven interviews booked were completed and the interview material was used in the data analysis.

The selection of the seven institutions where interviews were conducted out of the total eleven designated clinics was based simply on where telephone contact was successful. Some clinics were telephoned by the researcher but the designated person could not be reached, and contact was made at another clinic instead. In other instances there appeared to be problems with the telephone line, and the researcher could not get through. It is acknowledged that this might have prejudiced the study toward those institutions with better communication systems.

Throughout the period of conducting interviews the researcher maintained close contact with her supervisors, reporting on progress and presenting samples of the interview transcripts. It became evident that sufficient rich data had been generated by the time the seventh scheduled interview was conducted so that further interviewing was not needed as saturation of the themes had been reached. In consultation with her supervisors it was also decided to include the material from the interviews with counsellors which had already taken place.

#### **3.3.4 Data collection**

Data was collected for the study by means of audio-taped face-to-face interviews. The researcher used an interview schedule to guide the dialogue, and a dictaphone recorder was placed, with the participants' permission, on a nearby surface (usually a desk). Notes were jotted down on the interview schedule during the interview and written up during the transcription to

capture the researcher's own feelings and observations. These observations made during data collection assisted the researcher during data analysis, providing additional insight into emergent themes and sub-themes.

Use of the dictaphone recorder offered several advantages:

- a) It gave the researcher the exact wording of a participant's responses, not just hastily jotted notes.
- b) It allowed the researcher to review a particular comment or observation several times by replaying it later.
- c) It enabled the interview to be conducted as a conversation rather than a question-and-answer session, thus eliciting more from the participant.
- d) It allowed an auditory expression of the interview setting to be captured. The background noises recorded on the tape served to enhance the researcher's understanding of the participant's work environment, including frequent interruptions by colleagues or phone calls, and, in one instance, the continuous crowing of a rooster directly outside the office window.
- e) The emotional component of a participant's reply to a question was not lost. Some interviewees became excited, or saddened, by certain topics, and this feeling was preserved in the recording.
- f) The lengthy process of transcription served to familiarise the researcher with the interview content.

There were also some disadvantages to this data collection method:

- a) Parts of some interviews did not record clearly, due to the dictaphone being placed too far from the participant, or background noises interfering.

- b) Some questions were omitted or overlooked due to the conversational nature of the interview, rather than note-taking with strict adherence to the schedule.
- c) Recording offered no filters to the interview content which might have been imposed by hand-written notes. Thus, a certain amount of irrelevant material was also recorded.

The researcher's observations were noted in the margin or on the back of the interview schedule during interviews. Each taped interview was then typed by the researcher in the form of a verbatim transcript. The researcher attempted to type the transcripts within a few days of the interview, and to complete the transcript of one before the next interview was conducted, although this was not possible in every case.

Transcription proved to be a valuable exercise in processing the interview material, and had the effect of ongoing moderation of the interview schedule. Thus, responses offered by each participant influenced the questions and style of later interviews. This fits into the constant comparative method which is a hallmark of grounded theory (Moghaddam 2006). As the researcher grew more familiar with clinic procedure, for example, questions became more focussed and appropriate. With better understanding of the issues pertaining to HIV testing models, new themes for questions emerged. Also, becoming more confident in using the recording equipment meant that the researcher was more at ease, if the participant's voice dropped, in pushing the dictaphone closer with a comment such as, *"What you are saying is really interesting. I don't want to miss it."*

Another advantage of the sequencing of the interviews was that it enabled the researcher to check attitudes of participants against each other. For example, the researcher might say, *"A previous participant told me that women are generally more willing to have an HIV test than men. Do you agree with this?"* Or, *"Others have told me that publicity testing is nothing*

*more than a waste of time. What do you think?"* This served to highlight areas of common ground as well as areas of difference, and gave participants a way of validating or questioning each other's perceptions. Building a conceptual model by making use of such constant comparison and negative case analysis is a well described procedure in grounded theory design (Ryan & Bernard 2000).

### **3.3.5 Data analysis and interpretation**

A system of thematic analysis similar to the framework approach described by Pope *et al* (2000) was used to reduce and sort the data. The process of transcription assisted with familiarisation of the material. Interview transcripts were carefully studied to identify emerging themes which linked to the research problem. There were general themes suggested ahead of time by the literature survey, themes which had been specifically looked for through the design of the interview schedule. However, a number of unanticipated themes and sub-themes emerged, both during the interviewing process and during analysis. As themes and sub-themes were identified, they were arranged in a table using numerical codes, which allowed for convenient addition of new themes.

This process yielded a first-level analytical framework comprising twelve major themes and twenty-nine sub-themes. Each of the sub-themes was assigned a numerical code, and the transcript material was then carefully marked according to the codes. After consultation with two experts in the field, a senior doctor and a researcher, the framework was simplified by grouping certain themes. The final framework enabled classification of the transcript material into five major themes and twenty-seven sub-themes. This thematic framework can be seen in the Appendix. Numbers were assigned to each theme and sub-theme, and these were used to index the original transcript material.

Once indexing was complete, a master code-book (Ryan & Bernard 2000) was created as a compilation of material from all transcripts in categories

according to the themes and sub-themes detailed in the framework. This charting enabled comparison of data across interviewees within a particular theme, while examination of individual transcripts enabled comparison of data from a given participant. By applying the codes to the original interview schedule it was also possible to illustrate which themes had not been anticipated beforehand. Once the code-book was complete it became possible to look for relationships between themes, the mapping and interpretation described by Pope *et al* (2000).

### **3.3.6 Trustworthiness and rigour**

Throughout the phases of data-gathering and data analysis the researcher worked in close collaboration with her supervisors, referring samples of interview transcripts and coded analysis for comment and guidance. In addition, three strategies for ensuring rigour and trustworthiness in a qualitative study, namely reflexivity, audit trail and peer debriefing (Lietz *et al* 2006), were applied to this research.

During the process of conducting the interviews, the researcher was aware of the interaction occurring between herself and the “data”. Acknowledgement and analysis of this process is called reflexivity (Lietz *et al* 2006). Feelings of nervousness and inadequacy prior to the first interview were replaced with a sensation of euphoria upon discovering the participant to be far more interested, articulate and co-operative than had been hoped for. The second interview ended with the researcher feeling an overwhelming sense of obligation to the participant, who seemed to believe enthusiastically that the researcher was in a position to implement her suggestions and recommendations.

At some clinics the researcher felt painfully conspicuous, carrying a dictaphone and clipboard, walking past queues of patients who sat and stared. The researcher found herself wondering whether to make eye-contact and smile, which seemed condescending, or to avoid eye-contact all together, which seemed cold and uncaring. In these instances the researcher was

highly sensitised to her position as an outsider, someone who did not belong in that context. This led to much inner reflection on whether the personal gain to the researcher (completion of a research project) could be compensated for to the patient community. It was hoped that the findings of the study could, in time, lead to decisions being made which would benefit the patients themselves.

Most research participants were welcoming, and appeared to enjoy the opportunity of expressing their observations. Some, however, seemed politely annoyed by the interruption. One sister commented:

*“Especially because they (provincial and national health authorities) just want a report, and what, what, what, and when they come, they will come just like you, they will interview me and then it is over.”*

The comment *“just like you”* effectively put the researcher in the category of people who caused bothersome outside interruptions and offered no return. Such experiences affected the researcher’s sense of ease and confidence in the interview setting.

The use of an audit trail, as described by Lietz *et al* (2006), involves keeping track of the decisions which led to the choice of particular steps in the research procedure. Reasons for the choice of research design, sampling type and sample size, and methods of data collection and analysis have been outlined earlier. The purpose of an audit trail is to document the stages of investigation and provide justification for each decision so as to increase transparency and ultimately trustworthiness in the enquiry.

Finally, the strategy of peer debriefing as discussed by Lietz *et al* (2006) was used. Prior to adoption of the final analytical framework, the first-level analysis was discussed with two consultants. One, a senior doctor familiar with VCT and ARV services at clinics in the district, was asked to comment on the researcher’s understanding of clinic procedure, and whether the code words and thematic units employed in the framework described a typical

professional nurse's experience in this setting. The second consultant was a researcher with considerable understanding of public health services. This consultation process resulted in some changes being made to the framework, with certain codes being grouped together. It also resulted in corrections to a few misperceptions which the researcher had gained regarding the referral process and the status of some of the clinics.

### **3.3.7 Limitations**

A study such as this is limited in wider applicability by virtue of the small sample size. The findings reported in the next two chapters cannot be generalised to the wider population (International Development Research Centre 2008), although they are still of value in uncovering areas for further investigation. A second limitation lies in the fact that rigour is difficult to achieve in qualitative research. Barbour (2001) warns that checklists of strategies for improving qualitative research methodology can be misused to confer credibility where it is not due. Lack of experience on the part of the researcher cannot be fully compensated for by what Barbour terms the "technical fixes" of purposive sampling, grounded theory, multiple coding, triangulation and respondent validation (2001:115). In a study of this nature, the researcher is learning skills at the same time as she is collecting the data. Thus, an additional and important limitation is that the quality of the research is heavily dependant of the prior knowledge and experience of the researcher (International Development Research Centre 2008).

## **3.4 ETHICAL CONSIDERATIONS**

Ethical considerations for this study included gaining permission to conduct the research from the relevant university and health authorities, as well as gaining consent from the participants. The procedures followed for achieving this are outlined in the next section.

### **3.4.1 Permission to conduct research**

The research proposal for this study was submitted to the UNISA Research and Ethics Committee in April 2008, and approval was received in May 2008. Health authorities for uMgungundlovu District and KwaZulu-Natal Province were then approached, and permission to conduct the research was granted in June 2008. The Primary Health Care Coordinator for uMgungundlovu Health District issued the researcher with a letter of authority to visit PHC clinics and CHCs, and undertook to notify these institutions of the permission to conduct research via a faxed letter. Interviews with the professional nurses were arranged by the researcher, usually in consultation with the clinic manager, at a time convenient to both the participant and the clinic as a whole.

### **3.4.2 Informed consent**

The Primary Health Care Coordinator informed the researcher that faxes would be sent to the relevant institutions, notifying the managers at the clinics that the proposed research had been approved. The researcher would then contact the clinic manager and ask that an appropriate participant be identified. However, many of the clinic managers said they did not receive the faxed permission letter from the PHC Coordinator due to their fax machines not being in working order. The researcher found that the managers were nevertheless willing to arrange appointments without seeing the PHC Coordinator's letter, as long as a copy of the letter could be produced by the researcher at the time of the interview. While the absence of a working fax machine was nothing more than a minor inconvenience to the researcher, as illustrated in the case study from Chapter one, the implications for patients may be serious indeed.

Before each interview participants were provided with verbal and written information on the research, and were given consent forms to read through and sign (see Appendix). The consent form assured participants that their involvement in the interview was voluntary, that they had the right not to

answer any question they did not like or to withdraw answers later and that they could contact the researcher with any further questions. Participants were asked to indicate whether they agreed to being audio-recorded, and to being quoted provided they could not be identified. All participants indicated that they agreed.

While standard procedures for obtaining informed consent were used, the researcher was left with some questions related to how this had played out in reality. For example, the researcher was asked to deal with the clinic manager in setting up interviews. The clinic manager identified a professional nurse who was suitable, and in most instances then arranged the date and time of the appointment with the researcher. The researcher expected that these arrangements would be discussed between the manager and the participant within the clinic setting. In some instances the researcher was able to speak to the participant herself ahead of time in order to confirm the appointment, but frequently communication occurred only between the researcher and the clinic manager.

In at least two instances the channel of communication between manager and participant appeared to have been poor, and the researcher arrived to find herself not expected at that time. This was nothing more than a minor inconvenience to the researcher, and the possibility had been anticipated in advance. What was of more interest and concern to the researcher was the impression that participants felt that permission for the interview was ultimately vested in the manager rather than the interviewee herself. Thus, a participant might express surprise at the arrival of the researcher, but say, *"Did you get permission from the clinic manager? Yes? All right, then, no problem, I can speak with you."* Very few were interested in seeing the letter of authority, and very few seemed to feel that they were being asked whether they personally gave permission for the interview to proceed.

This raised questions for the researcher about attitudes to authority, suggesting that individual nurses believed that if their superiors had granted permission for the interview, their own opinion was not relevant. The

researcher felt she compensated for this in the interview setting by going through the informed consent form with participants. However, the parallel between the interview setting and required consent, and the HIV testing occurring elsewhere in the clinic with its voluntary consent, were noted, and the researcher wondered how well developed patients' own ideas of consent were. Did they sometimes feel themselves to be in the hands of people in authority over them, who either did or did not grant permission for them to be tested? Did the over-arching policy of the clinic shape their willingness to test?

### **3.4.3 Confidentiality**

Names of all participants were kept confidential. In presentation and analysis of data, pseudonyms are used for participants, and names of the PHC clinics and CHCs where they were employed are withheld to protect them from identification.

### **3.4.4 Provision of debriefing, counselling and additional information**

Participants were provided with a brief background to the study prior to the interview commencing. They were asked whether they wished to receive a summary of the interview transcript or the findings of the study. Participants were also given contact details for the researcher in case they required further information at a later date.

## **3.5 CONCLUSION**

This chapter has given an account of the selected research design and methodology for the study, as well as the rationale for making such a selection. The instruments and techniques for data gathering and the

strategies for data analysis have been described and explained. Attention has been given to how requirements for correct ethical procedure were complied with. Finally, observations on the limitations inherent in the research were discussed.

In the next two chapters the findings of the research will be presented. The reader will be introduced to the research participants and the clinics where they are employed. The themes which emerged from interview transcripts are then discussed and analysed, and the research participants' own recommendations are reviewed.

## CHAPTER 4: THE RESEARCH CONTEXT

---

### 4.1 INTRODUCTION

This chapter begins with a description of how the interviews were arranged and conducted. It goes on to give a short biographical sketch of each of the interviewees, enabling the reader to better understand who the research participants were. An overview of standard clinic procedures is then offered to give the reader an appreciation of the context in which the interviewees work. The final section addresses the important themes and sub-themes which emerged from analysis of the interview material and discusses these with reference to the research objectives as outlined in Chapter 1. These objectives were:

1. To provide insight into the experiences of professional nurses working in the field of HIV testing.
2. To identify attitudes of the research participants with regard to implications of the exceptionalism inherent within VCT.
3. To explore the research participants' perspectives on normalisation of HIV and AIDS through PITC, specifically with respect to improving testing rates and decreasing the stigma associated with a sero-positive status.
4. To present the findings in such a way as to offer insights which might prove useful in informing decision-making pertaining to HIV-testing policy.

## 4.2 THE INTERVIEW PROCESS

Nine face-to-face interviews were conducted, seven of which were held with interviewees who matched the characteristics outlined in the research design, namely:

- They were adult females over 30 years of age.
- They were professional nurses.
- They were employed at a VCT clinic in the Pietermaritzburg district.

Although not part of the original research design, two additional interviews were conducted. Of these, one was held with a senior VCT counsellor at one of the clinics, and the other was held with an informal workplace HIV counsellor employed by a Pietermaritzburg-based company.

Interviews with the senior nurses were arranged ahead of time by contacting their clinic managers who set up the appointments. This was the procedure which had been specified by the Department of Health authority who had granted permission for the interviews. Where possible, these appointments were followed up and confirmed before-hand by fax or phone-call. Confirmation was not always possible because many clinics did not have working fax lines, nor could the interviewee always be reached by telephone due to the line being engaged. In two instances the researcher was not expected at the time arranged, due to the agreed appointment time not having been communicated to the interviewee by the clinic manager. In one case it was necessary to reschedule the appointment, and in another instance the researcher was asked to wait until she could be seen. From these experiences, as well as from observations made by the researcher during the interviews, it was evident to the researcher that health care professionals

working in a public health setting need to be highly flexible individuals, able to adapt themselves to a variety of situations and unpredictable demands.

