

**Voluntary Counselling and Testing (VCT) for HIV as a beneficial tool in the health care delivery system from a developing world perspective; a psychosocial analysis of limitations and possibilities using qualitative grounded theory and quantitative methods.**

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Submitted in fulfilment of the requirement for the degree of  
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## **Declaration of Originality**

I hereby declare that the whole of this thesis, unless specifically indicated to the contrary in the text, is my original work.

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DEDICATION

*To the many cherished memories  
of my parents*

*Frank and Jane Ross*

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## ABSTRACT

The intervention of Voluntary Counselling and Testing (VCT) for the Human Immunodeficiency Virus (HIV) is rapidly gaining ground as an essential component in the health care system in an effort to combat and confront the spread of this disease. In South Africa where this intervention is gradually being introduced the application of VCT and the benefits and consequences likely to ensue from the application of the procedure were evaluated in-depth using a grounded theory and quantitative approach to describe the psychosocial dynamics. The interactive transfer of information embodied in VCT forms an integral part of the intervention and will continue to do so even when antiretroviral drugs are uniformly available throughout the South African healthcare service. The way in which the women who will undergo this procedure internalise and respond to the information imparted to them during the counselling is highly significant from an educational and empowering perspective, regardless of the outcome of the test result. The aim of the counselling is primarily to promote a rising consciousness amongst patients and subsequently within their communities in an endeavour to move away from what is termed 'exceptionalism' and towards 'normalisation' of the treatment of HIV/AIDS. Communicating the facts about HIV will help to dispel the myths and stigma which still surround the disease. A convenience sample of one hundred and twelve women were interviewed whilst attending antenatal clinics at four different sites in KwaZulu/Natal. In addition a small cross-sectional sample of service providers and key informants in communities situated near to the chosen sites were interviewed to explore the perceptions of VCT and HIV in the current health service and community environment. The findings revealed that there is to date no mandatory policy which offers VCT routinely at any of the health centres primarily due to the cost of testing, lack of posts for trained counsellors and timeous laboratory facilities. Confusion amongst health personnel regarding current policies of treatment regimens for HIV/AIDS patients, as well as differing opinions about feeding options for infants, can undermine counsellors' confidence to handle complex issues competently from an informed position. Recommendations are that trained counsellor posts with opportunities for updating of current policies, easily accessible laboratory facilities and suitable space for confidential counselling (both oral and visual) be implemented as a priority in the health service. A more comprehensive service should be universally implemented, not just in antenatal and communicable disease clinics for ethical reasons of equity between all members of society. In the same vein the networking and cumulative energy of NGOs, religious groups and health professionals must be harnessed to work synergistically to provide sustainable solutions for those living with HIV and those at risk of becoming infected.

## GLOSSARY OF TERMS

AIDS	Acquired Immunodeficiency Syndrome
ANC	African National Congress
ANC	Antenatal Clinic
ATICC	AIDS Training, Information and Counselling Centre
High-risk	Behaviours which place the individual at risk for contracting or transmitting HIV. High-risk behaviours include: any activity where body fluids and waste enters the body; having many sexual partners or engaging in any sexual activity with a person who engages in high risk behaviours; engaging in unprotected vaginal, oral and anal sexual intercourse; use of intravenous drugs and sharing of needles and syringes (SANCCFW)
HIV	Human Immunodeficiency Virus
HIV/AIDS: Exceptionalism	Policies that argue for treating HIV/AIDS differently from a traditional infectious disease control approach.
Normalisation	Refers to treating HIV/AIDS like any other infectious disease for which early diagnosis is essential for appropriate therapeutic and preventive measures, within the requirements of informed consent and respect for confidentiality. (De Cock and Johnson, 1998)
KAP	Knowledge, Attitudes and Practices
MCH	Maternal and Child Health
MTCT	Mother-to-Child Transmission - transmission of HIV to a child from an HIV-positive woman during pregnancy, delivery or breastfeeding. The more technical term is vertical transmission. Use of the term MTCT does not imply blame whether or not a woman is aware of her own infection status. A woman can acquire HIV through unprotected sex with an infected partner, through receiving contaminated blood, or through unsterile instruments or medical procedures. However, HIV

may possibly be introduced into the family through the woman's sexual partner (WHO, 1999)

PLWA	Person living with AIDS
PLWH	Person living with HIV
Psychosocial*	Pertaining to both psychological and social factors. (Macmillan Dictionary of Psychology, 1989: 356).
RDP	Reconstruction and Development Programme. This was initiated by the African National Congress in 1994 and it aimed to build on the tradition of the Freedom Charter by addressing policies and principles of democracy embodied in socio-economic programmes.
RTIs	Reproductive Tract Infections
SANCCFW	South African National Council for Child and Family Welfare
Serodiscordant	In a couple one partner is seropositive and the other seronegative for HIV
STDs	Sexually Transmitted Diseases
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
VCT	Voluntary Counselling and Testing - HIV testing with pre- and post-test counselling, which is voluntary, with fully informed consent and confidential (WHO, 1999).
WHO	World Health Organisation

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\*This term combines both the cognitive psychological and the sociological cultural components pertaining to an individual dealing with the disease of HIV, thus giving a holistic dimension to the interpretation of all aspects of the topic. It is currently more commonly used in the United States but is appropriate to the health discourse undertaken in this thesis. (Psychosocial Aspects of AIDS, U.S. Department of Health and Human Services).

## FIGURES AND TABLES

		Page
Figure 1	The HIV/AIDS Continuum of Care (WHO)	17
Figure 2	VCT as an entrypoint for HIV Prevention and Care (WHO)	18
Figure 3	Health Belief Model as applied to the reduction of sexual risk behaviour.	20
Table 1	Sociodemographic characteristics of the women	87
Table 2	Knowledge about HIV transmission	89
Table 2a	" "	90
Table 2b	" "	91
Table 3	Attitudes towards HIV/AIDS persons and perception of risk of HIV transmission	94
Table 4	Attitudes to testing	96
Table 4a	" "	97
Table 4b	" "	98
Table 5	Decisions concerning the test and HIV	103
	" " (continued)	104
Table 6	Attitudes towards partners and HIV testing	106



## TABLE OF CONTENTS

Title	i
Declaration of Originality	ii
Dedication	iii
Acknowledgements	iv
Abstract	v
Glossary	vi
Figures and Tables	viii

### CHAPTER ONE:

<b>1. RESEARCH OBJECTIVES</b>	<b>1</b>
1.1 Outline of the Research Topic	1
1.2 Reasons for Choosing the Topic	4
1.3 Broad Problems and Issues to be Investigated	5
1.4 Focus of the Study	6
1.5 Structure of the Dissertation	7

### CHAPTER TWO:

<b>2. INTRODUCTION AND BACKGROUND</b>	<b>9</b>
2.1 Human Immunodeficiency Virus (HIV)	9
2.2 Modes of Transmission	11
2.3 Mother-to-Child-Transmission (MTCT)	11
2.4 Reproductive Health including STDs	13
2.5 Voluntary Counselling and Testing (VCT)	16
2.6 South Africa and African Women	24
2.7 Health Services and Economic Implications of HIV	30

### **CHAPTER THREE:**

<b>3.</b>	<b>ORIENTATION TO THE RESEARCH TOPIC</b>	<b>42</b>
3.1	Exceptionalism to Normalisation	42
3.2	Behaviour Modification	46
3.3	The Formation of Attitudes	50

### **CHAPTER FOUR:**

<b>4.</b>	<b>RESEARCH METHODOLOGY</b>	<b>56</b>
4.1	Principal Theories and Framework of the Research Design	56
4.2	Sampling Procedure	61
4.2.1	Sites used for accessing the research sample	61
4.2.2	Eshowe Hospital	61
4.2.3	St Mary's Hospital Marianhill	62
4.2.4	KwaDabeka Community Health Centre	63
4.2.5	Addington Hospital	64
4.3	The Study Cohort	64
4.4	Data Collection	65
4.5	The Pilot Study	68
4.6	Community Visits	71
4.7	Data Analysis	74
4.8	Reliability and Validity	75
4.9	Ethical Considerations	76

## **CHAPTER FIVE:**

<b>5. FINDINGS</b>	<b>79</b>
5.1 Profile of Hospitals and Service Providers	79
5.2 Counselling Evaluation	81
5.3 Clinic attendees	86
5.3.1 Additional Comments by the Women Interviewed	108
5.4 Community Representatives	114
5.4.1 Interview with Mrs Dudu Ntshangase	114
5.4.2 Interview with Edward Masondo	116
5.4.3 Interview with Nyami Mbhele	117
5.4.4 Interview with Sister Mthlane	118
5.4.5 Extraneous field trips by the research	118

## **CHAPTER SIX:**

<b>6. PSYCHOSOCIAL AND ATTITUDINAL ANALYSIS OF LIMITATIONS AND POSSIBILITIES OF VCT</b>	<b>120</b>
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## **CHAPTER SEVEN:**

<b>7. RECOMMENDATIONS</b>	<b>130</b>
7.1 Dissemination of findings	134

- Appendices*
- A Letter of ethical approval
  - B Hospital Profile form
  - C Counsellor Evaluation form
  - D KAP Survey Questionnaire in English and isiZulu.

# **CHAPTER ONE**

## **1. RESEARCH OBJECTIVES**

The primary objective of this thesis was to conduct an in-depth examination of the intervention of Voluntary Counselling and Testing (VCT) for HIV/AIDS from a grounded theory and quantitative approach in order to enhance the understanding and relevance of this preventive and educational measure in the health service arena.

### **1.1 Outline of the research topic**

The XIIIth International AIDS Conference held in Durban, South Africa from 9-14th July, 2000 spectacularly drew the world's attention to Africa and uniquely exposed the dilemmas and controversies being played out surrounding the Human Immunodeficiency Virus (HIV). It highlighted the complexity of a myriad of sociocultural issues, not least of which is the disparity between health care in First and Third world countries. For the first time the conference was held on the African continent, appropriately, since HIV is the pre-eminent health problem for sub-Saharan Africa, and specifically in KwaZulu/Natal, which is the epicentre of this country's epidemic.

Despite there having been an awareness for some years now of the impending Acquired Immunodeficiency Syndrome (AIDS) crisis, there has been a reticence on the part of the government to tackle the problem effectively. New preventive measures are at last being introduced into the South African health care system although there is a perception amongst some of the most eminent and internationally renowned AIDS researchers in the country, that it may be too little too late (Coovadia, 2001).

From 1985, when testing for antibodies to HIV became possible, the question of who should be tested was the subject of considerable debate (Bury, 1988: 73). Women and children form a rapidly growing proportion of people with HIV, particularly in sub-Saharan Africa. Policies designed to reduce the incidence of paediatric AIDS currently focus on counselling and HIV antibody testing of women in high risk groups when they are either pregnant or contemplating pregnancy (Marjan and Ruminjo, 1996: 665).

In the "HIV/AIDS Continuum of Care", Voluntary Counselling and Testing (VCT) has been identified as a valuable entrypoint (van Praag and Baggaley, 1999: 3). This model embodies health care on five levels, namely tertiary, secondary, primary, community and home care. The benefits to be gained from VCT as an entrypoint for HIV prevention and

care cover a comprehensive list of interventions. However, in the current health service system in South Africa it is doubtful whether all these benefits are available to women attending antenatal clinics. The quality of counselling embodied in the preventive intervention of VCT for HIV, which is gradually being introduced into the health system in South Africa for HIV infected women attending antenatal clinics, is an important component of programmes to curb the HIV epidemic.