Upon arrival at a clinic for an interview, the researcher would ask either for the clinic manager or the designated interviewee. In most instances the clinic manager took the researcher to meet the interviewee, but in cases where the clinic manager was not available another staff member would assist. In such a case the interviewee would typically ask whether permission had been granted by the clinic manager for such an interview. It was clearly a matter of some importance to the research participants that permission had been granted, and once this was established they were generally well-disposed to meet with the researcher.

In the case of the VCT counsellor, the interview had not been planned ahead of time but was set spontaneously by a senior nurse who had just been interviewed. This was her suggestion, as she felt the counsellor was in a better position to answer some of the interview questions. She approached the VCT counsellor to ask whether he was willing to be interviewed and he agreed. The final interview, conducted with an informal workplace counsellor known to the researcher, was arranged after this person showed an interest in the research being undertaken and expressed a desire to articulate her own observations. The interview was held at the interviewee's place of work.

Interviews were conducted privately in offices with closed doors, although in one instance the interviewee chose to leave the door open. A brief introduction was given by the researcher, stating the purpose and objectives of the research, and the interviewee was given a letter from the researcher which provided additional background to the study as well as contact details for the researcher. Interviewees were asked to sign informed consent sheets and to indicate whether they wished to receive a summary of the main points of the interview. They were also asked whether they would agree to the interview being recorded, and all agreed.

In all interviews with the professional nurses as well as with the VCT counsellor, there were repeated interruptions throughout the interviews, either by colleagues who had questions to ask, or by telephone calls. At times the interviewee might be called away for a short time to attend to something. Throughout one interview a rooster could be heard crowing loudly and continuously directly outside the open office window. It was evident to the researcher by her observations made at all of the clinics that this atmosphere of noise and constant interruption constituted a normal working environment for the interviewees. Although this was distracting to the researcher it did not seem to be a source of difficulty to the interviewees who carried on expressing their insights apparently unperturbed. However, it occurred to the researcher that this could have implications for patients undergoing counselling, for whom a quieter environment might more easily facilitate the experience of receiving an HIV test result.

### **4.3 BIOGRAPHICAL INFORMATION ON THE INTERVIEWEES**

Here a brief biographical description is given of each interviewee. In all cases pseudonyms have been used and their places of work have not been identified in order to protect confidentiality.

#### **4.3.1 Eva**

Eva is a professional nurse in her early thirties who is in charge of the VCT and ARV programmes at a city clinic. Her ambition was to become a social worker, but after undergoing a school guidance course she developed an interest in nursing. She completed her training at a Durban hospital, and has experience working at a private hospital as well as a state hospital. She has worked at the present clinic for the last seven years. Eva described herself as satisfied with her chosen profession but said it was demanding, commenting, *“I am happy, though the challenge is very high. People are really sick out there.”* Nevertheless, she believed that the benefits to her family, friends and particularly the community made her work worthwhile.

The researcher experienced her as a strong and compassionate person who was able to articulate her thoughts clearly. Interactions observed between her and both staff and patients revealed her to be a person of warmth, who was viewed with respect and appreciation by colleagues and patients.

#### **4.3.2 Nancy**

Nancy is a professional nurse in her forties who completed her basic nursing training at a state hospital in 1999. Thereafter she was employed at a clinic in a rural area, and during this time she studied further to become a professional nurse. She has experience working in a state hospital as well as for a private non-governmental organisation, and has been employed at the clinic for one year. It was evident to the researcher that Nancy is a woman of great compassion who feels overwhelmed by the health and social needs of the community she serves. She expressed frustration at what she perceived as the unwillingness of patients to do what was in their best interests, and frustration at the health care system which is unable to offer a better service due to staff shortages and budget constraints.

Although she initially appeared to be reluctant to speak to the researcher, wanting to know how much of her time it would take, she warmed to the opportunity to articulate her observations and the researcher ultimately had to bring the interview to a close. Nancy expressed the need to receive counselling herself because of stress experienced in her job. She also offered her assistance if any sort of community outreach was planned.

#### **4.3.3 Gertrude**

Gertrude is in her sixties, and has been working at a rural clinic for two years, having come out of retirement to take up the post. She completed her nursing training in Pretoria in the 1970s. She lives in Pietermaritzburg but stays in accommodation at the clinic during the week.

As in other interview situations, interruptions afforded the researcher opportunities to observe Gertrude in interactions with both colleagues and patients, and Gertrude, like the other professional nurses, gave the researcher a clear impression of her dedication and caring nature. What was unique about this interview was Gertrude's habit of answering many of the researcher's questions in a dramatic whisper, often turning her head slightly away and looking out the office window. This had the effect of emphasising to the researcher the difficult nature of the subject material. She often spoke in the voice of an anonymous patient in order to illustrate a particular attitude or belief. The whispering served to add an element of emotion to the message of the unknown patient, underscoring the painful feelings of censure and stigma. She also demonstrated to the researcher a hand gesture which is used by local residents to refer to HIV testing without having to speak openly.

#### **4.3.4 Miriam**

Miriam, the acting head of the ARV section in a semi-urban clinic, is in her late thirties. She completed her nursing training at a state hospital, and furthered her qualifications at a university outside of KwaZulu-Natal, necessitating weekly trips to attend lectures. Like Gertrude she stays at the clinic during the week and returns to her home on weekends. Miriam would have preferred to have studied in the field of business or economics, but was not able to afford it. She described herself as having adjusted to her current profession, and said she likes her job, but would be willing to leave the health services if there were an alternative.

Miriam's work setting was the most visually attractive to the researcher of all the sites visited. The clinic grounds were neat and clean, with flowerbeds filled with freshly planted annuals and vegetables. The park home in which the interview was conducted was warm and well lit. Nevertheless a sense of disengagement on Miriam's part was noted by the researcher. It is possible that this was due to Miriam's perception that the researcher was getting a report out of the interview but leaving nothing behind. Miriam commented in the context of her recommendations that senior health officials should be

visiting the clinic and showing more concrete support, noting her perception that visits from senior health care personnel were simply to collect reports.

The interview was interrupted repeatedly, and at one point had to be moved to another venue. Miriam referred the researcher to the clinic's senior counsellor for additional information.

#### **4.3.5 Thomas**

Thomas is a senior counsellor at the clinic where Miriam is employed. No arrangement had been made ahead of time to meet with him, but he gave his consent to be interviewed. Thomas is a man in his forties who has worked with several non-governmental organisations and has considerable counselling experience. He was articulate and communicative during the interview, and described himself as having a love for people. However, he showed a tendency to dominate the interview, leading the researcher to speculate about what might occur in a counselling situation with a quiet or reticent patient.

#### **4.3.6 Dorothy**

Dorothy is a professional nurse in her mid-thirties who runs the VCT and ARV programmes at a township clinic which serves a large area. Like Eva, Dorothy would have liked to become a social worker, or a teacher, but due to financial considerations chose to do nursing instead. Also like Eva, Dorothy feels that there are personal gains to family members because of her knowledge and experience as a nurse. Dorothy lives in some thirty minutes drive from the clinic and commutes daily.

Dorothy was very softly spoken and appeared tired and possibly depressed. Although the interview was conducted in a private setting with a door which could be closed, Dorothy left it open throughout the interview. She had strong views and opinions about the issues pertaining to HIV testing which she expressed articulately.

#### **4.3.7 Elizabeth**

Elizabeth is in her mid forties and heads the VCT and ARV programmes at a large and busy township clinic. Her training took place at a rural hospital in the 1980s, and she has worked in many different settings. Like Eva, she impressed the researcher as a particularly strong and effective leader, motivated by compassion and guided by her own experiences. She lives openly as an HIV-positive person and has found senior staff and colleagues to be supportive. She had not been informed by her supervisor of the time of the appointment, and it was necessary to reschedule the interview for the following day.

#### **4.3.8 Theresa**

Theresa is in her late thirties and works at a semi-rural clinic near Pietermaritzburg. She trained as a nurse at a state hospital in Pietermaritzburg, and has had several years' experience working overseas. Although she found the overseas work to be financially rewarding, she chose to return to her home area for family reasons. Like Elizabeth, Theresa had not been told when to expect the researcher, and was initially annoyed at being interrupted during lunch. However, after a short wait on the part of the researcher, Theresa was prepared to conduct the interview. This interview setting was possibly the least conducive of all the interviews. The room was small and cramped, and colleagues repeatedly came in and out to use office equipment and make telephone calls. The researcher's impression, however, was that this was less of a distraction to Theresa than to the researcher, and as the interview progressed Theresa was willing to share her impressions and observations most articulately.

#### **4.3.9 Lily**

Lily is not a nurse and was not selected to be interviewed on the basis of the research criteria. She is a domestic worker known to the researcher, and is

employed by a small Pietermaritzburg-based company. During the past year she became extremely ill and was forced to take extended sick leave. She tested positive for HIV and began ART in September 2007. Some eight months after leaving work she was able to return on a part-time basis. She has done very well on ART and now acts as an informal workplace counsellor amongst her colleagues. She expressed a willingness to be interviewed after learning of the research being conducted, because she felt her own experiences made her opinions relevant.

#### **4.4 BACKGROUND INFORMATION ON CLINIC PROCEDURES**

In this section a brief overview is provided to the reader on the standard procedures and operations of the clinic with regard to HIV testing and provision of ARVs, as described to the researcher by the interviewees. The researcher verified her understanding of these procedures following completion of the interviews in consultation with a senior doctor employed by the KwaZulu-Natal Department of Health. Literature sources were also consulted to confirm the procedures and to offer a more complete account.

All of the clinics represented in this study offered VCT services and had an ART programme in operation. The numbers of patients presenting daily for VCT ranged between 10 and 50, depending on clinic size and whether it was urban or rural (higher numbers of patients attended VCT at the urban centres). Patient numbers for ARVs also varied as some clinics had been running programmes longer than others. The clinic with the highest figure reported approximately 350 patients on anti-retroviral therapy.

The number of counsellors employed varied between one and ten, depending on the size of the clinic. Counsellors had attended a 10-day training course, and it was reported that they received additional training through workshops from time to time. Their responsibilities included:

- VCT (pre-counselling, testing, and post-test counselling);
- Group counselling of pregnant mothers at antenatal clinics;
- Conducting ARV treatment adherence classes, known to patients and staff as “Classes 1, 2 and 3”. These classes are a required part of the ART initiation programme during which patients are given essential information about HIV and AIDS, and are taught about basic nutrition, opportunistic infections, antiretroviral medicines and how to take them and how to live positively with AIDS (AIDSbuzz.org 2008a).
- Counselling patients on anti-retroviral therapy who return monthly to collect medication;
- Formal/informal group counselling and information-giving to patients waiting in the general clinic.

Interviewees at all clinics reported that patients requesting VCT were attended to on the same day and in a matter of hours. Clinics are sometimes busier on certain days, and then waiting times are longer. None of the respondents felt that patients waited an unreasonable length of time to be counselled, and none believed patients who presented for testing were ever turned away because of staff shortages. This is encouraging when compared with the findings of a study conducted in 2004 which analysed calls to the national AIDS helpline and reported that counselling services were not universally available (Birdsall *et al* 2004).

Patients who tested positive were immediately sent to have blood samples taken to test their CD4 counts. The purpose of the CD4 count is to assess the strength of the patient’s immune system (AIDSbuzz.org 2008b) and is used to determine whether the patient should be initiated onto ART. Currently in South Africa a patient is eligible for free treatment when presenting with either of the following: the CD4 count has dropped to 200 or below, or symptoms manifest of stage 4, the final stage of HIV disease, which include profound weight loss and/or an AIDS-defining illness (AIDSbuzz.org 2008b). The South African Clinicians Society recommended earlier this year that these guidelines be revised to fall in line with those of the World Health Organisation, which

advocate treatment at a CD4 count of 350 and/or stage 3 of the disease (IRIN 2008b).

Results of the patient's CD4 count were reportedly returned to the clinic after two or three weeks unless there were technical problems at the laboratory, in which case a second blood sample would need to be taken. Patients who qualified for ART would be given an appointment to start attending treatment adherence classes at the clinic where they had tested. Attendance at these classes is a prerequisite for treatment (AIDSbuzz.org 2008b). Another requirement is that the patient identifies a treatment partner or "buddy" to attend classes with them. The purpose of the treatment buddy is to assist the patient in learning the treatment regimen and being aware of possible side effects.

The next step was to book the patient for initiation of ART at the nearest hospital. The patient would first be seen by a doctor at the clinic, and since some clinics had doctors available only once a week, this was regarded by the interviewees as a potentially significant delay. However the senior doctor who was consulted later informed the researcher that if a patient's health indicated immediate attention based on the clinical markers mentioned earlier (CD4 count below 200 and/or stage 4 illnesses) the patient did not have to be seen by a doctor first. In such cases referral could be arranged by the professional nurses.

For most clinics, patients beginning ART would be referred to the nearest hospital and this was known as "up-referral". The appointment might be anywhere from one to three months later, due to high numbers of people being initiated onto ART. In some instances, interviewees said they were able to "fast-track" patients who presented with low CD4 counts and stage 4 symptoms, in order to ensure that the waiting time was not too long. Of the seven clinics, one clinic had its own initiation programme, and it was not necessary to refer patients elsewhere. One other clinic had been accredited as an initiation site and was due to begin initiation soon, but the process had

been delayed as certain equipment was awaited. The researcher learned shortly after her visit to this clinic that staff had begun initiation there.

A patient who had been referred to start initiation remained under care of the hospital (or, in the cases mentioned above, the clinics) for a period of approximately three months during which time they were monitored closely for opportunistic infections and adverse reactions to the therapy. Thereafter they were referred back to the clinic where they had originally been tested. This was known as being “down-referred” or “decanted”, and the patient’s further treatment would be managed by the clinic.

The procedures surrounding this progression, from pre-test counselling to down-referral after initiation of ART, provide the background for the research participants’ experiences as revealed in the interview material.

## **4.5 THEMES EMERGING FROM THE INTERVIEWS**

In the next section the major themes and sub-themes which emerged from analysis of the interview transcripts are introduced. These are explored and discussed in depth in Chapter 5, but are outlined briefly here.

### **4.5.1 Barriers to testing**

This explores participants’ perspectives regarding what might act as barriers to testing uptake. Stigma, problems of access to clinic facilities, “bottlenecks” in the health care system and issues of reliance on traditional medicine are sub-themes dealt with.

### **4.5.2 Willingness to test**

This category addresses the question of why people may or may not be willing to test. The researcher attempts to interpret the transcription material which was coded under the following sub-themes:

- The tendency to delay testing
- Male reluctance to test
- Factors affecting female willingness to test
- Public awareness of HIV issues and appropriate health-maintaining behaviours
- Declining testing after pre-test counselling
- Publicity testing and incentive schemes

#### **4.5.3 Attitudes to VCT and other testing models**

Here the perceptions of participants are reviewed with respect to the counselling procedures and demands of confidentiality inherent in VCT. Their views on the normalisation of HIV testing and integration of services is discussed and contrasted with an exceptionalist approach. One sub-theme of particular interest in this section is the perceived inconsistency in clinic procedure between the intention to protect patients' confidentiality regarding HIV status, and the *de facto* practice of singling them out.

#### **4.5.4 Participants' observations and recommendations**

This category groups together several sub-themes which dealt with personal comments and insights offered by the participants. It also discusses the interviewees' own recommendations for changes to the current system of HIV testing and treatment.

### **4.6 CONCLUSION**

The purpose of this chapter has been to introduce to the reader the context in which the study was conducted by offering descriptions of the interview process, the research participants and the clinic settings. This is intended to form a basis for understanding the research findings which are presented and discussed in the next chapter.

## **CHAPTER 5: PRESENTATION AND ANALYSIS OF FINDINGS**

---

### **5.1 INTRODUCTION**

This chapter presents the findings of the study under four main sections, each with two subsections. The first three sections relate directly to the research questions, namely:

1. What do the interviewees see as the major barriers to testing for HIV in the communities which they serve?
2. In the opinion of the interviewees, how do people feel about the special approach to HIV testing, which requires both pre- and post-test counselling?
3. How do the interviewees think attitudes to testing might change if an HIV test was offered routinely to all patients attending a primary health care facility?
4. What perceptions do the interviewees hold regarding the introduction of PITC or routine opt-out testing? Could this increase uptake of HIV testing without compromising human rights?

The fourth section deals with additional comments made by the research participants about patterns of patient behaviour which are perceived to have an impact on testing uptake. Finally, the recommendations for changes which interviewees were invited to make are reported and discussed.

## **5.2 BARRIERS TO TESTING**

All of the interviewees agreed that people generally delayed testing, often waiting until they had become very ill before seeking intervention. This finding is in agreement with a report from the Reproductive Health & HIV Research Unit of the University of the Witwatersrand which found that more than 20 percent of patients at the clinic studied never reached the treatment stage, succumbing to illness before treatment could commence (IRIN 2008a). One sister, known as Eva in this report, described the problem of late testing graphically when she commented that it would help so much if people tested earlier, as then they could get to the clinic when they were still walking, rather than having to use a wheelchair. Another interviewee, Dorothy, referred to patients' deteriorating health as the "push" which would get them to test. The following section explores participants' responses to the question of why people delay testing even in communities where ART is freely available. A number of issues emerged, and these are grouped under the headings of stigma and other barriers. Stigma is discussed first.

### **5.2.1 Stigma**

Stigma was by far the prime barrier to testing identified by the research participants. It is pervasive, deeply rooted and effective in keeping people from accessing treatment through testing (AVERT.org 2008c). As noted by Skinner and Mfecane (2004) the discrimination which follows from stigma can result in people believing there is no benefit in testing because of the negative consequences of a positive diagnosis. The stigma may be feared more than the disease itself, thus blocking access to available treatment.

Several participants explained to the researcher their understanding of the origins of the stigma surrounding HIV and AIDS. They identified two main roots, both stemming from the early days of HIV and AIDS in South Africa:

- The belief that testing positive meant death, as there was no cure;

- The belief that testing positive linked a person with risky behaviours such as commercial sex work, alcoholism or drug addiction.

Thomas described what people felt in this way:

*“It is for those people with drugs, those people who are commercial sex workers, those who are alcoholics, those people in prison, not us.”*

The association of HIV and AIDS with already marginalized groups such as sex workers, gay men or drug users is well documented (Parker and Aggleton 2002; Skinner & Mfecane 2004). Research participants believed that this message had been communicated by the government, through radio broadcasts in the early years, as well as by health workers trying to warn people of the risks. Indeed, *“AIDS kills”* and *“AIDS cannot be cured”* were slogans used in initial government warnings in Zimbabwe (Ilfie 2006:81). The implication was that a person who rejected commercial sex work and substance abuse also rejected HIV and all that went with it. To willingly present for an HIV test would immediately suggest one had engaged in one of these taboo behaviours. A secondary effect of this perception was that people who were not part of these epidemiological risk groups genuinely did not believe they were in danger of HIV infection.

Stigma and discrimination push the epidemic underground and counteract trust in relationships (Skinner & Mfecane 2004). In her interview, Nancy explained that people become too confused by the conflict between the need to know their status and fear of the possible consequences to actually follow through. Another source of confusion is the long incubation and lack of distinctive symptoms associated with HIV (Ilfie 2006). In order to cope with these conflicting pressures, people pretended they were not at risk. Some who had tested pretended they had not. Gertrude commented:

*“Some stay at home until they are sick, very sick . . . I think some have tested long ago and they found that they are HIV positive, and they are*

*scared to tell their family members that no, I know what is wrong with me. So they just keep quiet and stay at home.”*

And Miriam explained it like this:

*“I think they pretend they don’t know. Some are scared to disclose to family members, to friends, even some are scared that they will be chased away from work if they ever disclose that they are positive.”*

In addition to the fears of rejection by family or employer, people feared the sense of imminent death which they associated with a positive diagnosis. As Lily put it:

*“The thing is that they know that ‘AIDS kills’. That’s the only thing, the words they say, ‘AIDS kills’. If I know that I’m having it, I will die.”*

This comment may be directly linked to the slogan mentioned earlier which was used in Zimbabwe in the early days of the epidemic. The fear and hopelessness associated with this perception often lead to denial, “a coping device by which to preserve dignity in unspeakable circumstances” (Iliffe 2006:81). At least three types of denial were identified by the research participants:

1. **The denial of risk status**, when the person adopts the attitude, “It won’t happen to me!” despite engaging in behaviour known to be risky. For example Gertrude observed:

*“. . . others, they don’t believe they’ve got that virus. Especially pregnant ones, they don’t.”*

In some instances this is not denial but genuine ignorance, where the person does not perceive herself to be in danger of HIV infection because she herself does not engage in risky behaviour, but may nevertheless be at risk through the behaviour of her partner.

2. **The denial of a known serostatus**, where the person, having tested and received a positive test result, claims he or she does not know his or her status. This is a defence against the discrimination and rejection associated with a positive diagnosis. Interviewees described people denying previous tests, or moving from one clinic to another, possibly seeking a negative result after testing positive elsewhere. Miriam said:

*“Most of them they just run away from the truth. You will see that maybe they have been counselled somewhere else, like Johannesburg or Durban, or somewhere else, and they also come here being not counselled. So you only find out when the patient is sick. You enquire about whether the patient was counselled or not, sometimes he will say, no, fear of the family, that they will know the truth that he is HIV positive.”*

3. **The denial of another person’s self-proclaimed status**, where people were unwilling to believe another person who made a claim about their serostatus, either positive or negative. A person who claimed to be negative might be suspected of lying, particularly if they showed symptoms of ill health. If a person claimed to be positive, it was likely to be believed only if that person was visibly ill. Thus, an HIV-positive person who was receiving ART and looked healthy would find it difficult to convince another person that they were in fact HIV-positive. Lily, having been initiated onto ART a year ago, said:

*“But if I go to maybe the area where people don’t know me, they won’t believe that I am HIV positive. If I can tell them, they won’t believe.”*

And Dorothy commented:

*“Because they don’t trust you. Like people who are talking on TV, they see those people who are telling them they are HIV positive . . . Yes, unless you look sick and then you tell them, ‘I am HIV positive.’”*

Because of the fear of stigma and discrimination, patients often prefer to attend a clinic which is not in their own area. The chance to remain anonymous when testing, rather than run the risk of meeting up with a neighbour, is less threatening. This has been noted in a previous study on barriers to VCT in South Africa (Van Dyk & Van Dyk 2003a), and was expressed by Eva who works at a city clinic in this way:

*“I think it is easier to come here (rather than to attend a clinic in the community) because of the transport. Number two, it is not nice, you know people can talk in your community. They know this room is for testing, this room is for what, you know for you to be free, patients prefer to come to town.”*

And later in the interview:

*“Imagine I am here at the clinic. My neighbour is sitting next to me. I don’t want my neighbour to know I am HIV positive, you know. I haven’t accepted the condition, that I am HIV positive. I am slowly going there, I am adjusting myself. Now I am sitting next to her.”*

The fear of stigma with the resulting discrimination served to keep people in a state of turmoil and denial, and so to act as a barrier to testing. It also meant that people who had tested were unwilling to disclose their status to family members and friends, and were thus denied access to significant sources of potential support (Skinner & Mfecane 2004). Men were regarded as particularly prone to denial, and this is discussed in more detail in section 5.3.1.

### **5.2.2 Other barriers to testing**

While stigma was seen as the greatest barrier to testing, other significant obstacles were highlighted by the participants. These included the physical accessibility of clinic services, problems of access related to time, bottlenecks

in the system which meant lengthy waits on the part of patients, and the conflict posed by traditional medicine. An additional potential barrier, that of perceived inconsistencies in some procedures and policies within the VCT model, is discussed in section 5.3.

#### **5.2.2.1 Physical accessibility**

Access to facilities was regarded by interviewees as a problem for some communities, both in terms of getting to the clinic and travelling between home and the hospital where ART was initiated. Miriam explained:

*“There is no access on this road, because the taxis drop them quite far. We are faced with that problem . . . If they are not well, they have to hire private cars, or they have to call us . . . Yes, it (the hospital) is quite far. Patients are not having enough money. Usually we are having a bus here which only goes on Thursdays, so if the patient has been booked for Monday, Tuesday, or Friday, they must go on their own. Because they have to book the bus, if it is full for this coming Wednesday, they must do it for another Wednesday when it is their date. That is a problem.”*

If a person became too ill to make use of public transport, a private taxi would need to be hired. Once treatment adherence classes were begun, and sometimes for the process of initiation onto ART, both the patient and a “treatment buddy” or support-giver must travel to the clinic or hospital, thus doubling transport costs, as described by Gertrude:

*“It costs too much for transport, and the people are not working, they don’t have money and it is too expensive to go hospital. And they must go, the person who is sick, and the treatment buddy too. So they pay a lot of money. We don’t have transport to take them to the hospital.”*

### 5.2.2.2 Time accessibility

In addition to the problems of physical accessibility, it was mentioned that clinics did not offer testing on a Saturday. The provision of VCT services at public health care clinics only during the standard working week is a deterrent to testing which has been highlighted in a previous study (Birdsall *et al* 2004). The implication of testing not being available on weekends is that employed people are effectively denied access to testing unless they arrange leave with their employers. Elizabeth felt strongly about this, saying:

*“I have been negotiating with management to include VCT counsellors on the weekends. I don’t know what came up in their meeting this week, but I have seen that there is a need. Some of these people are working, they cannot miss their work. These people come on weekends and they do request testing, and we will say, “No, we don’t do the testing on weekends.”*

Because the process of getting onto treatment for a sero-positive person involves many repeat visits to the clinic or hospital (testing, collection of CD4 count results, attending three adherence classes and multiple appointments for initiation of ART), an employed person who must arrange leave for each appointment might feel this was a threat to confidentiality, or might simply be unable to negotiate the necessary leave.

### 5.2.2.3 “Bottlenecks”

Research participants identified several points of delay in the progression from testing to treatment:

1. **The waiting period for CD4 count results:** While this usually took approximately two weeks, in some instances delays of several weeks or even months were noted. Some interviewees reported blood samples sent for CD4 count results going missing, such that when

results were not returned for a particular patient and enquiries were directed to the laboratory, the laboratory staff insisted the sample had not been received. In other cases the laboratory might contact the clinic to inform staff that there were technical problems delaying the release of CD4 count results. Nancy explained:

*“(Getting CD4 count results) takes two to three weeks. But we are still having a problem with the results. Sometimes it takes a month and sometimes it doesn’t come back at all, so we have to repeat . . . Sometimes they do tell us that it is a technical problem, but sometimes it is just quiet, and we don’t know what is happening. Even if you phone them, they will tell us that they didn’t receive that sample. And then you will have to repeat the test again.”*

- 2. The waiting period to see a doctor after testing positive:** Patients who are eligible for ART are usually booked to be seen by a doctor at the clinic before they are referred for initiation of treatment. Many clinics have a doctor available only once a week and this means another delay between time of testing and initiation of ART. Gertrude expressed her feelings like this:

*“If I could do this, I would like each and every clinic to have a doctor to initiate ARVs!”*

And Elizabeth commented:

*“Yes, the problem then is with the shortage of doctors that makes it impossible to initiate new patients.”*

However, while this was described by the interviewees as a problem, a doctor who was asked later to comment on this stated that in urgent cases a patient did not have to be seen by a doctor, since the nursing

staff could make an appointment directly with the hospital for initiation of ART.

3. **The time spent waiting for an appointment to start initiation of ART:** Interviewees reported that it often took two to three months for a patient to begin the process of initiation of ART. This was due to the shortage of doctors at the hospitals, according to Elizabeth:

*“You will find that there are still patients that are booked for November (to start initiation of ART). (Interview took place in July.) We may book them, but along the line we try to see the patient’s condition; if we see there is a need to push, we go and negotiate with the doctor, to try and squeeze them in. And depending on the CD4 count – if the CD4 count is very low, no, we try and squeeze, we fight with the doctors, we squeeze, we squeeze.”*

A factor contributing to the pressure on doctors’ services is that a patient on antiretroviral therapy requires life-long maintenance. Elizabeth went on to say:

*“Because with ARVs it is not like you initiate and then, ‘Bye, bye’. The patient is still going to come back every six months for the bloods, for the assessment, handling all the problems he has whilst on treatment.”*

Waiting for a counsellor was not thought to cause a bottleneck at any of the clinics in this study. All of the research participants reported that their counsellors were able to counsel clients within a few hours of arrival and said that the counselling did not serve to appreciably slow the process of accessing testing. This is in contrast to an analysis of calls to the National AIDS Helpline undertaken in 2004 which found that counsellors were not always available (Birdsall *et al* 2004). It should however be noted that in this study the perceptions of nurses and counsellors were investigated, and that

patients themselves did not have the opportunity to comment on their experiences at the clinics.

#### **5.2.2.4 Reliance on traditional medicine**

Preference for a traditional approach to illness, and traditional remedies, kept some people away from testing. Thomas explained:

*“I think the reason for the low number of people coming, one of the reasons is the stigma attached to the disease. And the other one is the traditional culture. Most people who live in the rural areas, they still believe that if they are sick, they have been bewitched by somebody. And the first people they go to is the inyanga and the sangoma, and once they get there, they have hope that everything will be OK for them, that they will be healed, they will be right, and because of the reason that there is stigma attached to HIV, they feel that HIV is not something that they should associate themselves with.”*

The availability of traditional remedies, such as “uBhejane” which was mentioned by several interviewees, confused people. Some participants spoke of patients who had been initiated onto ART, but who secretly continued with a traditional medicine, either in conjunction with ART or in the place of ART. Elizabeth explained:

*“Because we find that a client who is on ARVs, taking them and sees that they are working, two months, three months down the line, she’s wearing this sangoma attire. We really don’t know what is happening in their minds, or they want to grab both – this side and this side, this side and this side.”*

Nancy attributed this to upbringing:

*“Others are still relying on the herbal medicine. They don’t want to use ARVs. They just go to these inyangas and take the bottle, herbal*

*bottle. Then you'll find that the person will die quickly, because they were supposed to take the ARVs instead of this bottle, because it won't help . . . It is because they rely on inyangas, the majority rely on inyangas. That is how they were brought up."*

The researcher was informed by one interviewee that a month's supply of "uBhejane" would cost approximately R1 000, whereas ART is supplied to patients free of charge. This led the researcher to wonder whether some patients feel more confidence in a remedy for which they are charged. The idea that nothing valuable is offered free might cast suspicion on the efficacy of ART.

The fact that the Minister of Health has issued a number of misleading statements regarding the toxicity of ARVs, while at the same time joining the KZN Health MEC and eThekweni's mayor in encouraging people to use uBhejane (Cullinan 2006; IRIN 2006), must contribute to people's uncertainty about how to manage their health. Another factor is that ART requires strict lifelong adherence, whereas some traditional remedies are thought to effect a cure, or at least provide an easier treatment (IRIN 2006). A traditional approach to illness is preferred by some people because of its cultural acceptability (AVERT.org 2008b). Finally, traditional healers can offer the personal attention which may be lacking in busy clinics and overcrowded hospitals (Iliffe 2006).