There has been some concern that the counselling may not always be adequate, appropriate, accurate or ethically sound. Counselling may not be given its proper due by policy makers and service managers, partly because of the inherent difficulty of measuring its quality and impact on psychological stress reduction and behaviour change (UNAIDS, 1997). Prevention programmes involve highly charged personal, moral and political issues. Goldthorpe (1996: 35).

This project aimed at providing a psychosocial analysis of the limitations and possibilities of VCT as a beneficial tool in the health care delivery system, from a developing world perspective, in an attempt to provide a holistic examination of the processes involved in the intervention.

## 1.2 Reasons for choosing the topic

The findings of a recent study undertaken amongst HIV-seropositive women who were questioned about feeding choices for their infants, highlighted both the value and limitations of the interactive counselling communication method. These findings showed that VCT provided information that ran counter to tradition, was inadequate in providing realistic alternatives, and exacerbated women's vulnerability. However, the psychosocial and educational aspect of the interaction between the counsellor and the women was evident and this was perceived as an opportunity in which the mothers could speak openly about their position and the concomitant hardships they faced in their daily lives. This analysis formed the basis for the current research (Ross, 2000: 2208).

At present the most viable means of dealing with HIV in situations where limited resources preclude the availability of antiretroviral drugs (Kindra, 2000), [although this issue is currently being addressed], is behaviour change and modification of sexual practices. For this reason it is important to explore the processes involved in the intervention of VCT for HIV, and the likely outcomes they will have on service providers and recipients, in order to inform policy regarding this strategy. The attitude of service providers, women attending antenatal clinics and community members



towards HIV will largely determine the successful application and integration into the health service of this intervention.

### **1.3 Broad problems and issues to be investigated**

The discourse taking place in many developing countries around the topic of HIV deals with this predominantly sexually transmitted virus and appropriate preventative measures. The cultural mores surrounding discussion of sexual topics embodied in the counselling component of VCT needed to be explored, to ensure clients make informed choices about their sexual practices. Whiteside and Sunter (2000: 60) state that there is a lack of pertinent data concerning sexual behaviour and HIV but explain that people do not like talking openly about sex therefore taboos and prejudices mar any debate on the matter. This difficulty hampers communication when in a counselling situation and is compounded by the fact that many of the clients visiting health centres in South Africa are illiterate, unemployed and marginalised members of their communities.

HIV is perceived as “exceptional” and differentiated from other illnesses. AIDS is the most political disease around (*The Economist*, 2000). Trying to “normalise” the attitude of society towards this disease is one small part of the bigger picture, which VCT can address, by educating and imparting

health messages regarding all aspects of the virus to anyone who undergoes this intervention.

The socio-economic conditions pertaining to health services are directly linked to the outcome of any medical intervention and can exacerbate the provision of adequate health strategies for prevention because of the lack of funding for optimal standards of care and facilities. For VCT to have a positive impact the socio-cultural context within which it is situated must be considered in order to inform future policy.

#### **1.4 Focus of the study**

The focus of the investigation was on the understanding and comprehension of clients regarding HIV and their attitude towards VCT. The way in which the women, who are undergoing this procedure, internalise and respond to the information imparted to them during the counselling, is highly significant regardless of the outcome of the test result. Questions relating to the limitations and possibilities of VCT as a useful intervention in the current health care environment, were posed to service providers and key informants in communities situated near to the chosen sites.

## 1.5 Structure of the Dissertation

Chapter one outlines the research topic, the reasons for choosing the topic, the broad problems and issues to be investigated, the main focus of the study and lastly the overall structure of the dissertation.

Chapter two provides background information and describes the relevant components of the topic, the human immunodeficiency virus, the modes of transmission, mother-to-child transmission, reproductive health and the intervention of VCT. The historical perspective of South Africa, the disparity in the allocation of resources, and in particular, the position of African women in this context, the health services and lastly the economic implications of HIV in relation to health service provision are examined.

Chapter three provides an orientation to the topic, focusing on the route from exceptionalism to normalisation of HIV in society, as well as on behaviour modification and the formation of attitudes, all factors which play a pivotal role in dealing with HIV prevention programmes.

Chapter four describes the research methodology used for the study, the principal theories and framework of the research design, the sampling procedure, the data collection methods, the pilot study, the data analysis process, reliability and validity of the study and ethical considerations.

Chapter five reports the findings of the research. The demographics of the sites are described, as well as details of the outcomes of the interviews with the service providers, the counsellors and the community representatives. The information gathered from the clinic attendees is reported including additional comments made during the interview procedure.

Chapter six discusses the implications of the findings and provides a psychosocial grounded theory analysis of the limitations and possibilities of VCT.

Chapter seven proposes recommendations including suggested future directions for resolving some of the issues. Mechanisms for the dissemination of the results conclude the thesis.

## **CHAPTER TWO**

### **2. INTRODUCTION AND BACKGROUND**

This chapter provides an introduction to the relevant components of the topic from a health perspective. In addition the history of South Africa and in particular that of African women in this context are described. Lastly health services and the economic implications of HIV in relation to health service provision are examined.

#### **2.1 The Human Immunodeficiency Virus (HIV)**

The human immunodeficiency virus has catapulted from being regarded as primarily “a rather serious health crisis”, to reaching macro-level impacts around the globe, and more specifically, in the developing world. At the beginning of the 21st century it is apparent that the Acquired Immunodeficiency Syndrome (AIDS) is also a development crisis (UNAIDS, 2000).

The virus has uniquely highlighted the complexity of a myriad of socio-cultural and economic issues, not least of which is the disparity between health care in First and Third world countries. Sub-Saharan Africa has the highest prevalence rate of HIV in the world, and South Africa, with projected 4.2 million infected people, has the largest number of people

living with HIV/AIDS in the world (UNAIDS, 2000). In 1999 the prevalence rates for South Africa were highest in KwaZulu-Natal at 32,5 percent (Marais, 2000).

Headlines such as the one in the *Sunday Independent* of 26 November 2000, entitled "Macabre interplay of poverty and sexual habits adds fuel to the HIV/AIDS furnace", give testament to the exceptionally negative socio-cultural and economic influences it is having on the African continent. A comment by a South African government official who stated "It [HIV] goes to the heart of the society we have inherited and the one we are building", spells out the controversies and dilemmas being faced by the government in South Africa. "The epidemic transcends and defies a mainly medical or health response. The often grim social transactions along which the HI virus spreads, remind us that the epidemic is an index of accumulated developmental failures that date back decades" (Marais, 2000).

As the epidemic has matured and knowledge and understanding of the disease increased, it has become necessary to acknowledge and accommodate the complexity of sexual behaviour and confront ways in which it is rooted in social history and relationships (Richter and Griesel, 1998: 20).

## **2.2 Modes of transmission**

HIV is mainly transmitted through four mechanisms, i) unprotected sexual intercourse, both vaginal and anal, ii) infected blood given by transfusion or injection, iii) sharing or re-using injection drug equipment containing infected blood, and lastly iv) pregnancy, childbirth and breastfeeding (Berer, 1993). In developing countries modes i) and iv) are the most common forms of transmission but the main route for transmission of HIV in Southern Africa is via heterosexual relationships.

## **2.3 Mother-to-Child-Transmission**

An article which critically reviewed 18 randomised trials and other relevant studies from developing and industrialised countries, concerning population-based intervention programmes for preventing MTCT of HIV-1 in Africa in the year 2000, noted that MTCT is the dominant mode of acquisition of HIV type-1 for children, resulting in about 1,600 of the approximately 16,000 new infections occurring each day, mostly in sub-Saharan Africa (UNICEF In: Dabis, Leroy, Castetbon, Spira, Newell and Salamon, 2000: 1017).

A review of HIV in pregnancy (WHO/UNAIDS, 1999: 18) provided minimum requirements for the implementation of appropriate interventions to reduce MTCT. These included *inter alia*, adequate pre- and post-test counselling services, ability to afford the cost of reliable HIV testing, acceptance and uptake of the intervention by HIV-infected women, and a regimen which is affordable for the health service. The review also states that provision of adequate strategies to prevent MTCT should not further overburden existing services.

Dr Peter Piot, Executive Director of UNAIDS sums up the reality of introducing new strategies by saying;

“There is no magic bullet for preventing mother-to-child transmission. You can’t just arrive in a country with a vial of pills. You need to strengthen local health and community structures to deliver ‘combined prevention’”, (Piot In: *SAfAIDS News*, 1998: 13).

Prevention of MTCT of HIV infection is the major objective of introducing VCT services into the antenatal setting, but there are other significant benefits (WHO/UNAIDS, 1999).

A multicentre trial undertaken in Kenya, Tanzania and Trinidad, whose subjects (N=3120) were randomised to receive VCT or standardised health information, showed that when women learn they are not infected,



apart from being a great relief it also helped them to make changes in their sexual behaviour to remain uninfected (Coates, Sangiwa, Balmer, Gregorich and Kamenga, 1998).

In a trial of short course AZT among pregnant women undertaken in the Ivory Coast, several problems relating to the acceptability of HIV testing surfaced; 20% of women refused to be tested, and half of those who were tested did not return to collect their results. This accentuated the fact that acceptability of HIV testing is a complex issue (Feinmann In: Chazal-Bertolotti, 1998: 31).

## **2.4 Reproductive Health including Sexually Transmitted Diseases**

Reproductive health has been described as:

"a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive health system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so". (United Nations In: Palmer, Lush and Zwi, 1999: 1691).

HIV has altered this landscape dramatically and the inherent rights ensconced in this description have been eroded and undermined, more especially for women living in developing nations. Most women acquire HIV in their reproductive years as a result of heterosexual transmission from an infected man (Preble, Elias and Winikoff, 1994: 500).

Co-existing, often asymptomatic, reproductive tract infections (RTIs) may exacerbate women's biological vulnerability to HIV. This biological vulnerability is of great significance because it compounds the already difficult position that women are in, and the cultural pressures they experience, in largely patriarchal societies. Tallis (1998) stated that unprotected vaginal and anal intercourse with an HIV positive man can be considered very high risk behaviour for women.

A recent study undertaken in Kenya and Zambia suggests that the greater susceptibility of women to HIV infection is an important factor both in explaining the male-female discrepancy in HIV prevalence and in driving the epidemic (Glynn, Caraël, Auvrtet al. 2001: S51).

The high level of infection found in very young women in some regions reflects very early sexual encounters, in most cases, with older men (Preble et al, 1994: 500). Sub-Saharan Africa and the Caribbean have particularly high levels of disassortative mating between young girls and

older men. In an area where AIDS is already highly prevalent, older men are a high-risk group; they are far more likely to have picked up the virus than younger ones. This helps to partially explain why the rate of infection is higher in young African women than it is in young African men (Anderson, 2000).

Other important risk factors that have been identified include the presence of sexually transmitted infections and lack of male circumcision (Auvert, Ballard, Campbell et al, 2001: 886). KwaZulu/Natal which has the highest transmission rate in South Africa is the only region where male circumcision is not traditionally practised (Webb In: Simon, 1998:225).

The interrelationships between HIV/AIDS and RTIs/STDs are critical (Wasserheit, In: Preble et al, 1994: 501). The presence of untreated RTIs make women (and men) more vulnerable to acquiring HIV infection and accelerates the progression to HIV disease (Laga 1992, Wasserheit 1992, In: Preble et al, 1994: 501).

These interrelationships are particularly important because women often have asymptomatic RTIs, and silent infections may cause infertility, ectopic pregnancy and chronic pain, as well as congenital infection of new-borns. As a consequence, RTIs are a source of significant maternal and neonatal morbidity and mortality. Such complications are especially

prevalent in developing countries where the health care infrastructure is frequently inadequate (Preble et al, 1994: 502).

Preble et al (1994: 502) also state that in high seroprevalence areas of developing countries, AIDS will have a major impact on all phases of women's reproductive lives, and will significantly increase women's morbidity and mortality. The HIV/AIDS epidemic will also challenge maternal and child health (MCH) service providers by increasing pressures to engage in HIV/AIDS prevention and treatment efforts, while at the same time reducing the pool of trained MCH workers through AIDS-related mortality.

## **2.5 Voluntary Counselling and Testing (VCT)**

According to a study regarding the cost-effectiveness of VCT for HIV-1 in reducing sexual transmission of HIV-1 in Kenya and Tanzania, there are compelling arguments for the provision of HIV VCT services in sub-Saharan Africa. Firstly, individuals have a right to know their infection status to protect themselves and others from infection and to plan for their future. Secondly, VCT may enable people to cope with the anxiety associated with HIV-1 serostatus. Thirdly, early detection of HIV-1 may improve medical and psychosocial support for HIV-1-infected individuals.

Lastly knowledge of the status of HIV-1 promotes behaviour change in the short term (Sweat, Gregorich, Sangiwa et al, 2000: 113).

In the HIV/AIDS continuum of care, VCT has been identified as a valuable entrypoint for prevention and care. The multi-factoral components of this intervention are comprehensively illustrated in figures 1 and 2 (WHO, 1999: 5).

**Figure 1**

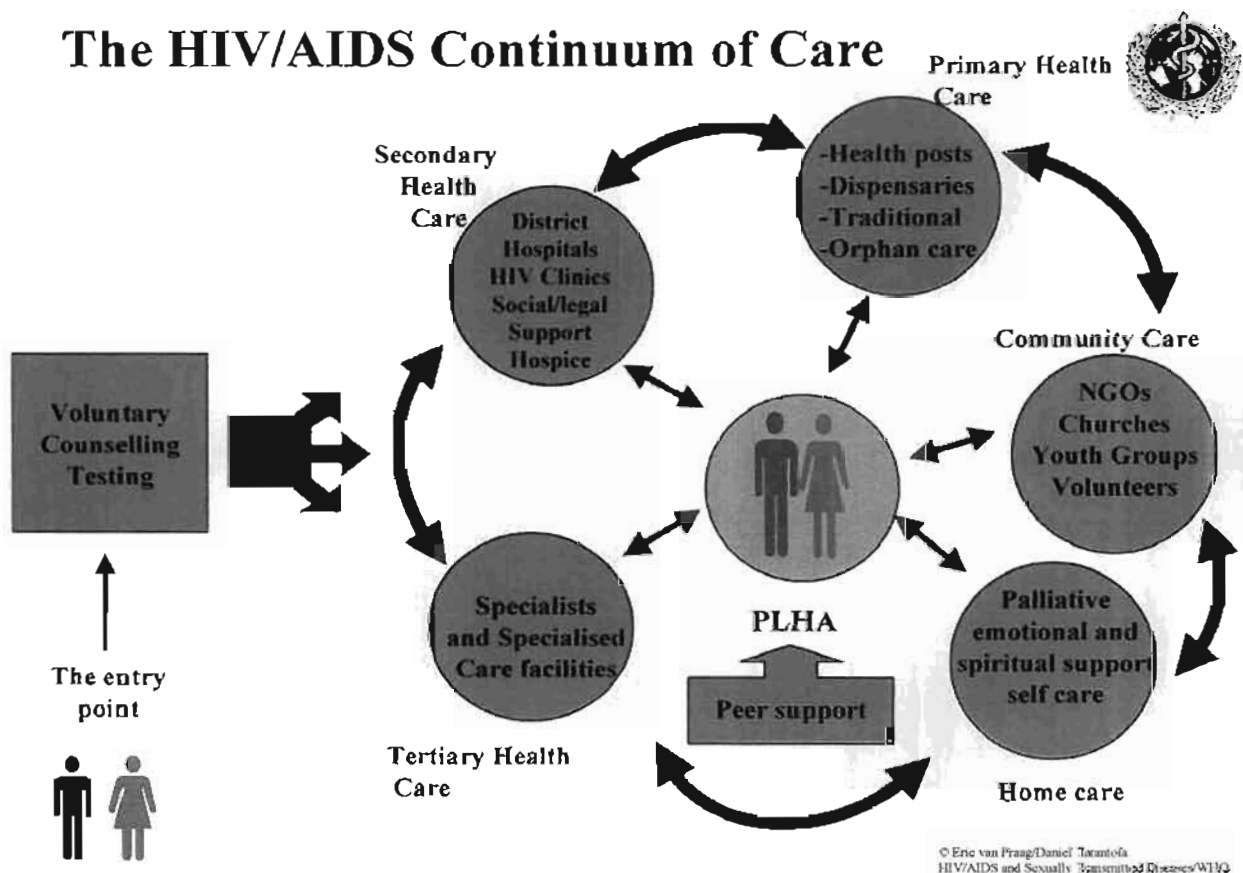
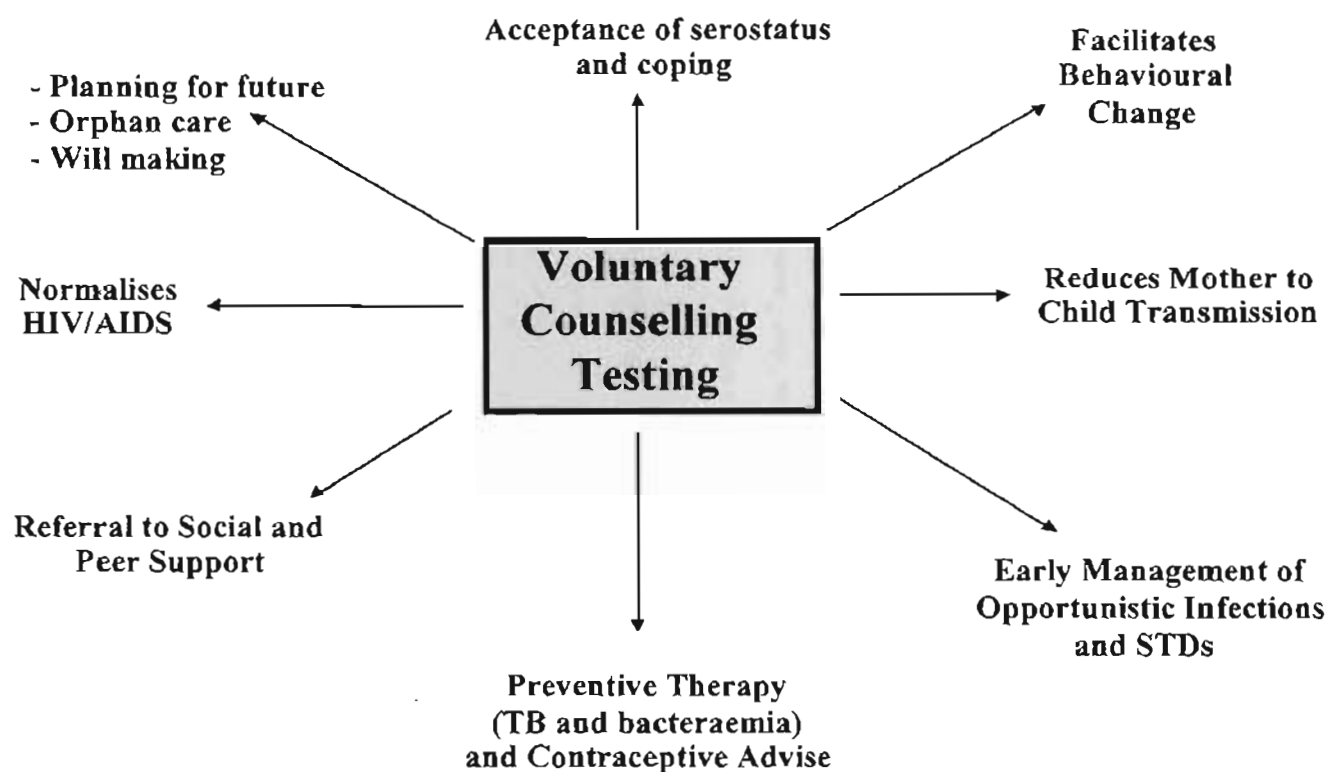


Figure 2

## VCT as an entrypoint for HIV Prevention and Care



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However in South Africa the health care system has been undergoing dramatic changes since the democratically elected African National Congress took over the reins of government. Factors such as the reduction of mother-to-child transmission, early management of opportunistic infections and STDs and referral to social and peer support may not be universally available in South Africa due to the current health and economic policies of the government. This lack of functioning of health care systems in sub-Saharan Africa is now a major obstacle to the provision of care and, in particular, there has been a lack of resources for HIV testing and counselling (Kallings and Vella, 2001).

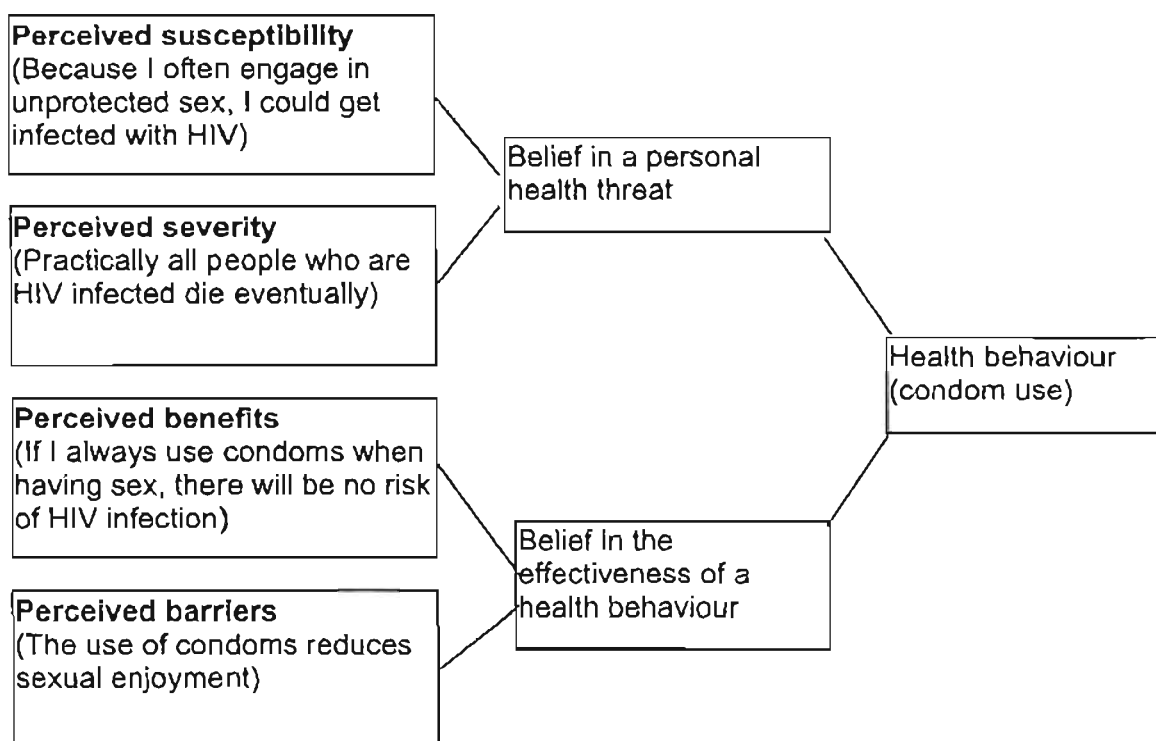
The core focus of the counselling interactive process sees health as being embodied in everyday actions and behaviour of human beings. The Health Belief Model (HBM) developed by Rosenstock and Becker in 1974 to explain why people did not use health services has been applied to many aspects of health behaviour as well (Hubley, 1993: 39). The key proposals of the HBM are that a person would perform certain actions under three conditions;

1. that one of the precedents of taking health action is a perceived benefit; women should see the health problem as preventable (i.e. avoid risk of transmission of the virus by taking avoiding action)
2. that they are personally susceptible to the health problem, and

3. the seriousness of the health problem should be a determinant of action (Chazal-Bertoletti, 1998: 16).