### **5.3 WILLINGNESS TO TEST**

The barriers to testing uptake even where testing services are relatively easily available and ART is on offer are numerous and complex, as has been discussed. What remains in question is how some people overcome the barriers already mentioned and choose to test while others do not. In this section gender differences are explored and ideas for effecting attitude changes are discussed.

### 5.3.1 Male reluctance and female willingness to test

When asked whether they noticed any gender differences in willingness to test, all of the participants stated that women were more prepared to test than men. Elizabeth replied to the question like this:

*“Eh, that’s a given! The health institution is a women’s thing.”*

At least seven different reasons were put forward to support the perception of higher female willingness to test:

1. Women are encouraged to test during pregnancy since HIV testing is offered routinely as part of antenatal care (Aidsmap 2004).
2. Because women use health care facilities more often than men, both for pregnancy and for child-health issues, women feel more comfortable in a clinic setting. A clinic is more familiar and thus less threatening to a woman than to a man.
3. Women are the primary caregivers in the communities, and the sense of responsibility for their children acts to override the effects of stigma. They will do for the sake of their children what they would not do for themselves. Eva responded in this way to the question of why willingness to go for testing is higher amongst women:

*“A woman thinks of the unborn child. I am saying ‘I am positive, but what about my child?’ You know that thing for the child? My child, I must protect, my baby, from being HIV positive. Then I will decide, ‘Let me go and test, so that I will see where I stand, because of my unborn baby.’”*

4. Women were perceived by some interviewees as being fundamentally different to men in their ability to talk amongst themselves about the problem of HIV and AIDS. As Eva put it:

*“Women are people who don’t keep things to themselves. They really preach the word, ‘Hey, you go and test, you go and test!’ Men are very contained and selfish and they don’t expose their feelings anyhow, they are not like us.” You know, we talk and talk and you know I think that makes the women come and test.”*

5. Nancy and Elizabeth believed that HIV-positive women became sick more quickly than HIV-positive men. Physical symptoms motivated them to test. The reasons given for this difference were the belief that a woman’s body traps infected body fluids and thus increases exposure and that women experience more stressful living conditions than men.
6. Men may find it more difficult to attend a clinic because of their employment situation. In some communities the men are away for the working week, or even for a whole month at a time. Testing is not available on Saturdays, so leave from work must be negotiated in order to test, then again to collect CD4 count results if a positive serostatus is found. Thereafter more leave will be needed in order to attend adherence classes and to be initiated onto ART. This is inconvenient and acts as a deterrent to employed men.
7. Men were also seen as more likely to engage in denial. Gertrude reported:

*“They don’t like to test. They tell you that they are just sick, they don’t want to test, they say, ‘Why should I? Eh, it is only that I’ve got ‘flu today, not that I’m sick.’”*

Another manifestation of male denial noted by Gertrude was in the perceived unwillingness of men to make use of condoms at the female partner’s suggestion, accusing her in turn of unfaithfulness:

*“If their wife wants to use condoms, ‘I don’t think we should use condoms! Why?! Why?! You don’t behave well, you have other friends . . . !”*

Such gender differences can be self-perpetuating as women who have tested speak to other women and encourage them to test as well. This was highlighted in the excerpt from Eva’s interview transcript quoted earlier when she described women’s to testing in evangelistic term, *“Women . . . really preach the word!”*

### **5.3.2 Changing attitudes to testing**

Participants had many different ideas of how testing uptake could be increased. There was, however, general agreement that ignorance was not to blame. The respondents portrayed a picture of communities remarkably well-informed about health issues, yet unwilling or unable to make the necessary changes in behaviour. This insufficiency of the provision of information to alter the effects of stigma and discrimination and to effect behaviour change has been noted by other researchers (Iliffe 2006; Skinner & Mfecane 2004), and has been ascribed to a lack of personal autonomy and the fact that increased awareness of AIDS does not necessarily result in an increased sense of personal risk (Day *et al* 2003; Iliffe 2006).

The perceived mismatch between knowledge of HIV and low voluntary testing uptake presented a problem to the interviewees. The opinion was that if a lack of knowledge could account for the poor response in the face of available health care, then the obvious remedy would be further health education. What was clearly disturbing to all of the research participants was the conviction that people did not automatically act on the information received. As long as this applied to the communities in which they served, it engendered a powerful professional frustration. Nancy commented with strong feeling:

*“You know, these people can amaze you! They know everything, but they don’t want to do what is supposed to be done for their life.”*

However for several research participants the experience was especially poignant because it was personalised. They spoke of close family members, friends, and even spouses who were fully aware of the facts about HIV and AIDS and yet did not access the health care on offer to them. Interviewees expressed grief and bewilderment at the persistent denial amongst those nearest to them. Miriam said with feeling:

*“I don’t know, I don’t know, because even in my place there is one person who is having all kinds of HIV symptoms, but when you confront her and say, ‘You must test for HIV and do this and this,’ she will say, ‘No, I’ve done everything and they say I have nothing, that’s all.’ But she is dying. She is skin and bone. I don’t know what really to do . . . I don’t know.”*

Elizabeth spoke of the conflicts which ensued at home:

*“At a community level, yes, we can shout, we can say . . . but it is another thing in my home! Truly speaking, even for myself it is very, very difficult at home. I can preach it to the next person: ‘Condomise, come test yourselves’ . . . but at home, it is a struggle . . . I have tried to counsel him (her husband) but I am not winning, so I have just given up trying.”*

Despite these frustrations, the participants offered suggestions for what might help to change attitudes. Nancy believed that health authorities seriously underestimated the extent of the problem in the rural districts, and recommended that campaigns be held in these areas. She envisioned working with local leaders and indunas, and planning a big community event with special speakers. An on-the-spot HIV testing service would be available:

*“The best way is to go there in the rural areas. They must call the very big Imbizo, then you have a tent there, others are addressing the Imbizo, and others are busy testing.”*

Schemes which offered a reward in the form of material or financial incentives (payment or gifts) were also seen by some respondents as likely to increase testing uptake. Gertrude responded enthusiastically to the idea of a financial incentive:

*“Oh! Because everybody wants money, they will come! Everybody! They will even push their children, ‘You go and test!’, because they want money.”*

However if a competition was involved, for example the “Right to Know” campaign sponsored by Discovery Health and Sunday Times ([www.righttoknow.co.za](http://www.righttoknow.co.za)), some interviewees were uncertain whether people in rural areas really would benefit. Thomas expressed scepticism:

*“It may confuse people. People from the rural areas, how are they going to follow the instructions? Are they going to understand everything? . . . So I want to say, the competition is ok, but it is only helping people who have got cell phones, land lines, faxes, whatever, so that you can really get communication.”*

A competition was also seen as potentially open to corruption. Miriam had heard of CD4 counts being bought in order to access disability grants, and thought something similar might result.

Elizabeth saw potential in school outreaches, where testing would be portrayed as “cool”. She reported groups of children coming to test during school holidays, and noted that these groups demonstrated cohesion and offered their members support.

Thomas described an approach characterised by caring and integration of services at clinics. Clinic staff should be proactive in meeting patients at their point of immediate need, he felt, and he described it like this:

*“For example, the client might come for burn wounds, for a dressing. Try to help them. Get a wheelchair for the client, find out how did it happen, has he seen the doctor, find out who the patient stays with at home. Ok, then you can integrate the HIV/AIDS issue: ‘Have you ever been tested? How about testing today? Or are you in pain today, would you be able to come next month to test?’ A couple of days or weeks down the line, when the person has healed a bit, you will see him coming and saying, ‘Can I test?’”*

He argued that by establishing rapport, by demonstrating interest and concern for the patient, a relationship of trust could be developed. In this manner, he felt, the issue of testing would not be isolated from the broader context of health services, but would be presented as a natural part of the whole.

#### **5.4 ATTITUDES TO VCT AND OTHER TESTING MODELS**

This section of the chapter deals with interviewees’ responses to questions related to the second and third research objectives, namely:

- How do people feel about the special approach to HIV testing, which requires both pre- and post-test counselling?
- How might attitudes to testing change if an HIV test was offered routinely to all patients attending a primary health care facility?

Proponents of routine testing argue that the pre-test counselling required by VCT protocol may act as a barrier to testing (Koo *et al* 2006). The researcher hypothesised that the pre- and post-test counselling coupled with the emphasis on confidentiality might inadvertently serve to increase the stigma

surrounding HIV testing. Whereas other life-threatening or chronic health problems were diagnosed and treated in a standard way, HIV testing and treatment were “hedged around” with unique procedures designed to protect patients from discrimination (Cameron 2006:7). The researcher anticipated that patients could harbour negative feelings about the counselling process because it added a time delay or that the counselling drew attention to them and thus increased the risk of stigma. It was considered that a “normalised” approach would be preferable, and this idea was explored with interviewees using the questions and prompts from the interview schedule. These questions encouraged the research participants to express a range of attitudes to the current approach to HIV testing, which are discussed in the next section.

#### **5.4.1 Counselling and confidentiality**

Counselling was regarded by all of the interviewees as “good” and “necessary”. The counselling process was seen to provide essential information about HIV, AIDS and ART. But, for the research participants, counselling offered far more than information, presenting an opportunity for the creation of a rare environment of trust and honesty in a climate of doubt, fear, suspicion and intrigue. Long after the initial pre-test counselling, ongoing counselling at follow-up appointments provided, amongst other benefits, a “confessional”.

The value of having someone to confide in was illustrated in a story told by Nancy. Earlier that day she had counselled a repeat client, a man well-known to her from his regular visits to collect ARVs. He had come in presenting with symptoms of a STI and during the course of the counselling session he confessed to her that he had recently had unprotected sex. While he found it difficult to talk about his actions to the sister he also wanted to tell her what he had done. Nancy emphasized the importance of counselling within the clinic setting, commenting at one point that *“people are not just sick in body, they are sick in their minds”*. Another interview, Lily, herself HIV positive, said of a counsellor, *“You can tell her anything”*.

In his book, “The African AIDS Epidemic,” author John Iliffe (2006) describes nurses who were hostile to enforced confidentiality because of the secrecy which they felt was in conflict with full performance of their professional responsibility to contain the epidemic. By contrast most interviewees in this study saw the privacy and confidentiality of individual counselling as very important. One sister described it as a “conducive environment”. Because of the ever-present problem of stigma, nearly all of the research participants believed that one-to-one counselling was essential. Some felt that pre-test counselling could be offered in a group if patient numbers rendered individual counselling impossible. In this case group counselling could have its place as an emergency response, but not instead of individual counselling. Eva felt that people would not be able to concentrate on information given during pre-test counselling if this was done in a group, as they would be distracted by the presence of others. Theresa felt that only within the safety of individual counselling would a patient be likely to speak about important personal issues, such as rape.

Dorothy had a different perspective. She believed there were serious negative effects associated with the emphasis on confidentiality and thought it contributed significantly to stigma:

*“To me, I think it is the way it was started – ‘This testing is confidential, nobody is going to be told’ – as if this thing is something private. To me, that is part of it that contributed to people not coming . . . the minute you tell a person that it is confidential . . . to me, I think that is one of the things that has contributed to the stigma . . . I think the confidentiality of it is not good, because really, they must talk, they must really talk.”*

Elizabeth expressed similar sentiments about the secrecy surrounding testing. She felt that openness was preferable to strict confidentiality. Nevertheless she believed that people differed greatly in what they were able to cope with,

and for the sake of some it was necessary to maintain the protection offered by individual counselling.

Interviewees were asked whether there was a noticeable difference in time spent in post-test counselling of sero-positive patients as opposed to sero-negative patients. The researcher referred during the interview to a community where it was claimed that sero-positive patients could easily be identified by the length of time they stayed in post-test counselling. Responses to this question were varied. Some interviewees insisted that similar amounts of time were spent in post-test counselling regardless of whether patients had tested positive or negative. Eva denied that negative patients received “shorter” counselling, insisting:

*“When someone is negative, we become happy. ‘Let me keep this person negative!’ you really emphasise”.*

Nancy, on the other hand, felt there could well be a difference in counselling time, saying that a patient who learned that she or he was negative would go running out of the counselling room to celebrate the good news. Several participants felt that the post-test counselling time was determined largely by the patient herself or himself and how much she or he wanted to discuss.

Interviewees were also asked whether patients sometimes declined testing after receiving pre-test counselling. Several participants responded that they had not experienced this. Other participants said that it did happen but very rarely. Eva said she felt it would reflect poorly on the counsellor who had conducted pre-test counselling. Theresa was particularly encouraging about the effectiveness of pre-test counselling:

*“You know, after the pre-test counselling we are surprised. Everybody wants to go, everyone, in such a way that when you say, ‘the first one must come’, they all rush”* (she then clapped her hands together to suggest hurry).

In summary, the counselling currently offered at HIV testing facilities was regarded by all the research participants as very important. Information could be given in a group setting but individual counselling offered trust, a rare commodity in communities impaired by fear and suspicion. Whether the emphasis on confidentiality might be having unintended consequences, however, was a matter of concern to some research participants.

#### **5.4.2 VCT and routine testing: observations on HIV exceptionalism**

In this section the interviewees' comments on the effects of HIV exceptionalism within current clinic policy are explored. Several perceived programmatic inconsistencies are highlighted, and the implications for patient willingness to test are discussed. A process of normalisation of procedures which appears to be occurring spontaneously is also described. Finally, participants' attitudes to a policy of routine testing are reviewed.

##### **5.4.2.1 Exceptionalism of HIV procedures**

"HIV exceptionalism" was not a term with which interviewees were familiar. However, certain procedures of VCT which rendered HIV testing and treatment exceptional they could easily identify such as voluntary testing, confidentiality, double counselling and the separation of facilities for HIV patients. This partition of facilities has its roots in the time before treatment was available when there seemed little point in widespread testing within a medical context (SAIIA 2004). However, this separation has been encouraged by an exceptionalist approach. Although not often articulated as such, a strange discrepancy appears in the current testing model. HIV exceptionalism insists on confidentiality for the client. It also insists on special procedures (pre-test counselling and informed consent) which in practice results in a protocol of separation (Cameron 2006). Far from being an act of discrimination, the separation is intended for the good of the patients themselves: a private entrance to VCT testing, away from the eyes of other patients; a special fast queue for collection of ARVs; a separate venue to

guard against stigma, possibly even to offer protection from infections which could be picked up from other patients.

In addition, for reasons not understood by the interviewees, HIV and AIDS patients are issued with clinic files that are a different colour to the standard clinic files. A patient walking through the clinic with an “HIV file” held under his or her arm might just as well be wearing a T-shirt proclaiming his or her status, as Thomas commented:

*“I can see that it could create a stigma . . . When those that are HIV positive are running around the clinic with the white files, and only those that are negative have the brown folders. You can see that it is a problem . . . It shows, yes. ‘Why do you have a white file? Why do I have a brown folder?’ We are trying by all means to avoid that. And look, people want to scrutinise everything.”*

Theresa expressed her thoughts about it like this:

*“And also with the file. I don’t get the idea why the clients are separated. I really don’t understand why. Because these files here in the clinic, they are brown, mine are yellow or white. And even the clients, when they carry this file, he is ashamed, because he knows these are files for ARV clinic, so everybody knows I am attending that clinic.”*

Many clinics have a separate park home or trailer which is used for HIV patients. To the researcher this looked as if it was there to provide additional space, to accommodate increased patient numbers resulting from a health crisis unforeseen at the time the clinics were built. Gertrude explained that the park home at her clinic had been a donation from a non-governmental organisation. It did not yet have electricity, and it was cold and dark on the day of the interview, yet she expressed gratitude for the facility. However, the physical separation from the main clinic seemed to the researcher to underline the partition between patients who did, or did not have, HIV.