A useful diagram illustrating the application of the health belief model to the reduction of sexual risk behaviour follows;

**Figure 3**



Source: Stroebe W, 2000.

Therefore the focus of the counselling intervention amongst other things is to draw attention to the facts associated with transmission of the HI virus



and offer alternative ways of counteracting and protecting oneself against the dangers of high-risk sexual behaviour.

For women to benefit from the intervention of VCT they must first know and accept their HIV status (WHO, 1999). In a three-country trial carried out in Kenya, Tanzania and Trinidad, both VCT and health information were shown to reduce sexual risk behaviours among study participants. The efficacy of VCT as an intervention that can help reduce HIV transmission was demonstrated (Coates, Sangiwa, Balmer et al, 1998). However this educational and preventive measure may be seen as "idealistic" and unattainable as far as the service offered to marginalised groups in some developing countries are concerned.

The subject of disclosure compounds the difficulties of introducing this intervention and carries with it stigma, prejudice and frequently serious consequences for the mother and her infant. Rejection by her partner, husband or family, which can translate into untold hardship and often result in no financial support for her survival. Although disclosure is a sensitive issue, when VCT is offered to women attending antenatal care clinics, the opportunity should also be explored to offer it to their partners. It has been shown that up to 25% of couples in which one partner is seropositive, are serodiscordant. Therefore if both partners were

counselled, transmission of HIV infection could be reduced (WHO,1999: 2).

As daunting as the barriers to HIV testing are, it is important to tackle them because when individuals learn their infection status early on, there are benefits for both prevention and care. When VCT is properly carried out it can help to break the vicious circle of fear, stigma and denial. (UNAIDS, 2000).

A study incorporating focus groups and in-depth interviews concerning attitudes to VCT for HIV among 208 pregnant women, maternity staff and other identified groups, in rural south west Uganda, concluded that VCT during pregnancy was acceptable in principle, but there was still much groundwork to be covered regarding confidentiality and women's fears of stigmatisation and discrimination. The training of staff and providing adequate protection for them was of concern (Gysels, Pool and Nyanzi, 2000). This highlights the multi-dimensional perspective of both the service providers and the service recipients towards HIV/AIDS confidential counselling and voluntary testing.

In an exploratory investigation into the psychosocial impact of an HIV positive diagnosis in a small sample of pregnant women in KwaZulu Natal, the powerlessness of women was evident. The access to, and

usefulness of VCT as a preventive intervention were constrained by the inability of the women to challenge their partners to engage in safer sex practices (Tallis, 1997).

There is substantial evidence that the extent to which social relationships are strong and supportive, and individuals are integrated into their communities, is related to the health of the individuals who live within such social contexts. To improve health among vulnerable and high-risk populations, preventive efforts, at their core, must promote social support and develop family and community strengths (Berkman, 1995).

Both pre- and post-test counselling are essential components of the testing procedure and the relief experienced by those who test HIV negative should be capitalised on and used as both an educational opportunity and a communication outreach for family, friends and partners of the client (WHO/UNAIDS, 1999)

The Department of Health in Pretoria has produced a document on voluntary counselling and testing strategies to be introduced to combat HIV/AIDS transmission. This national endeavour is aimed at developing a country-wide self-initiated proactive VCT programme as an effective way of dealing with the epidemic. The goal over the next three years is to provide HIV counselling and testing to 100% of the adult population aged

15 to 49 years, targeting the youth and rural communities through improving linkages between health, welfare and education sectors at district level (MINMEC, 2000).

## **2.6 South Africa and African women**

Poverty is the single greatest burden of South Africa's people, and is the direct result of the apartheid system and the grossly skewed nature of business and industrial development which accompanied it. Poverty affects millions of people, the majority of whom live in the rural areas and are women (African National Congress, 1994). Although South Africa is classified as an upper middle income country the past economic exploitative policies have caused extreme imbalance and inequalities amongst the different race groups.

In relation to poverty in South Africa the study of development and human life necessitates the examination of shared values and their multifaceted transformations. Religion and kinship are equally as important as economic transactions and the political life of nation states, they are not separable or comparable, they do not exist in isolation (Allen and Thomas, 1992).

Amartya Sen, winner of the Nobel prize in economics (1998), states that human rights and political liberty are now very much a part of the prevailing rhetoric. However, there is still a persistence of poverty and unfulfilled elementary needs, not least of which are the extensive neglect of interests and agency of women. Overcoming these problems is a central part of the exercise of development and bridging the gap between the rich and the poor is a topic which receives constant attention on the agendas of world leaders. Sen refers to five distinct types of freedom, and these are; political, economic facilities, social opportunities, transparency guarantees and protective security (Sen, 1998: 38).

To highlight one of these freedoms, social opportunities refers to access to education and health care. World-wide, women face limited access to financial services, technology, and infrastructure (The World Bank, 1995). In South Africa these freedoms have been particularly lacking in regard to the black population and women have been the most disadvantaged.

Literacy, along with education, is acknowledged world-wide as a fundamental human right. According to the latest ABET DATA (Statistics South Africa, Census 1996) it is estimated in South Africa that approximately 54% of the adult population are without a general education. When designing appropriate intervention strategies aimed at educating individuals about HIV this high figure must be recognised and

embraced as a factor to be incorporated in the models to be utilised. The development of mass education is closely related to democracy and the belief that education can reduce social inequalities.

Another factor which has had a profound effect on black family life is that of migrancy and this can be divided into two types, namely the exodus of mineworkers to the gold and mineral areas near Johannesburg and the other universal phenomenon of urbanisation. A consequence of migrancy has been the erosion of parental authority and the weakening of the traditional kinship group. Many black parents had little or no school education in their traditional rural homelands which broadened the gap between parents and their children and in addition the absence of working parents diminished the influence of parental authority (Bester, 1994). This lack of authority and breakdown of the traditional family unit has influenced the changing behaviour patterns of the youth.

Statistics show that in KwaZulu/Natal 45% of the population are under 18 years of age (Durban Functional Region Draft Health Plan, 1995). In relation to HIV problems associated with this statistic are rising unemployment, an increase in orphans whose parents die from HIV/AIDS and street children who become misplaced in society and who are not in the natural cultural catchment of any particular community.

To understand the issues surrounding the "powerlessness of women" it is necessary to take a look at the historical context of African women under customary law as a platform for reform and progress in the field of health services in the future.

The African family in South Africa's customary societies was patriarchal and polygynous. Women neither owned nor inherited property. They were perpetual minors, subject to male tutelage, no matter what their age or marital condition might be (Simons, 1997: 80). African women carry a double burden of disabilities. They are discriminated against on the grounds of both sex and race. (Simons, 1968: 285). Historically women in most European countries obtained the vote after they had achieved a fair measure of equality with men in the field of family law. Asian and African women, in contrast, have been enfranchised while still subject to male domination under the law relating to marriage, guardianship, succession, contract and property (Simons, 1968: 287).

Migration as mentioned previously added to the hardship faced by women and children left behind in the rural areas of South Africa while primarily male workers went to seek work in the mines or urban areas. Migration literature however remains fragmented and diverse in terms of both its theoretical underpinnings and methodological considerations. The relatively new focus on gender has led to a re-examination of

traditional migration theories and methods within a feminist framework. In addition the creation of impoverished reserves has been attributed to the penetration of capital into peasant societies, the undermining of self-sufficiency of these societies and their subsequent transformation into labour exporting peripheries (Wolpe; Parson; In: Simon, 1998: 206).

Bozzoli (1983) argued that kinship and 'purity' ideologies provided a system for the control of women. The underlying fear of women's migration was that it would result in their sexual emancipation. Women who migrated to towns were viewed as 'trouble' by African men and European settlers and were thus portrayed as being morally loose and trying to behave like men (Simon, 1998: 210). Another issue brought into the debate was that women in southern Africa faced a struggle on two fronts; between women and capitalism and between women and men (Simon, 1998: 206).

In South Africa, African women have been identified as the most disadvantaged group, black, female and from low socio-economic circumstances. The majority of South African women are not merely poor, they are impoverished. They are made poor and kept poor by the dominant social, economic and ideological forces that define their lives (Marais, 2000).



Historically, the role of women in society and their empowerment was largely ignored in South Africa. Women's issues became subsumed under the national liberation struggle against apartheid (UNISA, 1995). Under the apartheid system South Africa was subjected to extreme social engineering, designed for the benefit of the minority white population. South Africa's black population was forced into crowded, impoverished homelands which led to the breakdown of traditional cultural structures (Whiteside and Sunter, 2000: 62).

Traditionally, women are seen as the caregivers in heterosexual relationships. Women's sexual relationships with men are characterised by unequal power relations with men being dominant and women being submissive (Tallis, 1997). Powerlessness is widely recognised as a risk factor that adversely affects quality of life and health (Kar, Pascual, Chickering, 1999: 1432). How women are valued and treated in society, including their level of education, affects their ability to feed and care for their children (UNICEF, 1998).

In 1954 the Federation of South African Women (FEDSAW) adopted a Woman's Charter which acknowledged that women and men form a single society. They share the same problems and efforts to remove social evils. Lilian Ngoyi, a renowned leader of the 1950's rebuked

husbands who preached democracy, but held their wives and daughters back from taking part in the struggle for equal rights (Simons, 1997: 124).

In summary the struggle for equality between men and women continues universally but for black women in South Africa the difficulties which were entrenched by racism and their own customary law are far from being resolved. The HI virus highlights these continuing injustices for women and their children.

## **2.7 Health Services and the Economic Implications of HIV**

Different concepts of health and ill health are not independent of social context. Gender, sexuality and race have played an important role in the construction of health (Curtis & Taket, 1996). The sociological approach to health and illness makes us aware of the fact that one's chances of falling ill are not determined purely by biological factors such as viruses, but also depend on, *inter alia*, social factors such as class, gender relations, government policy on housing, sanitation, and minimum wages (UNISA, 1995).

Health policy reflects a society's approach to health care. According to Cockerham (1992) this approach is based on historical experience, culture, political ideology, social organisation, literacy level, standard of

living, attitude towards welfare and the role of the state in this regard (Cockerham In: Pretorius, Marais and Martin, 1997). The main components of the health care system are economic support, human resources, facilities, service delivery patterns, preventive services, regulation and administration, and planning (Elling; Roemer; In: Pretorius, Marais and Martin, 1997).

The relationship between fertility and HIV is important because much of the data about levels of infection come from testing of pregnant women (Pisani, 1997: 6). Maternity services in areas of high HIV prevalence have several responsibilities: to enable women to be tested and to use these results to maintain their health in an optimal manner, to utilise appropriate interventions to reduce the rate of mother-to-child transmission of HIV and lastly to train staff and provide equipment to prevent nosocomial transmission of HIV and other pathogens (WHO/UNAIDS, 1999).

In an overview of social, cultural and political issues Brown (2000: 236) comments that studies from different countries show that there are wide variations in the nature of the problems observed. This extreme variability drives home the need to use local data and sources to obtain in-depth understanding of the local situation to adapt programmes to local needs. In addition Brown states that programmes must take into account

the social, cultural, political and economic forces that drive the epidemic and slow the implementation of effective responses.

The development of a successful pre-natal programme for routine patient education and the identification and care of HIV-infected pregnant women can be accomplished through strong collaborative working relationships between medical, nursing, social work and clerical staffs. Extensive prior education for all professional staff form the building blocks of the programme (Mason et al, 1991: 122).

Staff training served as a foundation for a comprehensive patient program in a major urban teaching hospital in the USA, which reached all prenatal patients regardless of risk behaviour. The program succeeded in involving a large population of women in an educational program, identified HIV-1 seropositive pregnant women through voluntary testing, and provided them with the necessary medical and social work services (Mason et al, 1991: 118).

The results of a study undertaken in the United States concerning implementation of guidelines for HIV counselling and voluntary HIV testing of pregnant women, found that women were more likely to be tested if they received HIV counselling and more likely to be offered testing if they

received such counselling (Joo, Carmock, Garcia-Bunuel and Kelley, 2000: 275).

A study analysing statistics from the New York State Obstetrical Initiative found that the individual counselling length variable demonstrated that as counselling time increased, there was a dramatic linear increase in acceptance of testing. Counsellor characteristics of empathy, warmth and genuineness were considered vital for continuation of counselling uptake (Sorin, Tesoriero and La Chance-McCullough, 1996: 83).

The psycho-social aspects associated with HIV/AIDS place a great burden on the staff of any agency. Staff have to come to terms with their own fears and prejudices and may hold patients responsible for their disease (South African National Council for Child and Family Welfare, 1993: 15).

A qualitative study amongst selected groups in the populations of Arusha and Kilimanjaro, Tanzania, found that informants were more concerned with the social consequences of the disease than with the technical facts of AIDS. The findings also indicated that counsellors must balance a fact-giving approach with a person-centred approach, exploring the client's problem conception and identifying who in the client's network can give further necessary psycho-social support (Lie and Biswalo, 1994: 139).

Counselling is often accepted in some instances because of the perceived low risk of HIV infection. In an evaluative study undertaken in Abidjan, women able to analyse the potential adverse consequences were more likely to develop a negative attitude to HIV testing, and were less likely to return for their results (Cartoux et al for the DITRAME study group. 1998: 2343).

When local experience deviates from inapplicable health care counsel, it becomes more difficult to influence everyday practices to support health. Resistance to health care advice can occur when mothers feel they know better, or when health care admonitions are regarded as inappropriate or inapplicable to the circumstances of the people to whom they are directed (Richter and Griesel, 1998: 21).

Much of the emphasis of health promotion has been on the "health consumer" as an individual (Grace In: Seidel, 1996: 1) and this neo-liberal discourse is problematic in that it ignores the crucial importance of social actors and new social forces in bringing about change (Escobar In: Seidel, 1996: 1). The concept of neo-liberalism is a doctrine aimed at confronting social and economic crises which capitalism charges are caused by populism (Forest In: Castells, 2001: 68). Seidel (1996) considers this neo-liberal discourse ignores the different experiences of

women and men, and consequently the historical and social construction of gender.

Within the context of HIV prevention in sub-Saharan Africa there is a growing move away from information-based health education towards the development of community-based participatory interventions. Programme evaluators still rely overwhelmingly on individual behavioural and biomedical outcome measures, paying less attention to the processes underlying such outcomes (Campbell and Williams, 1998: 1).

Campbell and Williams (1998: 11) expand this theme by suggesting that social and sexual identities are negotiated within the particular social, community and cultural contexts in which people and their families live and work. These contexts often determine the extent to which people have access to opportunities for empowerment/self-efficacy.

A social network or support intervention is based on the premise that the individual who is ill or at risk and his or her network represent an interdependent and dynamic system. The role of self-efficacy or the belief that one can successfully perform behaviours to produce a desired outcome is the core of social learning theory. Self-efficacy is believed to be shaped by past and present behaviour and by the social environment

through observation of behaviours in others and verbal support and persuasion (Berkman, 1995).

A study in several rural districts in Africa showed that where a third of all adults are HIV-infected, nearly half of all households have at least one resident who is HIV-positive. Therefore more people have a direct experience of infection, illness and death in the household than straight prevalence figures would at first suggest. The observation is important because people's behaviour is often shaped by experience in the home (Pisani, 1997: 10).

People infected with HIV must be diagnosed early to translate therapeutic advances into public health benefit (De Cock and Johnson, 1998: 3). This report also proposes that in areas where HIV prevalence is high, systematic voluntary HIV testing should be strengthened in hospital patients and in the traditional settings of sexually transmitted diseases clinics, testing should be offered universally as part of routine antenatal care.

A cross-sectional study amongst 400 antenatal clinic attendants in Nairobi, Kenya also recommended that HIV testing be made available at antenatal clinics, together with competent pre- and post-test counselling. (Marjan and Ruminjo, 1996: 665).



Rapid on-site HIV testing, in an evaluative programme carried out in two clinics in Dallas, Texas, was found to be feasible, preferred by clients, and resulted in significant improvement in the number of persons learning their serostatus, without increasing the costs or decreasing the effectiveness of counselling and testing (Kassler et al, 1997: 1045).

Labour related migration is the norm in many rural areas and is likely to be associated with changes in risk behaviour. Similarly urbanisation is radically altering the whole social landscape, eroding the strength of the extended family and with it the means to cope with the shock of high adult mortality (Pisani, 1997: 5).

Poverty is both a national and an individual risk factor. During the early stages of the HIV epidemic socio-economic status is no protection against infection (Whiteside, 1995: 5). Low levels of education, crowded and unsanitary living conditions, limited access to basic services, high rates of unemployment, and rapid urbanisation are all poverty phenomena that are increasingly associated with HIV/AIDS (Hope, 1994: 82).

Many women in developing countries are unaware of even the most fundamental aspects of HIV risk reduction and even those armed with this knowledge frequently face the harsh reality of living in circumstances in

which sexual disempowerment is a fundamental aspect of their economic survival (MacDougall, 1997: 1).

The glaring connection between prosperity and good health is one of strong positive association (Sen, 1999). Sen also states that the fact that health care, basic education, and other crucial components of social opportunity are highly labour-intensive activities make them affordable even in poorer economies, where labour is also cheaper.

In 1998 President Thabo Mbeki warned that, "for many years we have allowed the virus to spread ...[and now] we face the danger that half of our youth will not reach adulthood. Their education will be wasted. The economy will shrink. There will be a large number of sick people whom the healthy will not be able to maintain" (UNAIDS, 2000: 39).

National health expenditures are rising dramatically as HIV-infected individuals progress to AIDS and require treatment. HIV/AIDS-related costs will affect health budgets in developing countries which are already beleaguered by declining economies (Preble et al, 1994: 509).

Demand for VCT services may increase as medical management of people infected with HIV-1 improves in less-developed countries. Prophylaxis of opportunistic infections by simple generic drugs, prevention

of perinatal transmission of HIV-1 through short-term oral treatment regimens, and safe alternatives to breastfeeding are major advances that may change readiness and acceptability of VCT (The Voluntary HIV-1 Counselling and Testing Efficacy Study Group, 2000: 111).

The study group also reported that cost-effectiveness analysis has shown that the benefits are especially evident when high-risk populations are targeted, and that these VCT services attract higher-risk individuals than those found in the general population, and may thus be a cost-effective resource for reducing risk among individuals more likely to contract or spread HIV-1. Finally the importance of confidentiality, trust between client and counsellors with respect to information management, and the inadvisability of promoting VCT in the absence of effective human rights assurances was underlined (The Voluntary HIV-1 Counselling and Testing Efficacy Study Group, 2000: 111).

In a letter to the editor of the Lancet regarding mandatory HIV testing in both developing and developed countries, Müller (1993) stated that increased financial support for AIDS prevention is likely to be cost-effective in the long term. He also suggested that confidential HIV/VCT services, preferably non-governmental were likely to benefit the community.

A substantial concern raised about HIV counselling and testing in the developing world is the cost of providing this prevention service. HIV counselling and testing competes for scarce resources along with prevention treatment for other infectious diseases such as malaria, yellow fever, tuberculosis, and diarrhoeal and respiratory diseases (Campbell, Marum, Alwano-Edyegu, Dillon, Moore and Gumisiriza, 1997: 94).

According to Coovadia (1999), in an address given at the second conference on Global Strategies for the Prevention of HIV Transmission from Mothers to Infants concerning access to VCT in developing countries, the HIV pandemic has stretched health services in developing countries, which were just barely sufficient to cope with the demands of existing diseases, to breaking point.

An economic report entitled 'Economic Impact of AIDS in South Africa: A dark cloud on the horizon' by ING Barings (2000: 3) states that some 70% of the global total of HIV infected live in sub-Saharan Africa. Life expectancy at birth in southern Africa, which was 59 years in the early 1990s, is set to drop to just below 45 years between 2005 and 2010. Further statistics in the report for sub-Saharan Africa were that 3,800,000 adults and children were newly infected with HIV in 1999 and women as a percentage of HIV positive adults were 55. The main mode of

transmission for adults living with HIV/AIDS was heterosexual relationships (ING Barings, 2000: 4).

This concludes the introduction and background information to the subject of HIV, transmission, reproductive health and the preventive intervention of VCT. The historical perspective of South Africa, the disparity in the allocation of resources, and in particular, the position of African women in this context, the health services and lastly the economic implications of HIV in relation to health service provision were examined.

## **CHAPTER THREE**

### **3. ORIENTATION TO THE RESEARCH TOPIC**

Chapter three provides an orientation to the topic, focusing on the route of “exceptionalism” to “normalisation” of HIV in society, behaviour modification, and the formation of attitudes, all factors which play a pivotal role in dealing with HIV prevention programmes.

#### **3.1 Exceptionalism to Normalisation**

Since the recognition of the first cases in 1981, AIDS has been handled differently from other infectious diseases (De Cock and Johnson, 1998: 2). In the USA and UK, men who have sex with men, argued when HIV/AIDS was first recognised for policies that differed from a traditional infectious disease control approach. This strategy has been termed “HIV/AIDS Exceptionalism”. The use of HIV antibody tests was restricted in a way not seen previously for other diagnostic investigations. Concerns about abuses of civil rights was influenced by the vocal involvement of members of affected communities in the science and politics of HIV/AIDS (AIDS activism).

Initially generalised antenatal testing in women retained a low profile because women accounted for a minority of people in industrialised countries infected with HIV. "Normalisation" refers to treating HIV/AIDS like any other infectious disease for which early diagnosis is essential for appropriate therapeutic and preventive measures, within the requirements of informed consent and respect for confidentiality (De Cock and Johnson, 1998: 2).