Theresa explained how patients were seen inside the main clinic, and might then be referred to the HIV unit if it was thought they needed to be tested. The act of walking out of the main building directly to the HIV unit would make it obvious to any onlooker that the patient was going for an HIV test. For many, this would be too difficult and they would choose to leave. She said:

*“The client won’t go there; he will just go out the gate.”*

She argued for an all-in-one type of consultation, in which the nurse attending to any patient would be able to follow through with counselling and an HIV test without the patient leaving the consulting room.

Elizabeth similarly expressed exasperation with the policy of running a separate clinic for patients on ARVs, arguing that it did not provide the intended protection at all. She said separate queues were operated so that people’s differently-coloured cards or files were not noticed by other patients, and a separate dispensary was provided to offer privacy and faster collection, but the effect was to make the person’s serostatus all the more obvious.

Interviewees were also aware of a non-physical separation of patients, a distinction in the way patients were treated. Theresa gave the following example:

*“I think for instance in the other clinic it is very easy for the nurses to say (in a loud voice, as if speaking across a hall), ‘Hey, check the sugar for me for that patient!’ But you cannot say, (loudly), ‘Please take HIV for that patient!’”*

The interviewees explained that many of the measures designed to offer HIV patients protection from being identified and possibly stigmatised within the clinic setting were in fact betraying their identity through a policy of separation. This was evident to the interviewees, and while they appreciated the intention

to guard against discrimination, the inconsistencies which occurred in practice were discernible to them and caused them frustration.

#### **5.4.2.2 The move toward normalisation**

In nearly all of the interviews participants described measures they were implementing to compensate for exceptionalism. Several explained how they used other chronic conditions, such as diabetes or hypertension, as reference points by which to “normalise” HIV and AIDS for patients. Nancy put it this way:

*“ . . . These are lifelong conditions, both of them, high blood pressure and diabetes . . . That is what we tell them. We tell them that HIV is like the other conditions, because you will be taking the tablets on a daily basis, like the diabetic people, you will be taking the treatment like hypertensive people . . . Do you remember long ago there was a very big stigma if you had TB? It is like that now. They prefer to be called TB patients rather than HIV.”*

Gertrude described the approach at her clinic:

*“You know what we do, we are trying to mix them so that nobody can say, Oh that one goes to that clinic; he or she is HIV positive. We are trying to do away with that. So we mix them. We take all the chronic, who have come to collect treatment . . . Why do we do that? Because of stigma. HIV. So we just mix them so that nobody can see, those are HIV patients . . . It’s much, much, much better. Because nobody knows, that one has HIV.”*

However, Dorothy felt that the confidentiality required by VCT protocol meant that HIV and AIDS were never really treated like other chronic conditions. Special procedures set HIV and AIDS apart. She argued for an increase in openness and disclosure for HIV testing:

*“With me, I would stop the confidentiality. Go for testing like sugar and blood pressure.”*

Gertrude described all chronic patients being grouped in the park home with the deliberate purpose of “mixing them up” to combat stigma. Elizabeth bemoaned the ineffectual efforts at her clinic to disguise HIV patients. As she put it:

*“We try to mask it by including TB, and other communicable diseases, but it is obvious.”*

Eva disagreed with this approach. She felt the risk of cross-infection posed by integrating patients was too great:

*“The procedures and systems running in HIV, they need their space. It’s the same like TB, we cannot say TB must go and mix with other people, because with us, HIV, our people are prone to infections. Our people are having TB. Imagine now, we are mixing them with other people. What about the infections? Because now we are translating the infections to other patients.”*

The risk of nosocomial infection was discussed recently in an interview with Dr Eric Goemaere, medical co-ordinator for MSF in South Africa (MSF 2008). At several clinics in Khayelitsha which have recently begun providing fully integrated TB and HIV services it has been shown that the relative risk of such infection has hardly increased, since many undiagnosed patients have in fact been sharing waiting rooms for some time. In the Khayelitsha clinics the extensive use of natural ventilation, controlled patient flow and ultra-violet light have been employed successfully for infection control.

Many interviewees argued the benefits of a normalised, integrated approach. Lily explained that having a mother who was diabetic and a nephew with chronic cardiac problems had helped her to place her own diagnosis within

the context of other manageable lifelong health problems. She expressed it in this way:

*“You know that (name of her nephew) is using his tablets for the whole of his life, from thirteen years up until the full of his life. Now he is 21. He accepted, and he has got something like a washer – you can hear it beating. But he did accept it. That’s the thing that I did ask myself the time I went for testing. There is this young boy, accepting his disease. Why must I not accept my disease? So I think maybe just because I was living with my mum who has sugar, so he is using the tablets for the rest of his life. And that young boy, what about me?”*

In summary, the research participants expressed views in favour of a normalised approach to testing and treatment for HIV and AIDS, for the purpose of reducing stigma and discrimination.

#### **5.4.2.3 Attitudes to routine testing**

During discussion about perceptions of HIV testing and treatment programmes the researcher asked interviewees for their comments on a routine opt-out approach. Some had heard of PITC but were not sure what was meant by it. To make certain that there was a common understanding of the term, the researcher presented a simple description of routine testing and how it might operate in their clinic, and asked for observations on whether such an approach would be effective and acceptable. Since HIV tests are offered routinely to pregnant women as part of standard antenatal care, the concept was easy to communicate to interviewees. Several interviewees expressed their approval, for example:

Thomas: *“So I think, yes, the routine testing is a good idea, an ideal kind of activity.”*

Gertrude: *“I think it is a good idea . . . a good thing, yes.”*

Eva: *“This is nice . . . it’s a good thing . . . they will come, because at antenatal care clinic, that is exactly what we are doing!”*

Elizabeth: *“Actually, what we should be saying for every person, ‘Have you tested for HIV?’”*

They welcomed the suggestion of measures which might increase testing uptake. However, some had reservations, saying that while they would personally be in favour of such a policy they did not think patients would accept it. Theresa felt it might lead to people not attending the clinic. She said:

*“It is like forcing them. And that thing might decrease the number of people coming to the clinic.”*

Gertrude pointed out that in order to be effective, routine testing had to be an overt clinic policy, something which was publicly known. A patient who returned home from the clinic and reported she had been tested, under current policy might draw criticism. In Gertrude’s words, a partner may demand:

*“Did you do testing? Why?!!”*

Gertrude’s comments suggested to the researcher that voluntary testing may be perceived by some patients as a burden. To voluntarily have oneself tested indicates a perception of personal risk, which the researcher surmised could pose problems of trust within a relationship. The researcher reasoned that voluntary testing implies either that the person’s own behaviour has placed them at risk, or that their partner’s behaviour has placed them at risk. Choosing to test could then be construed as pointing a finger at one’s partner or as an admission about one’s own behaviour. This is illustrated by Gertrude’s earlier quote, where the patient’s partner demands to know why the patient has been tested and hints at a breach of trust.

Gertrude suggested that if routine testing were official policy it would be easier for some patients:

*“Others will tell you that, No, if it is a policy it will be much better, but at the present moment . . . we were told, if I feel like, I can go for testing, if I don’t feel like, I don’t.”*

Within the context of routine testing a person who returns home from the clinic having tested has not done anything to suggest they perceive themselves to be at risk either through their own behaviour or their partner’s. They have merely complied with stated clinic policy. Gertrude’s views imply that for some patients routine testing could in fact be more “voluntary” than VCT because it takes the burden of a stigmatising choice off the individual.

The purpose of routine testing is to integrate and normalise the disease (SAIIA 2004) by communicating to patients that HIV testing is a standard part of health care. As this discussion has attempted to illustrate, the research participants in general showed a warm interest in moving toward such an approach.

## **5.5 OBSERVATIONS REGARDING PATIENT BEHAVIOUR**

This section reports additional observations made by the research participants on two characteristics of patient behaviour relevant to the question of willingness to test: firstly, that where people are concerned, “one size does not fit all”, and secondly, that patients’ behaviour may be influenced by their “need to please” clinic staff and authority figures.

### **5.5.1 “People are not the same”**

The researcher noted that interviewees often modified their replies to a question or prompt. An answer describing a particular behaviour, for

example male willingness to test, would be given in general terms and would be followed by the proviso: “. . . *but others are not like this*”.

Elizabeth, commenting on her own experience of being HIV positive, put it eloquently:

*“Ever since I found out, it’s not an issue. I’m free. I can talk about it. But there is one thing I understand, that we are not the same. For other people, it’s not like me . . .”*

Thomas, referring to delayed uptake of testing, said:

*“People are starting to change now, and the reason for that is many people have died in front of them . . . but people are not the same, as I have said to you, the huge majority of people are still attached to stigma, they still see themselves as not being part of it.”*

Miriam, commenting on publicity testing and claims made by public figures about their serostatus, said:

*“Some will believe, some don’t.” And later: “People are not the same.”*

Dorothy, also on publicity testing:

*“Some are being encouraged. People are not the same.”*

It was the researcher’s impression that this was not offered as a disclaimer in the sense that an interviewee wanted to excuse a potential inaccuracy. Rather, it appeared to be a genuine observation about how much people differed. Iliffe (2006:80) quotes a Ugandan woman who said, “Everybody suffers from ‘*silimu*’ (a local term for AIDS) *differently*”.

The phrase, “*people are not the same*” was repeated by nearly all of the interviewees, and it served as a reminder to the researcher of the need for

humility in a study of this nature. There is no simple answer to the question of why people display an unwillingness to test.

### 5.5.2 The need to please

Against the background of patient individuality, one particular pattern of behaviour described by many of the interviewees stood out to the researcher, that of the patients' need to please clinic authorities. Elizabeth related the story of a patient on ART who despite faithfully attending all appointments and collecting medication on designated days for two years, had come in and admitted that she had actually been using "uBhejane" and not ARVs. She presented the sister with all the medication she should have used, and begged to be forgiven and allowed to continue with treatment. The sister's interpretation of this behaviour was that the patient wanted to keep both options open, and needed to please the clinic staff in case she decided to return there later.

Miriam reported a similar observation:

*"Some will come and collect treatment but they never take it. They will just keep it. We only recognise it from their CD4 count when we find there is no improvement . . . I think that is to please us. I don't know why they are lying about their life. They're giving us the wrong impression."*

Thomas described patients taking health information pamphlets which were later found torn up outside the clinic.

Apart from frustration to clinic staff, there were other important implications of this trend which occurred to the researcher. Firstly, the patients' need to please staff suggests they could be susceptible to the attitudes projected by nurses and counsellors. For example, a counsellor saying, "This is a secret between the two of us" in reference to a positive test result might communicate to that patient, "This is something to keep secret". An African

proverb states: *When deeds speak, words are nothing* (The Quote Garden 2008). So, although sisters and counsellors would verbally encourage patients to disclose their status to a supportive friend or relative, their assurances of confidentiality might colour the experience “private”. A point of interest is that in isiZulu the word *“imfilho”* is used for both “secrecy” and “confidentiality” (Seidel 1996:423).

Secondly, the overall policy at a clinic would, in the researcher’s opinion, send a strong signal to patients who feel the need to please. For example, if people expect to be told what to do by figures of authority, and are not often encouraged to evaluate health care decisions for themselves, testing which is emphasised as “voluntary” in nature could be construed by them as “not necessarily recommended”. It occurred to the researcher that a VCT approach with its emphasis on individual choice might thus inadvertently be telling patients, “It doesn’t matter to us”, or even, “We don’t think you need to test,” whereas a clinic which offers routine testing tells them, “We really think you should test”. This illustrates how difficult it is to ensure that the choice to test or not is truly voluntary, as is the question of whether socio-cultural factors confuse the informed consent process (Kaldor & Millwood 2005).

These additional observations made by research participants, namely that each patient is unique and “one size does not fit all”, but that for some there is a need to please clinic staff, are offered to increase understanding of the central question of testing uptake. In the next section the interviewees’ suggestions for improving health service related to HIV testing and treatment are reviewed.

## **5.6 RESEARCH PARTICIPANTS’ RECOMMENDATIONS**

At the end of each interview, participants were asked to share their recommendations. The researcher encouraged a broad range of ideas by saying, “If you had the power to change one thing about HIV testing policy. . .” or “If you were the Minister of Health and had the power to make changes to

existing testing and treatment programmes . . . what would you do?" This served to generate a wide array of suggestions. All interviewees had many ideas and appeared to enjoy the chance to articulate them. One sister admonished the researcher for relying on the dictaphone recording, and urged that the recommendations be written down.

The participants' recommendations have been grouped into three categories: suggested changes involving staff numbers or training, suggested changes to clinic procedure, and suggestions for community level interventions.

### **5.6.1 Staff changes**

Interviewee's recommendations about staff improvements were numerous, mostly signifying the perception that clinics were understaffed. Both nurses and doctors were felt to be in short supply, and it was mentioned that higher salaries would act as an incentive. Gertrude and Theresa advised that clinics should offer outreach services into the communities where orphans lived with grannies who were often poorly informed about the facts of HIV and AIDS. Theresa suggested that more community workers should be made available, but stressed the need for close supervision.

Eva spoke passionately about the potential benefits of developing the professional nurses' training so that they could be used to initiate ART. She saw this as an attainable means by which waiting time for patients could be reduced.

Miriam articulated the sense of isolation experienced by professional staff at remote clinics. She felt that it would be helpful if there could be more support offered in the form of contact with provincial and national health care officials. Nancy referred to the stresses she experienced in her work and expressed her need to receive counselling support herself.

### **5.6.2 Changes to procedures**

Many interviewees' suggestions involved changes in the way clinic procedures were conducted. A common focus was the problem of separation of services between HIV patients and general patients, with the recommendation being to integrate the approach. Some urged a move to routine testing.

A few suggestions sounded impractical or even impossible to the researcher, such as Miriam's idea that ART should not be contingent on attending adherence classes, or Gertrude saying that CD4 count results should be returned on the same day. While these recommendations may not be realistic, they do illustrate the frustration experienced by the research participants due to delays in treatment availability.

Many suggestions related to how testing could be increased. Mobile clinics and community outreach programmes were thought by Nancy and Theresa to be an effective way of reaching rural areas. School awareness programmes were advised by Elizabeth, who also felt there would be an advantage in offering food parcels to patients on ART. She saw this as an acceptable incentive, and preferable to a financial reward.

The need for patient tracing was highlighted by Dorothy. She reported that patients sometimes simply disappear, and staff members are left wondering whether they have died, moved away, or started attending another clinic. This is a problem which has been written about elsewhere (IRIN 2008a).

Much debate occurred over the question of disability grant regulations. Dorothy and Gertrude reported that some patients deliberately tried to keep their CD4 counts low so as to retain their grants. The obvious conflict to health care was of great concern to interviewees.

### **5.6.3 Community level changes**

This final category of participants' recommendations focuses on changes needed at a community level. A wide variety of opinions was held on the question of incentive schemes. Some participants felt there was merit in offering incentives, even fairly minor incentives such as a food parcel or small household gift. Thomas referred to the National Blood Donation Service's free tea and biscuits given to donors, and suggested something similar as an encouragement to people testing for HIV.

Whether public figures going for testing served as an inducement was an area of divergent opinion. Most agreed that it could only be of benefit if the public person involved was willing to disclose their status after testing. Some felt that public testing of community leaders, also with disclosure, would be helpful in sending a message of support.

Nancy spoke passionately about the need for greater intervention in issues of drug and alcohol abuse. A person battling AIDS-related illness or trying to adhere to a strict ARV regimen can ill afford the potential health risks of substance abuse (AIDSbuzz.org 2008a). Nancy believed health authorities should direct greater efforts at combating problems of this nature.

The recommendations put forward by the research participants illustrate their perception that there is a need for public health care authorities to actively address the issues which were identified as obstacles to HIV testing uptake. Their readiness to engage in discussion directed at seeking solutions demonstrates the research participants' commitment to improving the level of health care service provided to the public.