In high prevalence areas HIV remains a stigmatising condition and denial and rejection are major barriers to HIV prevention programmes (WHO, 1999). An article entitled "Dirty, Diseased and Undeserving: the positioning of HIV positive women" described 'stigma' as being based on the assumption that women have departed from the socially prescribed behaviour worthy of 'good women'. (Lawless, Kippax and Crawford, 1996: 1375). They conclude by commenting that in taking on the view of themselves as stigmatised, they are faced with an added burden, namely the protection of those close to them from stigmatisation by association (1376).

De Cock and Johnson (1998: 4) state that a major factor influencing rates of testing is the attitude of attending midwives and obstetricians. Negative consequences that may result from people knowing their positive HIV serostatus include psychological disturbance, rejection,

stigmatisation, social and financial discrimination. HIV seropositive women are at increased risk of domestic violence. The normalisation of HIV/AIDS will only occur when strong measures are taken to combat these issues.

Observational studies suggest that people with positive test results can change towards safer sexual behaviour and there is a widespread opinion that insufficient attention has been given to interventions aimed at promoting safer behaviour by people infected with HIV.

In response to the article by De Cock and Johnson, it was pointed out that HIV/AIDS "exceptionalism" in parts of Africa has led to an environment of stigma and denial, with the tacit support of policy makers and healthcare staff. HIV is rarely entered on African death certificates, yet treatment decisions are made on the assumption that a patient is infected. Half of those counselling others to consider HIV testing choose not to be tested themselves (Godfrey-Faussett and Baggaley, 1998: 1).

Continuing efforts will be needed to reduce the stigma of HIV and to improve the position of women both economically and socially. An article in the latest edition of *Social Science and Medicine* (2001) explores an alternative paradigm for epidemiologies, one which is explicitly informed by a feminist perspective. The authors highlight issues such as



persistent antifeminist biases in contemporary epidemiological research on women's health. These include: problem definition and knowledge production in women's health; biological essentialization of women as reproducers; and decontextualization and depoliticization of women's health risks (Inhorn and Whittle, 2001: 553).

Important elements cited by Inhorn and Whittle (2001) towards developing new methodological and theoretical strategies would include, amongst other things;

“The active engagement of women themselves in the epidemiological knowledge production process; this will involve women “talking about their health”, defining their own health problems, and being actively listened to by feminist epidemiological researchers committed to empathic engagement in the lives of those they study;

*and*

the connection of women's local lived experiences of health and illness and the various forms of oppression they encounter to larger social, economic and political forces” (Inhorn and Whittle 2001: 564).

The research in this thesis has been undertaken with the last point in view and that is to inform the discourse of local knowledge in regard to women's health experiences.

If counselling is found to be worthwhile, it is likely to be more effective if more attention is paid to the beliefs, anxieties and role of the counsellors (Baggaley, Sulwe, Kelly, Macmillan and Godfrey-Faussett, 1996).

Health and illness have traditionally been matters concerned with physical conditions of the body only but in fact social factors have a profound effect on both the experience and the occurrence of illness, as well as on how people react to being ill (Giddens, 1993).

### **3.2 Behaviour Modification**

Behaviour change and modification of sexual practices in light of this infectious disease are at present the most viable means of dealing with this issue (Choi and Coates, 1994: 1386). Limited resources currently preclude the availability of antiretroviral drugs in South Africa although the government is currently considering this option, but even if, and when, they do become available, it may be a long time before the health care infrastructure is able to support and sustain this service adequately.

It is now well accepted that the degree to which one feels that one has control over important aspects of one's life is an important determinant of one's health-related behaviour (Bandura, 1996). Social and sexual identities are negotiated within the particular social, community and cultural contexts in which people and their families live and work. These contexts often determine the extent to which people have access to opportunities for empowerment/self-efficacy (Campbell and Williams, 1998: 11). Sexual behaviour is inextricably linked with the norms characteristic of the social groups with which we identify (Stockdale, 1995).

In an article concerning the effectiveness of psycho-educational interventions in reducing emotional distress after HIV antibody testing, the need to develop and test psychoeducational interventions for at-risk adults that are easy to learn and administer, cost-effective, and acceptable to a wide range of clinicians and patients was emphasised (Perry, Fishman, Jacobsberg, Young and Frances, 1991).

Knowledge and behaviour change along with a deeper understanding of the psychological processes that underlie attitudinal and behaviour positions are important. Role models, social acceptance, political and cultural legitimacy are all necessary components of safer-sex promotion and condom usage (Perkel, Strebel and Joubert, 1991: 151).

The lack of access to drug therapies, psychosocial support and clinical care, were cited by Temmerman, Ndinya-Achola, Ambani and Piot (1995: 970) in a study debating the right not to know the HIV test result. They were of the opinion that there is not much to offer African women once they have been told the bad news. Another negative aspect which comes with the widespread public awareness of high HIV prevalence, is that people who are already infected may think there is no reason to change their behaviour since it won't benefit them (Campbell et al, 1997: 96).

In countries where HIV prevalence is high it is common for many to develop feelings of hopelessness and a misperception that behaviour change is futile. However evidence from counsellors suggests that for many clients, learning that they are not infected displaces the sense of futility and is a powerful motivator to behaviour change (Campbell et al, 1997: 99).

A meta-analysis of the effects of HIV counselling and testing on sexual risk behaviour between 1985-1997 concluded that HIV-counselling and testing should be viewed as one part of an overall HIV prevention strategy that also includes individual, community and policy-level interventions (Weinhardt, Carey, Johnson and Bickham, 1999: 1404).

According to Bandura (cited in Perkel, 1992: 29), perceived self-efficacy influences all aspects of behaviour, including the acquisition of new behaviours, inhibition of existing behaviours, and disinhibition of behaviours. Efficacy expectations refer to beliefs about how capable one is of performing a behaviour that leads to anticipated outcomes. According to Perkel (1992: 29) it appears to play a critical role in the initiation and maintenance of behaviour change.

The findings of a study undertaken amongst patients attending the Anonymous Clinic in Thailand, questioned about various aspects of HIV and sexual behaviour patterns, gave evidence of the value of voluntary HIV counselling and testing in contributing to the reduction of HIV transmission in Asia (Müller, Sarangbin, Ruxrungtham, Sittitrai and Phanuphak, 1995: 567).

Choi and Coates (1994: 1386) critically reviewed the scientific literature on AIDS prevention programmes in an attempt to determine the extent to which behavioural intervention research has demonstrated the efficacy of methods for reducing risk behaviours. One of the findings was that there is a serious disjunction between research on prevention and the intervention programs themselves. Prevention science needs to be tied clearly and closely to prevention practice.

According to Parker (1996: 27) the focus of HIV/AIDS prevention efforts has increasingly shifted from models aimed at changes in individual risk behaviour to models aimed at community mobilisation. An earlier emphasis on information-based educational campaigns has given way to intervention programs aimed at enablement and empowerment in the face of the epidemic.

Acknowledging an explosive epidemic in the general population very early on, President Yoweri Museveni of Uganda, took active steps to fight the spread of HIV infection through action by the government and other groups in society, including religious leaders and community development organisations, which were encouraged to tackle HIV and AIDS in ways that made best use of their particular skills. This broad-based approach to the epidemic contributed to a reduction in HIV infections and set a precedent for other developing countries to follow (UNAIDS, 2000).

### **3.3 The Formation of Attitudes**

A central tenet of this thesis revolves around an evaluation of the attitudes held by different constituents of this study. For this reason a definition of our understanding of attitude formation is necessary.

Allport (cited in Foster & Louw-Potgieter, 1994) provided an influential definition which stated;

"an attitude is a mental and neural state of readiness, organised through experience, exerting a directive or dynamic influence upon the individual's response to all objects and situations with which it is related" (p 124).

The major understanding of Allport's definition therefore was that attitude was located either mentally or neurally, in the individual and that it was learned. Allport also recognised that an attitude characteristically provoked behaviour that was favourable or unfavourable, for or against, the object or class of objects (Foster & Louw-Potgieter, 1994).

The idea fundamental to contact as an attitude-changing mechanism is that individuals are the source of negative attitudes, and that contact would provide people with the opportunity of discovering that, in reality, they share the same basic values and attitudes (Foster & Louw-Potgieter, 1994). In relation to HIV there are negative connotations surrounding the sexual transmission of the disease.

Social representations theory, as developed by Moscovici (cited in Augoustinos and Walker, 1996), attempts to reinstate the collective and social nature of cognitive constructs like attitudes, beliefs and values.

Social representations are the building blocks used to construct and thereby understand social reality.

To summarise this chapter the core aspects which form the main direction of this thesis were examined and these are, the exceptional way in which HIV has been treated by the medical profession and society, the preventative intervention of behaviour modification through increased awareness and knowledge about HIV, and finally the way in which attitudes are formed.

To review the main points of departure of the thesis a brief summary of the first three chapters follow.

The primary focus of the research was on describing the multi-faceted and complex combination of factors impacting on the lives of women undergoing VCT and the implications inherent in that decision.

There were three main aspects described in the first three chapters which combined to produce a three-pronged health intervention package, namely;

- i) The educational health messages embodied in the counselling component, for example, imparting knowledge and information



about HIV and different modes of transmission and ways of dealing with them. This included a reference to reproductive health with particular emphasis on sexually transmitted diseases and women's susceptibility to infection.

- ii) The actual application of the HIV test and the negative psychological trauma which can ensue as a consequence of a positive test result and conversely the factors which promote behavioural change and psychological relief when a negative result is given.

The negative consequences can be summarised briefly as having no hope, despair, stigma, isolation, fear and loss of both physical and mental health. Added to this list can be a sense of worthlessness. This negativism is compounded in society by the blaming culture. People want to blame someone or something, either the monkeys, the prostitutes, the homosexuals or the bisexuals instead of encouraging people to understand the transmission mechanisms and teach them how to take responsibility for their behaviour and protect themselves and their sexual partners.

In contrast the positive effect of a negative HIV result includes the window of opportunity to deal with the reality of the situation and provide possible coping mechanisms in areas such as medical care, family support, facing responsibilities and making provision for children, partners and other dependent family members.

"Finding ways of increasing one's ability to control one's life (e.g. supporting a decision not to give up, helping a PLWH/PLWA to broaden their life, helping to concentrate also on other things beside HIV" (Kylma et al, 2001) are important benefits which skilled counselling can promote. Illness is not fatalistic and the counselling facilitates communication thereby advancing a rising consciousness both in the women counselled and ultimately the wider community.

- iii) The historical perspective of African women in South Africa in relation to health interventions and their relevance to them. To date there has been limited in-depth research in South Africa on the actual application of VCT as a health intervention using a more holistic approach. A national survey carried out for the Department of Health in South Africa on the status quo of VCT took the form of an audit rather than an in-depth analysis (Richter et al, 1998). To gain the maximum impact of introducing VCT it was

considered essential that the relevance of the intervention from the standpoint of the service providers and the women undergoing the procedure was further considered and investigated.

This completes the first section of the research which includes the objectives, the introduction and background to VCT within the current health service in South Africa, and the orientation to the topic.

## **CHAPTER FOUR**

### **4. RESEARCH METHODOLOGY**

Chapter four outlines the research methodology used for the study, the principal theories and framework of the research design, the sampling procedure, the data collection methods, the pilot study, the data analysis process, reliability and validity of the study, and ethical considerations.

#### **4.1 Principal theories and framework of the research design**

The information obtained in this study was collected by using two methods, qualitative and quantitative. Qualitative research is naturalistic, holistic and inductive. Looking at research from a holistic perspective means that the whole phenomenon under study is understood as a complex system that examines interdependencies (Terre Blanche & Durrheim, 1999).

It is difficult to accept that lifestyle factors and psychosocial stress are important determinants of health and illness within the framework of the biomedical model which has been the dominant model of disease for several centuries (Engel In: Stroebe, 2000: 8). The biomedical model, which focuses mainly on biological causes of illness has little to offer in guiding the kind of preventive efforts that are needed to reduce the

incidence of chronic diseases by changing health beliefs, attitudes and behaviour (Stroebe 2000: 8). Health-care systems should be concerned with the "whole person" (Hall In: Giddens, 1993).

Behaviour in any community is regulated by social norms. The scientific community is governed by a set of professional norms and values which researchers learn and internalise. The scientific method is not one single thing (Neuman, 1997). "Most people learn about the "scientific method" rather than about the scientific attitude. While the "scientific method" is an ideal construct, the scientific attitude is the way people have of looking at the world" (Grinnell In: Neuman, 1997: 9).

Social research on the health-disease and health services delivery programme and evaluation has often been characterised as two opposing approaches. These two approaches can loosely be described as the quantitative-experimental and deductive model taken from the natural sciences, and the frequently disregarded one of subjective and phenomenological human experience. The latter qualitative method uses non-intrusive, naturalistic and inductive strategies with the emphasis being placed on interpreting reality from within i.e. the emic approach, in contrast to the external hard facts which is the etic or outside approach (Pedersen In: Scrimshaw & Gleason 1992).

An article in the *Psychologist* (1997) debating qualitative and quantitative methods the criteria for what constitutes "good" social and psychological research were considered. Scientific discovery does not only embody the application of the scientific method but also incorporates creativity and inspiration (Stevenson and Cooper 1997). This creativity and inspiration are encapsulated in the sociological method of grounded theory (Glaser and Strauss, 1967).

"The interrelated jobs of theory in sociology are:

- (1) to enable prediction and explanation of behaviour;
- (2) to be useful in theoretical advance in sociology;
- (3) to be usable in practical applications - prediction and explanation should be able to give the practitioner understanding and some control of situations;
- (4) to provide a perspective on behaviour - a stance to be taken toward data; and
- (5) to guide and provide a style for research on particular areas of behaviour.

Thus theory in sociology is a strategy for handling data in research, providing modes of conceptualization for describing and explaining." (Glaser and Strauss, 1967: 3).

Grounded theory (Glaser & Strauss 1967) was used to direct the investigation into the influence of community, culture and tradition, in relation to conventional beliefs about health and illness. Grounded theory is a qualitative research method that uses a systematic set of procedures to develop an inductively derived theory about a phenomenon (Strauss and Corbin In: Neuman, 1997: 334). The purpose of grounded theory is to build a theory that is faithful to the evidence. In relation to this health research project it was used to explore the understanding and acceptance of VCT and its implications to the service providers and the recipients. Similarly grounded theory was used to examine the responses of the selected community members interviewed about their perception of HIV within their personal community experience.

Quantitative research methods focus on measuring an array of social and individual objects, events and processes (Terre Blanche and Durrheim, 1999). Measurement consists of rules for assigning numbers to objects in such a way as to represent quantities of attributes (Nunnally In: Terre Blanche and Durrheim, 1999). Quantitative survey methods are used to describe and explain phenomena such as knowledge, behaviour or attitudes. In this project the survey questionnaires were used to gain an understanding of HIV and VCT to the interviewees.

The framework which formed the core of this research project was the biopsychosocial-structural and cultural factors that influence human behaviour and are incorporated in the HIV/AIDS Continuum of Care Model (van Praag & Baggaley, 1999 [see illustration page 17/18 of this thesis]). The biopsychosocial model maintains that biological, psychological and social factors are all important determinants of health and illness. According to this approach, medical diagnosis should always consider the interaction of biological, psychological and social factors to assess health and make recommendations for treatment.

The HIV/AIDS Continuum of Care Model provides a "gold standard" which espouses a comprehensive approach to Voluntary Counselling and Testing programmes. The criteria contained in the WHO model offered a comparative basis from which to measure the standards of health care service delivery at the health centres used for the study.

The different components of this model are dependent on a holistic approach to health care and they cover a wide and comprehensive multifactorial list. In a First World country these goals may be attainable but it is doubtful whether the type of service aimed at would be possible in the developing world context. In South Africa, which is considered to be a middle-income country, the infrastructure is being reshaped and unified after the segregated policies of the previous Nationalist



government. Working towards the HIV/AIDS continuum of care model should be the goal of the HIV/AIDS strategy in an effort to deal effectively with the disease and its multifactoral manifestations.

## **4.2 Sampling Procedure**

### **4.2.1 Sites used for accessing the research sample**

Four outlets where antenatal clinics are held were selected to reflect primary, secondary and tertiary institutions in rural, peri-urban and urban locations in KwaZulu-Natal, namely; Eshowe, Addington, and St Mary's Hospitals and KwaDabeka Day Clinic. These health care centres were chosen because they are situated in different localities and provide health care services, which are used by women from both urban and rural backgrounds.

### **4.2.2 Eshowe Hospital [19-22 June, 2000]**

Eshowe hospital is situated on the north coast of KwaZulu/Natal and is a 460 bed hospital with a staff complement of 560. Eshowe is situated in a town which serves a largely rural hinterland. An interview was held with Dr K McDonald, the Medical Superintendent of the hospital to discuss the research proposal and a further meeting was arranged for a presentation of the research proposal to the Ethics Committee. Ethical approval was given for the study to go ahead subject to permission being granted by the Ethics Committee of the Faculty of Medicine, University of Natal.

An interview was held with the part-time counsellor Mr Mzweli to discuss his position as counsellor at the hospital and assess his viewpoint of the service he was providing and his satisfaction with the way he undertook this work.

The interpreter used for administering the questionnaires in isiZulu and English, Mildred Thring, was recruited from Eshowe.\*

#### **4.2.3 St Mary's Hospital Marianhill [26 – 28 June 2000]**

St Mary's is a Catholic Mission district hospital which is state aided. It has 297 beds of which 200 are in current use. St Mary's is located in a peri-urban area bordering on a large industrial suburb and draws patients from as far afield as Durban and Pietermaritzburg. An interview was held with Dr A Ross, the medical superintendent, and he requested that I present my research proposal to the Committee dealing with HIV/AIDS at

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\*Although Mildred did not have a matric she had completed three HIV/AIDS counselling courses;

- I) Department of Health AIDS Training Information and Care and Counselling Centre,
- II) Doctors for Life in home and community based terminal care and
- III) A workshop on AIDS Information and acquired peer educators skills with the Tugela AIDS Programme Trust.

In addition she was well acquainted with the traditional customary law necessary to understand the position of the women being interviewed about such a sensitive topic.

the hospital. A presentation was made to the committee and approval was given for the study to go ahead after questions were answered satisfactorily.

#### **4.2.4 KwaDabeka Community Health Centre [18-20 July 2000]**

KwaDabeka is a peri-urban location situated in Clermont a large township with many informal residences. The clinic sees an average of 3,000 patients per month. The clinic has been awarded Baby Friendly Clinic status which means that it promotes breastfeeding practices. An interview was held with Dr Mbhele, the medical superintendent, to get permission to conduct the research project. Approval was given after consultation with the Matron and other staff members.

An interview was held with Mr V Sokhele who holds an official counsellor post. This was rather surprising when compared to a hospital such as Grey's in Pietermaritzburg (where the pilot study was undertaken) which did not have such a post. Mr Sokhele has a matric and has undergone training in HIV/AIDS counselling and Family and Group Dynamics counselling with the Pietermaritzburg and Durban ATICC organisations. He deals with STD's and health related illness in addition to conducting pre- and post-test counselling.

#### **4.2.5 Addington Hospital [24-26 July 2000]**

Addington is a 710 bed hospital in central Durban. It is situated in an urban area and is part of the academic metropolitan hospital service. Permission to conduct the research at this hospital was subject to authorisation from the Director of Hospital Services in Pietermaritzburg. An interview was held with Dr D K Naidoo the Senior Medical Superintendent to discuss the policy on HIV/AIDS at the hospital. Other interviews were held with Diane Kirkwood, a social worker at the hospital and Sister Ntuli, the person in charge of the HIV/AIDS services at the hospital.

#### **4.3 The study cohort**

Three distinct populations were included in the study, i) service providers and counsellors, ii) women attending antenatal clinics and iii) randomly chosen key informants from the communities in which the women attending the clinics live and who were all identified as people concerned about the HIV situation but not necessarily health workers.

A non-probability convenience sample of 120 was chosen amongst African women attending antenatal clinics, primarily because they are a defined group of people, they are amongst the most disadvantaged group in the country, black, female and from low socio-economic

circumstances. The intervention of VCT will be predominantly aimed at this group.

#### **4.4 Data Collection**

"Perdersen In: Scrimshaw and Gleason (1992) in his discourse entitled, "Two styles of viewing the world or two categories of reality?" proposes that scientific rigour should not be tied down to the selection of techniques and the proportions to which the quantitative and qualitative methods be applied, but rather to the quality of decisions that researchers make throughout the research process. The definition of the problem, the conceptual framework, the generation of hypotheses, fieldwork and the selection of informants, and the analysis and interpretation of results all form an integrated whole, to which data collecting methods and instruments are added" (p 47).

- i) A one-page document aimed at placing VCT in context of the clinic was used to guide personal interviews with service providers (Appendix).

This form consisted of three parts;

- 1) the profile of the hospitals and clinics
- 2) the role and function of staff
- 3) general contributing factors such as privacy, space and budget constraints.

ii) A one-page questionnaire for evaluation of the counselling procedure directed interviews with randomly chosen clinic attendees at each site. The form contained eight questions which are listed below. The questions were posed to five of the women who had been counselled at each site.

- Q1. Did the counsellor spend enough time with you during the counselling session?
- Q2. Were you treated with courtesy and respect?
- Q3. Did you feel comfortable talking to the counsellor?
- Q4. Were you satisfied with the counselling you received?
- Q5. Were you satisfied with the measures taken to ensure your privacy?
- Q 6. Would you recommend the services at this health facility to someone else?
- Q7. What do you think is not functioning well at the clinic/hospital?
- Q8. What could be improved?

The form was translated into isiZulu by Professor S Ngubane and the women were given the choice of the language they preferred to respond to the questions. The reason for this evaluation of the counselling procedure was to check if the women were able to communicate freely

with the counsellors, and also to identify any aspects they felt uncomfortable about the procedure.

iii) An Interview Survey Questionnaire adapted from a "rapid assessment tool" UNICEF/MoPH-Thailand (1988) was used as a data gathering tool. The questionnaire was based on knowledge, attitudes and practices of the women attending the clinics towards HIV and VCT. The questionnaire comprised 39 closed-ended questions.

- Questions 1 to 5 covered **background information** of the subjects; age, marital status, employment (self and partner), education level and number of children (alive).
- Questions 6 to 12 focused on **Knowledge about HIV transmission**.
- Questions 13 to 16 explored **Attitudes towards HIV/AIDS persons and perception of risk of HIV transmission**.
- (Question 17 is missing on all the questionnaires due to a computing error).
- Questions 18 and 19 covered **Attitudes to HIV testing**.
- Questions 28 to 39 concerned **Decisions of whether or not to take the HIV test**.