## **5.7 CONCLUSION**

In this chapter the major findings of the study have been presented according to the themes which emerged during data analysis. These have shown that

in the view of the research participants there are significant barriers to testing uptake, including stigma and discrimination, difficulties with access to clinic facilities, bottlenecks in the public health care system and an inclination toward traditional medicine. There is a perception that willingness to test is currently influenced by gender-related factors. Attitudes to VCT were discussed, with emphasis given to the research participants' observations on the exceptionalism displayed in certain clinic procedures and the attempts being made to normalise practice in order to reduce stigma. Interviewee's views on routine opt-out testing were explored. Additional observations made by the research participants on patient behaviour were reviewed, and attention was given to suggestions and recommendations which were made for improving testing uptake. In the next section these findings will be developed to inform the conclusions and recommendations of the study.

## **CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS**

---

The central research question of this study was whether, in the view of the research participants, HIV testing rates are being negatively affected by HIV exceptionalism demonstrated in current VCT practice in public health facilities. In this last chapter the findings of the study are presented in summarised form in order to introduce the major conclusions and recommendations which follow from the research.

### **6.1 SUMMARY OF FINDINGS**

This part of the chapter has two sections. The first contains a review of the main themes reported in the interviews. The second contains a brief analysis of current testing practice using the questions suggested in Chapter 2, which are based on the ethical standards of respect for persons, beneficence and justice.

#### **6.1.1 Summary of major themes**

Participants reported that, in their experience, many people postpone testing for HIV until the onset of symptomatic illness. Stigma and the fear of discrimination were perceived by the research participants to present major obstacles to both the uptake of testing for HIV and the beneficial disclosure of a positive serostatus. Interviewees said that they observed gender differences in willingness to be tested, with women generally more likely to make use of available health care services than men. Men appeared to the research participants to be more susceptible than women to the effects of stigma and resultant denial.

The research participants identified several other barriers which were thought to be significant factors in poor testing uptake. These included difficulties with physical access, particularly when patients are too sick to make use of public transport; problems with time access, since VCT and ARV services are not available at public clinics during weekends or public holidays; delays and long waiting lists between time of testing and initiation onto ART, which sometimes results in the death of the patient before ART is started, or the patient being otherwise “lost” to the health care system; and claims that traditional medicine offers a cure or an easier treatment regimen, which confuses people and can lead to poor uptake of testing as well as poor compliance with ART.

Educational efforts to increase awareness of HIV/AIDS were thought by the research participants to be essential but not sufficient to bring about change in willingness to be tested. There was limited support amongst interviewees for incentive schemes to encourage testing uptake, with some participants feeling anything that increased testing was worthwhile and others expressing scepticism.

Other studies (Birdsall *et al* 2004; Van Dyk & Van Dyk 2003a) have reported that problems with counselling quality and availability may partly account for poor rates of testing. Participants in this study did not identify counselling services as problematic, and instead testified to the vital role it plays. However, it must be remembered that this study reflects the views of nurses and counsellors rather than patients.

While all participants believed counselling was valuable and indeed essential, some participants felt that the emphasis on confidentiality had unintended negative consequences by creating an atmosphere of secrecy that could increase stigma.

Exceptionalist procedures at clinics, specifically the provision of separate facilities for HIV/AIDS and patient files of different colours to other patients, were thought by participants to discriminate against rather than to protect patients presenting for testing or treatment. The introduction at clinics of

informal measures intended to normalise HIV/AIDS, such as the integration of all chronic patients, illustrates the belief amongst staff members that reduction of stigma is more successfully achieved by normalisation of HIV/AIDS than by exceptionalist procedures. Routine opt-out testing was generally regarded in a positive light.

The importance of pleasing authority figures was illustrated in two aspects of the study. Firstly, the researcher noted in the interview context that participants wanted to ascertain that permission had been granted by a senior staff member before agreeing to participate in the interview. Secondly, participants reported that patients' behaviour was sometimes motivated by a wish to please clinic staff, such that an appearance of compliance might be created even when the patient was not compliant.

Participants made suggestions for changes in the areas of clinic staffing and clinic procedures and recommended interventions at community level.

### **6.1.2 Analysis of current testing model**

In Chapter 2, three questions based on the principles of the Belmont Report of 1979 were suggested for assessment of an HIV testing model. This section tries to answer these questions using the research material generated in the study. Each of the three questions is considered in turn.

- 1. Does the testing model rely on voluntary participation, and does it follow the informed consent process, by providing information in a manner which enables comprehension?*

The current HIV testing policy emphasises voluntarism and the informed consent process. However, the findings of this study suggest that there may be instances where the voluntary nature of current practice makes testing more difficult. Testing voluntarily, except in the case of rape, implies a perception of personal risk attributable either to own risky sexual behaviour or that of a partner. For some people, women in particular, the act of voluntarily

being tested could be construed by a partner as either an admission, or an accusation, of unfaithfulness. Where this is the case, the researcher contends that a routine opt-out model of testing may make it easier (and in this sense more “voluntary”) for a person to be tested, since it removes the burden of a stigmatising choice.

2. *Does the approach to testing balance risks and benefits, by providing a sufficient return on health-seeking behaviour to compensate for possible risks? Do the promised benefits outweigh the risk of harm?*

In general, the benefits offered by current testing practice sufficiently outweigh the attendant risks. Specifically, the advantages of knowing one’s status and gaining access to treatment outweigh the risks of discrimination, delays and the mental anguish which may follow positive diagnosis (Van Dyk & Van Dyk 2003b). However, the exceptionalist policy of separation of facilities adds to existing barriers to testing by further increasing stigma. In this sense it may be in breach of the principle of beneficence.

3. *Does it deny to any group of people the benefits to which they are entitled, or does it place on them an excessive burden?*

The multiple barriers to testing uptake which have been detailed in this study constitute a burden which can reasonably be described as excessive. Cumulatively, they may be seen to deny to certain people the benefits of treatment access to which they are entitled. However, the researcher contends that this burden is exacerbated by certain features of current testing practice. Firstly, the exceptionalist measures outlined in Chapter 5 serve to increase the stigma related to a positive serostatus, and this acts as an additional burden, possibly sufficient even to deny some people the benefit of access to treatment.

Secondly, Rennie and Behets (2006:84) suggest that: *“The establishment of any opt-out testing policy sends a powerful normative message: it appears as*

*an institutionally sanctioned judgment that being tested for HIV is the correct thing to do.”* Given that both clinic staff and patients are influenced by the need to please authority figures, the current emphasis within the VCT model on strict voluntarism can be argued to send the wrong message, creating the impression that testing for HIV is a personal, private affair and is not officially sanctioned. This places upon an already encumbered patient population the additional burden of having to actively make a stigmatising choice to be tested. By contrast, a routine opt-out model alters the situation by shifting the burden of choice to not being tested.

## **6.2 RESEARCH CONCLUSIONS**

Analysis of the research findings suggests that, in the experiences of nurses, there are significant barriers to HIV testing uptake which result in many people delaying testing until the onset of symptomatic illness. Exceptionalist procedures within current clinic practice, including the separation of facilities and patients, serve to increase stigma and therefore constitute a barrier to testing uptake. This may represent a violation of the ethical principle of beneficence.

In this study, counselling was not identified as a barrier to testing. However, a strict emphasis on confidentiality may be counterproductive to testing uptake because it creates an atmosphere of secrecy which increases stigma.

In certain instances VCT may not be truly voluntary. Current HIV testing practice requires an active opting-in which may pose too much of a threat for some patients because of the implications regarding their partners. This may pose a threat to the ethical principle of respect for persons.

A strict emphasis on voluntarism places an unfair burden on the patient population because it requires a stigmatising decision to be made. This suggests that the ethical principle of justice is not being upheld. Routine opt-out testing as outlined in the World Health Organisation guidelines (2007)

shifts the burden from opting in, to opting out and in so doing may provide relief from stigma.

### **6.3 RECOMMENDATIONS**

Many people in South Africa have no alternative to public health care service. In order to bring current HIV testing practice in public health care facilities in line with the ethical injunctions of respect for persons, beneficence and justice, the following recommendations are suggested:

- 1) The difficulties which patients experience in terms of physical access to public health care services should be addressed. This could involve improved clinic transport services as well as the wider implementation of mobile clinics, which would bring prevention, testing and treatment services within reach of people isolated through their distance from a public health care facility or by their inability to use public transport due to advanced illness.
- 2) Public health care facilities which offer VCT and HIV treatment services must be made available on weekends if testing uptake is to be increased. This will necessitate additional staff and possibly longer working hours for existing staff, with associated cost implications for the national budget. However, it should be remembered that routine opt-out testing has been found to be a cost-effective approach because early detection of HIV infection saves money (IRIN 2008b; Medscape 2008). The need for increased expenditure must be viewed in the light of the costs of inaction, which were highlighted in Chapter one.
- 3) Delays in the steps from testing to treatment illustrate the shortage of staff at public health care facilities. The newly appointed Health Minister, Barbara Hogan, referred recently to the current vacancy rate in the public health sector of some 46 000 nurses and 10 000 doctors, commenting on the impact which this has on morale (Health-e news

2008). Addressing this deficiency may involve incentives such as higher salaries. It should be also be considered whether professional nurses can be trained in initiation of ART so as to improve capacity within the clinic setting.

- 4) The practice of separation of facilities for HIV patients from those of other patients should be abandoned. Integration of HIV/AIDS within regular clinic services would help to normalise perceptions around the epidemic and so decrease stigma.
- 5) Testing for HIV should be presented as a standard part of health care. This process of normalisation can be encouraged through the provision of a routine opt-out approach to testing in line with the recommendations of the World Health Organisation (2007).

#### **6.4 SUMMARY OF CONTRIBUTIONS**

This study has used the perceptions of professional nurses as well as counsellors involved in VCT and ART to investigate the effects of exceptionalist practices in the current testing model, for the purpose of identifying the impact of such exceptionalism on testing uptake.

It has also proposed a framework for analysis of HIV testing models which makes use of the ethical principles outlined in the Belmont Report of 1979. Application of this framework to the current HIV testing practice as presented by the study's interview material suggests that despite the origins of VCT in human rights concerns, current practice may be in contravention of ethical requirements.

## **6.5 SUGGESTIONS FOR FURTHER RESEARCH**

The conclusions and recommendations reported in this chapter suggest that further research should be done to investigate how clinic procedures can be more fully integrated so as to minimise HIV-related stigma and thus facilitate an increase in testing uptake. In addition, the way forward with regard to implementation of a routine opt-out testing approach as described in the WHO guidelines should be explored. It should be noted that a revised approach to HIV testing would carry all the same ethical constraints and requirements outlined earlier. Thus, introduction of a new model must include careful monitoring to ensure that it adheres to the principles of respect for persons, beneficence and justice.

## **6.6 CONCLUSION**

In a recent interview Barbara Hogan, the new Minister of Health, declared that HIV/AIDS must be a priority for government (Health-e news 2008). Despite serious staff shortages and reports that some twenty health districts need urgent attention, Hogan promised to effect a turnaround in health care services within five years. She praised existing health care workers saying (Health-e news 2008:1):

*“We are blessed with incredible skills and dedication in this country.”*

Of those who had made personal sacrifices in order to care for people affected by HIV, which includes the research participants in this study, Hogan said (Health-e news 2008:2):

*“They are the silent heroes of our country.”*

## LIST OF SOURCES

---

African Commission on Human and People's Rights. 1981. *African charter on human and people's rights*. Available at [http://www.achpr.org/english/info/charter\\_en.html](http://www.achpr.org/english/info/charter_en.html). (Accessed on 7/10/2008).

African National Congress (ANC). 2007. *National policy conference commission reports and draft resolutions on health*. Available at <http://www.anc.org.za/ancdocs/policy/2007/conference/social.html>. (Accessed on 4/9/2007).

AIDSbuzz.org. 2008a. *All about antiretroviral treatment (ART)*. Available at [http://www.aidsbuzz.org/index.php?option=com\\_content&task=view&id=110&Itemid=89](http://www.aidsbuzz.org/index.php?option=com_content&task=view&id=110&Itemid=89). (Accessed on 19/9/2008).

AIDSbuzz.org. 2008b. *Voluntary counselling and testing (VCT)*. Available at [http://www.aidsbuzz.org/index.php?option=com\\_content&task=view&id=109&Itemid=89](http://www.aidsbuzz.org/index.php?option=com_content&task=view&id=109&Itemid=89). (Accessed on 19/9/2008).

Aidsmap. 2004. *Antenatal HIV testing*. Available at <http://www.aidsmap.com/en/docs/8872AA0E-26BC-44B6-B772-B21627769486.asp?type=preview>. (Accessed on 18/9/2008).

Aidsmap. 2006. *South Africans debating HIV testing: voluntary or opt-out?* Available at <http://www.aidsmap.com/en/news/DC93CD0F-BA12-4EB3-AEAF-DCF1939CD7F5.asp>. (Accessed on 14/10/2008).

Aidsmap. 2007. *South Africa: Activists welcome ambitious new AIDS plan*. Available at <http://www.aidsmap.com/en/news/69AA76D0-0B49-4D15-88CD-F16ED017B080.asp>. (Accessed on 14/10/2008).

Aidsmap. 2008. *Co-trimoxazole (Septrin)*. Available at <http://www.aidsmap.com/cms1032153.asp?type=preview>. (Accessed on 26/9/2008).

AVERT.org. 2008a. *HIV/AIDS in Botswana*. Available at <http://www.avert.org/aidsbotswana.htm>. (Accessed on 8/10/2008).

AVERT.org. 2008b. *HIV/AIDS treatment and care in resource poor communities*. Available at <http://www.avert.org/hivcare.htm>. (Accessed on 15/9/2008).

AVERT.org. 2008c. *HIV & AIDS stigma and discrimination*. Available at <http://www.avert.org/aidsstigma.htm>. (Accessed on 15/9/2008).

Barbour, R. 2001. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *British Medical Journal* 322(7294): 1115-1117.

Bassett, I, Giddy, J, Nkera, J, Wang, B, Losina, E, Lu, Z, Freedberg, K & Walensky, R. 2007. Routine voluntary HIV testing in Durban, South Africa: the experience from an outpatient department. *Journal of Acquired Immune Deficiency Syndrome* 46(2): 181-186.

Bayer, R & Fairchild, A. 2006. Changing the paradigm for HIV testing – the end of exceptionalism. *New England Journal of Medicine* 355(7): 647-649.

Birdsall, K, Hajjiannis, H, Nkosi Z & Parker, W. 2004. Voluntary counselling and testing (VCT) in South Africa: Analysis of calls to the national AIDS helpline. *CADRE*. Available at <http://www.cadre.org.za/files/CANVCT.pdf>. (Accessed on 16/9/2008).

Boyd, K. 1992. HIV infection and AIDS: the ethics of medical confidentiality. *Journal of Medical Ethics* 18: 173-179.

Brewster, M. 2007. HIV exceptionalism must end. *British Medical Journal* 335:60.

Buchanan, D. 2005. HIV testing and human rights in the era of scaling up access to treatments, in *Testing, trials and re-thinking human rights: reflections from the HIV pandemic*, edited by N Stephenson, C Webb & M Carman. Darlinghurst: Australasian Society for HIV Medicine: 11-13.

Cameron, E. 2006. *Normalising testing – normalising AIDS*. Forum lecture transcript, Ronald Louw Memorial Campaign. University of KwaZulu-Natal, Durban.

Canadian HIV/AIDS Legal Network. 2005. *Outcomes of the symposium on HIV testing and human rights*. Available at <http://www.aidslaw.ca>. (Accessed on 28/9/2006).

Constitution of the Republic of South Africa. 1996. *Bill of Rights*. Available at <http://www.info.gov.za/documents/constitution/1996/96cons2.htm#14>. (Accessed on 18/9/2007).

Csete, J & Elliott, R. 2006. Scaling up HIV testing: Human rights and hidden costs. *Canadian HIV/AIDS Legal Network HIV/AIDS Policy & Law Review* 11(1): 1-10

Cullinan, K. 2006. *Health officials promote untested uBhejane*. Available at <http://www.health-e.org.za/news/article.php?uid=20031380>. (Accessed on 15/9/2008).

Danziger, R. 1996. An epidemic like any other? Rights and responsibilities in HIV prevention. *British Medical Journal* 312: 1083-1084.

Day, J, Miyamura, K, Grant A, Leeuw, A, Munsamy, J, Baggaley, R & Churchyard, G. 2003. Attitudes to HIV voluntary counselling and testing

among mineworkers in South Africa: Will availability of antiretroviral therapy encourage testing? *AIDS Care* 15(5): 665-672.

De Cock, K & Johnson, A. 1998. From exceptionalism to normalisation: a reappraisal of attitudes and practice around HIV testing. *British Medical Journal* 316: 290-293.

De Cock, K, Mbori-Ngacha, D & Marum E. 2002. Shadow on the continent: public health and HIV/AIDS in Africa in the 21<sup>st</sup> century. *Lancet* 360: 67-72.

Dugger, C. 2008. Botswana's ex-president wins leadership prize. *New York Times* 21/10/2008.

England, R. 2008. *The writing is on the wall for UNAIDS*. *British Medical Journal* 336:1072.

Epstein, H. 2007. *The invisible cure: Africa, the west and the fight against AIDS*. London: Viking.

Fairchild, A & Bayer, R. 1999. Uses and abuses of Tuskegee. *Science* 284(5416): 919 – 921.

Family Health International. 2007. *Research ethics training curriculum*. Available at <http://www.fhi.org/training/en/Retc/s1pg2.htm>. (Accessed on 29/8/2007).

Flanagan, L. 2006. Avoid commercialisation for initiation schools to flourish. *Citizen.co.za*. Available at <http://www.citizen.co.za/index/popup.aspx?Type=PrintPage&pDesc=26109,1,22>. (Accessed on 28/10/2006).

Frieden, T, Das-Douglas, M, Kellerman, S & Henning, K. 2005. Applying public health principles to the HIV epidemic. *New England Journal of Medicine* 353(22): 2397-2402.

Gray, J, Lyons, P & Melton, G (eds). 1995. *Ethical and legal issues in AIDS research*. Baltimore: The Johns Hopkins University Press.

Halpern, S. 2005. HIV testing without consent in critically ill patients. *Journal of American Medical Association* 294: 734-737

Hancock, B. 1998. *An introduction to qualitative research*. Trent Focus Group. University of Nottingham. Available at <http://www.trentdsu.org.uk/cms/uploads/Qualitative%20Research.pdf>. (Accessed on 11/9/2008).

Hayden, M. 2006. *Qualitative research methods*. Available at [http://wasis.ou.edu/docs/qualitative\\_methods.pdf](http://wasis.ou.edu/docs/qualitative_methods.pdf). (Accessed on 13/9/2008).

Health-e news. 2008. *New minister promises health turnaround*. Available at [http://www.health-e.org.za/news/easy\\_print.php?uid=20032099&PHPSESSID=0f5ac7c5dfa7c47e3fa6670b9aa5fa0a](http://www.health-e.org.za/news/easy_print.php?uid=20032099&PHPSESSID=0f5ac7c5dfa7c47e3fa6670b9aa5fa0a). (Accessed on 21/10/2008).

Holloway, I. 2003. The status of method: flexibility, consistency and coherence. *Qualitative Research* 3(3): 345-357.

Human Rights Watch. 2007. *WHO/UNAIDS: Expanded testing guidelines should recognise reality*. Available at [http://hrw.org/english/docs/2007/05/30/global16020\\_txt.htm](http://hrw.org/english/docs/2007/05/30/global16020_txt.htm). (Accessed on 8/10/2008).

Human Rights Web. 1997. *A short history of the human rights movement*. Available at <http://www.hrweb.org/history.html>. (Accessed on 7/10/2008).

Human Sciences Research Council (HSRC). 2005. *South African national HIV prevalence, HIV incidence, behaviour and communication survey, 2005*. Cape Town: HSRC Press. Available at

<http://www.hsrbpress.ac.za/product.php?productid=2134&freedownload=1>.  
(Accessed on 24/9/2008).

Iliffe, J. 2006. *The African AIDS epidemic: a history*. Oxford: James Currey.

International Development Research Centre. 2008. Strengths and limitations of qualitative research. Available at [http://www.idrc.ca/en/ev-106468-201-1-DO\\_TOPIC.html](http://www.idrc.ca/en/ev-106468-201-1-DO_TOPIC.html). (Accessed on 12/9/2008).

Integrated Regional Information Networks (IRIN). 2006. *South Africa: small clinic at centre of debate over traditional medicine*. Available at <http://www.irinnews.org/Report.aspx?ReportId=58887>. (Accessed on 15/9/2008).

Integrated Regional Information Networks (IRIN). 2007. *Africa: HIV testing – a rethink needed, UN*. Available at <http://www.plusnews.org/report.aspx?ReportId=72460>. (Accessed on 12/6/2008).

Integrated Regional Information Networks (IRIN). 2008a. *South Africa: poor tracking means patients lose out*. Available at <http://www.plusnews.org/PrintReport.aspx?ReportId=76777>. (Accessed on 18/2/2008).

Integrated Regional Information Networks (IRIN). 2008b. *South Africa: Government urged to raise treatment standards*. Available at <http://www.plusnews.org/PrintReport.aspx?ReportId=78075>. (Accessed on 9/5/2008).

Kahn, T. 2007. Test every baby for HIV, pleads top specialist. *Business Day*. Available at <http://www.businessday.co.za/articles/national.aspx?ID=BD4A484476>.  
(Accessed on 8/6/2007).

Kaldor, J & Millwod, I. 2005. Ethical issues in trials of HIV prevention, in *Testing, trials and re-thinking human rights: reflections from the HIV pandemic*, edited by N Stephenson, C Webb & M Carman. Darlinghurst: Australasian Society for HIV Medicine: 14-16.

Kanya, M, Wanyenze, R & Namale, A. 2008. Routine HIV testing: the right not to know versus the rights to care, treatment and prevention. *World Health Organisation*. Available at <http://www.who.int/bulletin/volumes/85/5/06-032730/en/print.html>. (Accessed on 13/9/2008).

Kippax, S. 2005. A public health dilemma: the vexed question of Voluntary Counselling and Testing, in *Testing, trials and re-thinking human rights: reflections from the HIV pandemic*, edited by N Stephenson, C Webb & M Carman. Darlinghurst: Australasian Society for HIV Medicine: 7-10.

Koo, D, Begier, E, Henn, M, Sepkowitz, K & Kellerman, S. 2006. HIV counselling and testing: less targeting, more testing. *American Journal of Public health* 96(6): 962-964.

Kortenbaut, E. 1997. *The provision of professional nursing for South Africa*. Research paper. University of Western Cape.

KwaZulu-Natal Health Department. 2007. *Voluntary HIV counselling and testing*. Available at <http://www.kznhealth.gov.za/testing.htm>. (Accessed on 11/9/2007).

KwaZulu-Natal Health Department. 2008a. *Provincial clinics, community health centres, hospitals*. Available at [www.kzn.gov.za/](http://www.kzn.gov.za/). (Accessed on 24/9/2008).

KwaZulu-Natal Health Department. 2008b. Information on health services in the uMgungundlovu district communicated by e-mail 8/10/2008.

KwaZulu-Natal Health Department GIS unit. 2008c. *Map of uMgungundlovu health district*. Available at <http://www.kznhealth.gov.za/map/ARC%20IMS%20Data/Master%20Documents/Maps/uMgungundlovu.pdf>. (Accessed on 13/10/2008).

Leitch, R. 2003. George and the dragon. *U.S. Medicine Information Central*. August. Available at <http://www.usmedicine.com/column.cfm?columnID=138&issueID=53>. (Accessed on 28/10/2006).

Leithead, A. 2004. Hope out of pain: Botswana's AIDS story. *BBC News*. Available at <http://newsvote.bbc.co.uk>. (Accessed on 6/10/2008).

Lietz, C, Langer, C & Furman R. 2006. Establishing trustworthiness in qualitative research in social work: implications from a study regarding spirituality. *Qualitative Social Work* 5(4): 441-458.

*McGraw-Hill Concise Dictionary of Modern Medicine*. 2002. New York: McGraw-Hill.

Medicins Sans Frontieres (MSF). 2008. *HIV-TB co-infection: They're already sitting in our waiting rooms*. Available at [http://www.doctorswithoutborders.org/news/article\\_print.cfm?id=2878](http://www.doctorswithoutborders.org/news/article_print.cfm?id=2878). (Accessed on 9/9/08).

Medscape. 2008. *The role of public health in HIV opt-out testing: an expert interview with Dr Wayne A Duffus*. Available at <http://rmgh.net/news-room/global-health-news/835-the-role-of-public-health-in-hiv-opt-out-testing>. (Accessed on 9/9/2008).

Metz, T. 2005. The ethics of routine HIV testing: a respect-based analysis. *South African Journal on Human Rights* 21: 370-405. Available at

<http://web.wits.ac.za/NR/rdonlyres/78AC0AA5-8970-4471-91E5-A89C5E2304D1/0/MetzRoutineTesting.pdf>. (Accessed on 8/10/2008).

Moghaddam, A. 2006. Coding issues in grounded theory. *Issues in educational research* 16. Available at <http://www.iier.org.au/iier16/moghaddam.html>. (Accessed on 13/9/2008).

Nattrass, N. 2004. *The moral economy of AIDS in South Africa*. Cape Town: Cambridge University Press.

News 24.com. 2006. *Make HIV tests mandatory*. Available at [http://www.news24.com/News24/South\\_Africa/Aids\\_Focus/0,,2-7-659\\_2016868,00.html](http://www.news24.com/News24/South_Africa/Aids_Focus/0,,2-7-659_2016868,00.html). (Accessed on 8/10/2008).

New Zealand Ministry of Justice. 2008. *Key informant consent form*. Available at <http://www.justice.govt.nz/pubs/reports/2007/youth-offending-teams/appendix-4.html>. (Accessed on 15/05/2008).

Nieburg, P, Cannell, T & Morrison J. 2005. *Expanded HIV testing. Critical gateway to HIV treatment and prevention requires major resources, effective protections*. Available at <http://www.ponline.org/docs/1544/283461.html>. (Accessed on 13/9/08).

Nolen, S. 2006. A fine balance between rights and successful HIV testing. *Globe and Mail*. Available at <http://www.theglobeandmail.com/servlet/story/RTGAM.20060814.waids-nolan15/BN>. (Accessed on 16/8/2008).

Nolen, S. 2007. *28 stories of AIDS in Africa*. London: Portobello .

Nursing Act. 2005. *Act No 33 of 2005*. Available at [http://www.acts.co.za/nursing\\_act\\_2005/index.htm](http://www.acts.co.za/nursing_act_2005/index.htm). (Accessed on 9/2/09).

Parker, R & Aggleton, P. 2002. *HIV/AIDS-related stigma and discrimination: a conceptual framework and an agenda for action*. Washington: The Population Council.

Patania, S. 1998. Ethical issues in clinical practice, in *HIV and Social Work: a Practitioner's Guide*, edited by D. Aronstein and B. Thompson. New York: Harrington: 247-266.

Pope, C, Ziebland, S & Mays, N. 2000. Analysing qualitative data. *British Medical Journal* 320:114-116.

Rennie, S & Behets, F. 2006. Desperately seeking targets: the ethics of routine HIV testing in low-income countries. *Bulletin of the World Health Organisation* 84(1): 52-57. Available at <http://www.who.int/bulletin/volumes/84/1/52.pdf>. (Accessed on 13/9/2008).

Right to Know Campaign. 2008. *Discovery Health Sunday Time Right to Know campaign*. Available at <http://www.righttoknow.co.za/>. (Accessed on 22/10/2008).

Richter, M. 2006. *Different models of HIV-testing: What are the considerations in South Africa?* AIDS Law Project Discussion Paper. Available at <http://www.tac.or.za/documents/FinalHIVTestingPaper.pdf>. (Accessed on 13/10/2008).

Ryan, G & Bernard, H. 2000. Data management and analysis methods. In *Handbook of qualitative research*, edited by N Denzin and Y Lincoln. London: Sage: 769-802.

Sandelowski, M. 1995. Sample size in qualitative research. *Research in Nursing and Health* 18: 179-183.

Seidel, G. 1996. Confidentiality and HIV status in Kwazulu-Natal, South Africa: implications, resistances and challenges. *Health Policy and Planning* 11(4):418-427.

Skinner, D & Mfecane, S. 2004. Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Journal des Aspects Sociaux du VIH/SIDA* 1(3): 157-164.

Smart, T. 2006a. Access to treatment associated with declining stigma in Botswana. *Aidsmap news*. Available at <http://www.aidsmap.com/en/news/4112593B-475C-4C48-AF5C-757009D96741.asp>. (Accessed on 3/10/2008).

Smart, T. 2006b. Botswana mounts one of the most successful national responses to HIV/AIDS – but can it maintain the momentum? *Aidsmap news*. Available at <http://www.aidsmap.com/en/news/D9641F21-0EB1-454F-8602-F4BFD931F3E8.asp>. (Accessed on 6/10/2008).

Smart, T. 2007. Does the scale of the epidemic in South Africa call for compulsory HIV testing? *Aidsmap News*. 18/6/2007. Available at <http://www.aidsmap.com/en/news>. (Accessed on 20/6/2007).

South African Institute of International Affairs (SAIIA). 2004. Special feature: States, AIDS experts test boundaries of HIV testing. *eAfrica*. 2 (September). Available at [http://www.saiia.org.za/index.php?option=com\\_content&view=article&id=549:special-feature-states-aids-experts-testboundaries-of-hiv-testingspecial-feature-statesaidsexpertstestboundariesofFamily Health Internationalvtesting&catid=74:eafrica](http://www.saiia.org.za/index.php?option=com_content&view=article&id=549:special-feature-states-aids-experts-testboundaries-of-hiv-testingspecial-feature-statesaidsexpertstestboundariesofFamily Health Internationalvtesting&catid=74:eafrica). (Accessed on 18/9/2008).

South African Medical Research Council (SAMRC). 2006. *Ethics in health research*. Available at <http://www.sahealthinfo.org/ethics/ethicspolicy.htm>. (Accessed on 2/10/2007).

South African Nursing Council (SANC). 2007a. *Output bridging programme (1998-2007) overview*. Available at <http://www.sanc.co.za/stats/stat>. (Accessed on 27/7/2008).

South African Nursing Council (SANC). 2007b. *SANC geographical distribution 2007*. Available at <http://www.sanc.co.za/stats/stat>. (Accessed on 26/9/2008).

South African Nursing Council (SANC). 2009. Personal communication with Tebogo, SANC consultant, 12/2/2009.

Statistics South Africa. 2008. *Mid-year population estimates, South Africa: 2008*. Available at <http://www.statssa.gov.za/publications/P0302/P03022008.pdf>. (Accessed on 14/10/2008).

Steen, T, Seipone, K, de la Hoz Gomez, F, Anderson, M, Kejelepula, M, Keapoletswe, K & Moffat, H. 2007. Two and a half years of routine HIV testing in Botswana. *Journal of Acquired Immune Deficiency Syndromes* 44(4): 484-488.

*The Quote Garden*. 2008. Available at <http://www.quote garden.com/action.html>. (Accessed on 1/10/2008).

Thornton, R. 2008. *Unimagined community: Sex, networks and AIDS in Uganda and South Africa*. Berkeley: University of California Press.

Tolsi, N. 2007. Fierce debate over AIDS testing. *Mail & Guardian online*. Available at <http://www.mg.co.za>. (Accessed on 4/10/2007).

United Nations Programme on HIV/AIDS (UNAIDS). 2000. *Opening up the HIV/AIDS Epidemic: Guidance on encouraging beneficial disclosure, ethical partner counselling & appropriate use of HIV case reporting*. Available at

[http://data.unaids.org/Publications/IRC-pub05/JC488-OpenUp\\_en.pdf](http://data.unaids.org/Publications/IRC-pub05/JC488-OpenUp_en.pdf).

(Accessed on 25/9/2007).

United Nations Programme on HIV/AIDS (UNAIDS). 2007. *Provider-initiated testing and counselling in health facilities*. Reference Group on HIV and Human Rights. Available at

[http://data.unaids.org/pub/BaseDocument/2007/070216\\_HHR\\_1\\_PITC.pdf](http://data.unaids.org/pub/BaseDocument/2007/070216_HHR_1_PITC.pdf).

(Accessed on 24/9/2007).

United Nations Organization (UNO). 1948. *Universal Declaration of Human Rights*. Available at <http://www.un.org/Overview/rights.html>. (Accessed on 8/10/2008).

US National Institutes of Health. 1979. *The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research*. Available at <http://ohsr.od.nih.gov/guidelines/belmont.html>. (Accessed on 24/9/2007).

USAID/Synergy Project. 2003. *Women's experiences with HIV serodisclosure in Africa: Implications for VCT and PMTCT*. Available at <http://www.synergyaids.com/documents/VCTDisclosureReport.pdf>.

(Accessed on 24/9/2007).

Van Dyk, A. 2005. *HIV/AIDS care and counselling*, 3<sup>rd</sup> edition. Cape Town: Pearson Education.

Van Dyk, A & Van Dyk, P. 2003a. "To know or not to know": Service-related barriers to voluntary HIV counselling and testing (VCT) in South Africa. *Curationis* 26(1): 4-10.

Van Dyk, A & Van Dyk, P. 2003b. "What is the point of knowing?" Psychosocial barriers to HIV/AIDS voluntary counselling and testing programmes in South Africa. *South African Journal of Psychology* 33(2): 118-125.

Weiser, S, Heisler, M, Leiter K, Percy-deKorte, F, Tlou, S, DeMonner, S, Phaladze, N, Bangsberg, D & Iacopino, V. 2006. Routine HIV testing in Botswana: A population-based study on attitudes, practices, and human rights concerns. *PLoS Medicine* 3(7): 1013-1022.

World Health Organization (WHO). 2007. *Guidance on provider-initiated HIV testing and counselling in health facilities*. Available at [http://whqlibdoc.who.int/publications/2007/9789241595568\\_eng.pdf](http://whqlibdoc.who.int/publications/2007/9789241595568_eng.pdf). (Accessed on 24/9/2007).

Wolf, L, Donoghoe, A & Lane, T. 2007. Implementing routine HIV testing: The role of state law. *PloS One* 2(10): 1-5.

World Medical Association (WMA). 2004. *World Medical Association Declaration of Helsinki*. Available at <http://www.wma.net/e/policy/b3.htm>. (Accessed on 1/10/2007).

Zembowicz, F. 2008. Botswana takes on AIDS. *Harvard International Review: Healthy progress* 30(2). Available at <http://www.harvardir.org/articles/print.php?article=1759>. (Accessed on 29/9/2008).

Zimmerman, J. 1997. The Belmont Report: An ethical framework for protecting research subjects. *The Monitor*. Available at <http://www.impacting.com/docs/BelmontReport.pdf>. (Accessed on 15/10/2008).

Zimmerman, J. 2001. *The Belmont Report*. Available at <http://www.impactcg.com/info/belmont.htm>. (Accessed on 8/10/2008).

# APPENDIX

---

## UNISA LETTER OF ACCESS



2008/5/5

To Whom It May Concern:

### Letter of access for research

This is to confirm that Linda Still (student number 5798414) is an enrolled MA student with the University of South Africa (UNISA). As part of the requirements for the Master's degree, she has to undertake research activities to complete a dissertation of limited scope. Her proposal has served with the Ethics Committee of the Department of Sociology at UNISA and has been approved with clearance number SOC081401.

This letter requests that the Provincial Department of Health allows Mrs Still access to conduct research in the facilities as stated in her proposal and obtain access to information for the purposes of this research. Please note that Mrs Still will not start the research until the Provincial Department of Health has furnished her with a letter granting such access.

While undertaking the research, Mrs Still will remain accountable to her supervisors, Dr. G du Plessis and Mr L Roets. In this regard, she is bound to policies of ethical research conduct as set by the University of South Africa. Mrs Still will observe propriety in dealing with staff, clients, visitors, equipment and premises and act appropriately, responsibly and professionally at all times. She will ensure that all information regarding your services or furnished by staff remains secure and *strictly confidential* at all times.

Yours sincerely

Dr GE DU PLESSIS  
M & D Coordinator: Department of Sociology  
UNISA  
PO Box 392  
UNISA, 0003  
Tel 0124296507  
Cell 0824421528  
E-mail [dplescer@unisa.ac.za](mailto:dplescer@unisa.ac.za)



University of South Africa  
Fosker Street, Stockmans's Bridge, City of Tlokweng  
PO Box 392 UNISA 0003 South Africa  
Telephone: +27 12 429 3111 Facsimile: +27 429 12 428 4150  
[www.unisa.ac.za](http://www.unisa.ac.za)

# UNISA ETHICS COMMITTEE APPROVAL



Ethics Committee  
Department of Sociology  
PO Box 359  
UNISA  
0003  
23 April 2008

**PROPOSED TITLE: HIV EXCEPTIONALISM AND THE SOUTH AFRICAN  
HIV AND AIDS EPIDEMIC: PERSPECTIVES OF HEALTHCARE WORKERS  
IN PIETERMARITZBURG**

**PRINCIPLE INVESTIGATOR: LINDA JOY STILL  
STUDENT NO: 5799414**

**REVIEWED AND PROCESSED AS: EXPEDITED**

**APPROVAL STATUS RECOMMENDED BY REVIEWERS: APPROVED**

The committee has reviewed the proposal and considers the methodological/technical and ethical aspects of the proposal to be appropriate to the tasks proposed. Approval is hereby granted for the candidate to proceed with the study in strict accordance with the approved proposal and the ethics policy of the University of South Africa. In addition, the candidate should heed the following guidelines:

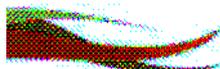
- To only start the research study after obtaining informed consent
- To carry out the research according to good research practice and in an ethical manner
- To maintain the confidentiality of all data collected from or about research participants, and maintain security procedures for the protection of privacy
- To notify the committee in writing immediately if any change to the study is proposed and await approval before proceeding with the proposed change
- To notify the committee in writing immediately if any adverse event occurs.

Approvals are valid for ONE academic year after which a continuation must be submitted.

Signatures:

  
Leon Plessis, Programme Convenor

  
Gretchen du Plessis, M&D coordinator



University of South Africa  
Pretorius Avenue, Pretoria, City of Pretoria  
PO Box 170 UNISA 0001 South Africa  
Telephone +27 12 429 3111 Facsimile +27 12 429 0120  
www.unisa.ac.za

# UMGUNGUNDLOVU HEALTH DISTRICT APPROVAL



Health Research & Knowledge Management sub-component  
10 – 102 Natata Building, 330 Langalibalele Street  
Private Bag x9051  
Pietermaritzburg, 3208  
Tel: 033 – 395 2805  
Fax: 033 – 394 3782  
Email: [xolani.xaba@kznhealth.gov.za](mailto:xolani.xaba@kznhealth.gov.za)  
[www.kznhealth.gov.za](http://www.kznhealth.gov.za)

Reference: HRKM035/08  
Enquiries: Mr X. Xaba  
Telephone: 033 – 395 2805

9 June 2008

Dear Ms Still

**Subject: Approval of Research**

1. The research proposal titled 'HIV exceptionalism and the South African HIV and AIDS epidemic: Perspectives of healthcare workers in Pietermaritzburg' was reviewed by the KwaZulu-Natal Department of Health. The proposal is hereby approved for research to be undertaken at VCT clinics in Umgungundlovu District.
2. You are requested to undertake the following:
  - a. Make the necessary arrangement with identified facility before commencing with your research project.
  - b. Provide an interim progress reports and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3208 and e-mail an electronic copy to [xolani.xaba@kznhealth.gov.za](mailto:xolani.xaba@kznhealth.gov.za)

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

Dr. S.S.S. Buthelezi  
Chairperson: Provincial Health Research Committee  
KwaZulu-Natal Department of Health

uMhlanga Wezamplo . Departement van Gesondheid

*Fighting Disease, Fighting Poverty, Giving Hope*

## UMGUNGUNDLOVU HEALTH DISTRICT PERMISSION TO VISIT CLINICS



UMGUNGUNDLOVU HEALTH DISTRICT  
252 Longmarket Street, Pietermaritzburg, 3201  
Private Bag X9124, Pietermaritzburg, 3200  
2<sup>nd</sup> Floor, Brasfort House,  
Tel.: 033 897 1000 Fax: 033 394 3235  
Email: [hlobi.langa@kznhhealth.gov.za](mailto:hlobi.langa@kznhhealth.gov.za)

Enquiries: Mrs H. D. Langa  
Telephone: (033) 8971000

18 June 2008

To: Lindi Still

### RE: REQUEST TO VISIT PHC CLINICS AND CHCs FOR A RESEARCH

Herewith are the clinics and CHCs that you may visit for your research purpose.

MUNICIPALITY	CLINIC NAME	CLINIC MANAGER	CONTACT DETAILS
UMshwati			
uMgeni			
Mpotana			
Impendle			
uMsunduzi			
uMkhambathini			
Richmond			

We have seven municipalities or sub districts in UMGungundlovu district. I believe it will be proper if all sub districts are covered. uMsunduzi sub district is the biggest and that is the reason there is more than one facility on the list.

Please let me know if this is acceptable so that I can inform the clinic managers, accordingly.

Mrs Langa  
Primary Health Care Co-ordinator  
uMgungundlovu Health District

uMnyango Wazempilo . Departement van Gesondheid

*Fighting Disease, Fighting Poverty, Giving Hope*

## PARTICIPANT CONSENT FORM<sup>2</sup>

Name: \_\_\_\_\_ Date: \_\_\_\_\_ Clinic: \_\_\_\_\_

- The interviewer has explained to me the purpose of the research, and has given me an opportunity to ask questions.
- I understand that my participation in this interview is voluntary.
- I have the right to not answer any question I do not like, or to stop the interview and withdraw my answers, at any stage of the interview, without having to explain why.
- I understand that what I say will be kept confidential and will only be used for research purposes.
- I understand that if I have any further questions I can contact the interviewer.
- I agree to the interview being audio recorded YES / NO
- I agree to some of my comments or statements being quoted in the report, provided that I cannot be identified YES / NO
- I would like to receive a summary of the main points of the interview YES / NO

If YES, please record your address below.

\_\_\_\_\_  
\_\_\_\_\_

### Declaration:

I, \_\_\_\_\_ agree to be interviewed for this evaluation.

Signed: \_\_\_\_\_ (Participant) Date: \_\_\_\_\_

Signed: \_\_\_\_\_ (Researcher) Date: \_\_\_\_\_

<sup>2</sup> Adapted from Key informant consent form, New Zealand Ministry of Justice 2008)

## **INTERVIEW SCHEDULE**

L J Still

MA (Social and behavioural studies in HIV-AIDS)

Student no 5799414

July - August 2008

### **Interview schedule**

---

- 1. Please describe the standard procedures for HIV testing at your facility.**

Prompts:

How many patients, on average, attend your facility each day?

How many counsellors do you have? Do you have both professional and lay counsellors?

- What is the average waiting time for a patient who presents for counselling and testing?
- What is the next step for a person who has tested positive (referral elsewhere / entry to treatment programme)?

- 2. What do you see as the major barriers to testing within this community?**

Prompts:

- Basic access – can community members get to the clinic easily?
- Denial, fear, stigma – what role do these play amongst people in your community?

- Are there “bottlenecks” in the system which discourage people; for example, waiting to see the counsellor, waiting to be put on antiretroviral treatment?
  - Are there gender differences in willingness to test (e.g. male reluctance)?
  - What could motivate more people to get themselves tested?
3. **How do people feel about the special approach to HIV testing, which requires both pre- and post-test counselling?**

Prompts:

- Do you think patients understand why they are given counselling?
- Do they see the counselling process as something positive or negative?
- Do people feel the privacy offered by one-on-one counselling is important for confidentiality?
- Do you think patients would be willing to have pre-test counselling in a group, as long as the testing and post-test counselling were conducted privately?
- In one community people felt that the length of time spent in post-test counselling made it obvious whether the patient had tested positive or negative. What is your response to this?
- Do people undergo pre-test counselling and then decline testing? If so, why do you think this occurs?
- If I were to say to you that some experts think that because we treat HIV-testing so differently (voluntary testing, confidentiality, double counselling), people are more reluctant to test, what would you say?
  1. Do you agree?
  2. Do you think we should normalise HIV-testing?
  3. Why / why not?

4. Have you ever heard the term “HIV exceptionalism”? What do you understand it to imply?

4. **How would attitudes to testing change if an HIV test was offered routinely to all patients attending a primary health care facility?**

Prompts:

- Do many people come for testing only when they are already very sick?
- Would patients benefit by learning their HIV status earlier?
- Do pregnant women see an HIV-test as a normal part of antenatal care?
  1. HIV testing uptake at antenatal clinics is much higher than in the general population. Why do you think this is so?
- Now that antiretrovirals are generally available, do you think HIV-testing and AIDS intervention could be seen as a normal part of health care?
- Would people accept an HIV test more easily if it were offered as part of the standard procedure to everyone who attended the clinic?
- There are campaigns that encourage people to test publicly to encourage others to test confidentially. Do these campaigns work?
- If there was ONE thing which you had the power to change today about HIV testing or VCT, what would that be?

## CODING FRAMEWORK ANALYSIS LEVEL 2

Major themes	Subthemes	
1. Barriers to testing	1.1 Stigma	1.1.1 ideas on origins of stigma
		1.1.2 stigma manifesting in denial and fear
		1.1.3 stigma as a barrier to testing
		1.1.4 openness, disclosure
	1.2 Other barriers	1.2.1 physical access
		1.2.2 time access
		1.2.3 "bottlenecks" in the system
		1.2.4 reliance on traditional medicines
2. Willingness to test		3.1 tendency to delay testing
		3.2 male reluctance
		3.3 factors affecting female willingness to test
		3.4 awareness of HIV issues and appropriate health-maintaining behaviours
		3.5 persuasion
		3.6 declining testing after pre-test counselling
		3.7 publicity testing and other incentive schemes
3. Attitudes to VCT and other testing models		3.1 counselling
		3.2 confidentiality
		3.3 normalisation of HIV testing and integration of services
		3.4 perceived programmatic inconsistencies
		3.5 exceptionalism of HIV and AIDS
4. Clinic procedure and clinic-specific data		3.6 routine testing model
		4.1 general procedure
5. Interviewees' observations		4.2 antenatal care procedure
		5.1 interviewee's sense of personal helplessness
		5.2 patients' need to please clinic staff
		5.3 "one size does not fit all"
		5.4 recommendations made by interviewees