Interview survey questionnaires have many advantages over other methods because the researcher is present when conducting the survey

and any misunderstandings can be addressed. Using the grounded theoretical approach the researcher was present during the interaction between the interpreter and the interviewees. The body language and ease or conversely difficulty with which the interviewee responded formed part of the research data gathering process and was analysed along with the verbal statements and answers to the questionnaires.

Additional information was elicited from the women whenever the interviewer felt the subject warranted it and the participants were encouraged to interject and dialogue when they had questions or additional relevant information they wanted to share. At the end of the interviews wrongly answered questions were corrected and the women were given the opportunity of discussing any other related matters that concerned them. For example some of the women thought that mosquitoes were able to infect them with HIV because they knew about malaria so the modes of transmission for HIV were reiterated and explained fully.

#### **4.5 The Pilot Study [9-12 May 2000]**

Prior to commencement of the study a small pilot study was conducted at Grey's Hospital in Pietermaritzburg to test the methodology and ensure that the questionnaires were appropriate and comprehensive for the



clients who would be answering them. Interviews were held with a service provider, the senior counsellor and 5 patients who had undergone VCT at the Communicable Disease Clinic.

The unit at Grey's hospital proved to be the most well-organised and pro-counselling and testing department of all the sites chosen for the actual project. Both the doctor in charge of the CDC clinic (Dr Kocheleff) and the chief counsellor (Mrs Jeanne Dixon), were pro-active about educating and empowering patients in respect of VCT for HIV.

Dr Kocheleff expressed interest in implementing a programme of prophylactic treatment of opportunistic infections for HIV seropositive patients and combining this with VCT. The ongoing follow-up counselling of patients is a service which he supports, one which is complimented by linking VCT to the prophylactic treatment. The lack of patient statistical records and the disadvantage of not having these readily available to maintain an audit of disease prevalence was one frustration which Dr Kocheleff mentioned.

A second interview was held with Mrs Jeanne Dixon the designated person in charge of counselling at Grey's Hospital. The unit at Grey's Hospital consists of one registered nurse on a part-time contract post only and two NGO lay counsellors. The budget constraints of the health

department translate into the necessity of having to use staff who are provided by outside organisations to cope with the counselling service. This has a negative effect on staff morale.

Mrs Dixon spoke about her concern that discussions held in the ward directly in front of patients, without including them in the dialogue concerning their health, are an infringement of the patient's rights. Patients frequently attend the clinic not knowing what was wrong with them when they were previously in-patients at the hospital. The lack of options to offer HIV seropositive patients were seen as a major shortcoming of the counselling procedure.

Another problem cited was that there were not enough training facilities available for counsellors to attend. The transformation in the Department of Health at Pietermaritzburg and the downplaying of ATICC's role in providing in-depth training and backup support in the form of posters, condoms and other items were cause for concern.

No alterations to the questionnaires were deemed to be necessary but it was decided during this process that time for interaction and discussion of some of the information contained in the questionnaires would be beneficial to the clients. It was also noted that the interview process was more time consuming than anticipated due to reviewing the responses,

correcting any wrongly answered questions and leaving space for the women to ask other questions about related matters which concerned them.

The pilot study uncovered many of the issues that are causing difficulties in the implementation of a comprehensive VCT service in the hospital setting, such as lack of staff posts and budget constraints. It was also a beneficial procedure to check logistical problems and challenges that face researchers in the hospital setting. Sensitivity by researchers to the busy workload of service providers was important and patience and flexibility paid off in the end. Provided time was taken to explain the purpose and intended outcomes of the research project medical personnel were found to be encouraging and informative. Reassurance was given to the relevant people that final reports and findings would be disseminated to the people who facilitated the research project amongst others.

#### **4.6 Community visits [20 and 21 June 2000; 24 August 2000]**

Two members of the community at Eshowe were interviewed, Mrs Dudu Ntshangase a secondary school principal at Gwebusha School, and Mr Edward Masondo of the Tugela AIDS programme, about different enterprises they were engaged in to inform their communities about HIV/AIDS.

Two field visits were arranged by Diakonia, an umbrella body for a number of churches, in response to a group of Christians investigating the possibility of opening a counselling service at Durban North Methodist Church. This initiative was started by Emma Francis a young social worker who is employed by St Margaret's Anglican Church in Glenashley. The visits were to the Claremont AIDS Centre which provides counselling and home visits to HIV positive people. The other was to the William Clark/Edith Benson Children's Home (Othandweni) which provides resident shelter for approximately 150 children from birth to 16 years of age. There is an HIV/AIDS wing specialising in the care of infants under 5 years of age.

The author participated in the early initial phase one meetings to look at the introduction of rapid testing for HIV combined with pre- and post test counselling from April to November 2000 of an initiative spearheaded by Professor Alan Smith, Head of the Virology Department at the University of Natal, Durban. The committee was chaired by Ms Gay Koti of the HIV/AIDS & STD Directorate Natalia, and the meetings were held at Prince Wing, Addington Hospital.

A one-day workshop on 29 June 2000, organised by the VCT Provincial Committee, was held at Princess Grant on the North Coast of

KwaZulu/Natal to cover all aspects of VCT. This meeting was attended by participants from all health districts in KwaZulu/Natal as well as an invited guest Dr E Isaacs the WHO representative for Africa. The workshop proved to be beneficial in augmenting the objectives of my own research project.

A visit was made on the 4 September 2000 to the Church of Scotland at Tugela Ferry with the Task Team of the above mentioned Addington Committee, who were investigating the feasibility of using this hospital as one of the sites for the pilot phase of the rapid testing programme.

Lastly a rural visit was undertaken on 7 September 2000 to two outlying hospitals with the help of the Red Cross Services. This trip entailed flying in a small plane to Mosvold and Manguzi Hospitals in Northern KwaZulu/Natal near the border of Mozambique.

The reason for participating in all these exploratory community visits was to get a firsthand perspective of current practices in regard to HIV/AIDS policies and also an insight into the problems encountered by service providers at the coalface of the epidemic in this province.

#### 4.7 Data Analysis

Data from the questionnaires was interpreted by using the SPSS programme. Quantitative researchers use statistical packages, such as SPSS, because they can compute a very large amount of data quickly. "An equally important function of this type of package is that it displays the data in ways that (a) show the data and analysis in one place, (b) allow the analyst to see where further analyses are called for, (c) make it easier to compare different data sets and (d) permit direct use of the results in a report" (Boyatzis 1998: 79).

The word "display" is understood to mean a spatial format that presents information systematically and in an organised framework. Thematic coding guided the analysis into the qualitative research and the exploration and building of concepts provided interpretation of the verbal responses.

According to Neuman (1997) data analysis means a search for patterns in data, recurrent behaviours, objects, or a body of knowledge. The use of both quantitative and qualitative analysis techniques should produce a comprehensive whole. In the health field there is a growing consensus that applying both sets of methods in an iterative mode can increase the reliability of data and lead to a more complete understanding of the phenomenon under study. The combination of methodologies used for

the study of the same phenomenon is termed triangulation (Pedersen, 1992).

Therefore the data analysis in this study attempts to examine the findings using different epistemologies to arrive at a holistic and meaningful conclusion.

#### **4.8 Reliability and Validity**

Reliability and validity are salient in social research because constructs in social theory are often ambiguous, diffuse, and not directly observable. Reliability tells us about an indicator's dependability and consistency. Validity tells us whether an indicator actually captures the meaning of the construct in which we are interested (Neuman, 1997: 138). The issue of external validity is important in health research because it determines whether research findings are generalisable to other populations.

In this study the reliability was adhered to by the consistent application of the interview survey questionnaires by one interpreter who recounted the same information to each person and the validity was reinforced by comparison of the interpretation of the verbal responses of the interviewees with the responses to the questionnaires. For example, some women chose not to answer particular questions (which they were reassured was acceptable) and the verbal comments about fear and

stigma gave credence and validity to their decision. In line with the grounded theory approach the researcher was present during the interviews and made observations of body language, such as facial expressions and degree of willingness of the women to participate in the procedure. These observations were detailed and analysed along with the information from the questionnaires and the verbal responses of the women interviewed.

#### **4.9 Ethical considerations**

According to Terre Blanche and Durrheim (1999) there are three broad principles upon which ethical guidelines are based. The first is autonomy which requires the researcher to respect the right of all individuals included in the research. This covers the freedom of participants to refuse to answer any questions they might find intrusive and can include the issue of anonymity specifically when questions are of a personal nature and confidentiality is ensured. The right of any participant who does not wish to be interviewed or participate in the research must be respected (Terre Blanche and Durrheim, 1999: 66). Informed consent was adhered to and clients were given the choice of whether or not they wished to participate after being informed of the nature of the research questionnaires. Any questions which they did not feel comfortable answering were omitted and no pressure was exerted on them to do so.



The second principle of nonmaleficence states that the research procedure should in no way harm any person involved in the process. This includes emotional, physical and social harm (Terre Blanche and Durrheim, 1999: 66). In respect of this HIV/AIDS research the topic was of a sensitive nature and some anxiety could have been experienced by clients who were being asked to discuss issues surrounding VCT. Patients were reassured of the confidentiality of their responses and anonymity of their responses to the questionnaires prior to commencement of the interviews.

The researcher was extremely cognisant of the need for confidentiality about the subject, particularly as the interviews were held with clients in busy out-patient clinics, but special arrangements were made to find separate rooms at each site to hold the interviews, where privacy was ensured and the vocal responses were not audible.

In a previous study (Ross, 2000) counsellors were found to perceive the interviews with themselves as personal evaluations of their competency rather than any attempt to illuminate the subject matter. Reassurance of the integrity of the research objectives and explanation of the purpose of the interviews were established before commencement of the interviews.

The third principle is beneficence which requires that the research design must be seen to have some benefit to the participants or at least to other researchers and society at large. In this study the information involved in the KAP survey questionnaires was educational and beneficial from a health promotion aspect. Mandatory discussions at the conclusion of the interviews were aimed at correcting any misconceptions about the subject matter and allowed for the participants to ask questions regarding matters about which they were concerned (Terre Blanche and Durrheim, 1999: 66).

A research application for Ethical approval was submitted to the University of Natal, Faculty of Medicine. Permission was requested from each of the four sites, via the Chief Medical Superintendents, to conduct the research. The questionnaires and the counselling evaluation forms were translated into isiZulu and the participants were given the freedom to be interviewed in the language of their choice. Final approval from the Ethics Committee was granted on the 8 June 2000 (Appendix A).

## **CHAPTER FIVE**

### **5. FINDINGS**

Chapter five reports the findings of the research. The demographics of the sites are described, as well as details of the outcomes of the interviews with the service providers, the counsellors and the community representatives. The information gathered from the clinic attendees is reported including additional comments made during the interview procedure.

#### **5.1 Profile of Hospitals and Service Providers**

The four sites used for the study were found to have similar service provision regarding Voluntary Counselling and Testing for HIV. The provision of service in any hospital is dependent upon the policies of the National Government, the Provincial Health Department and their budget allocation. All four superintendents interviewed stated that the cost of testing all patients was prohibitive. Currently there is a policy that if clinical signs are detected then voluntary counselling and testing is recommended but not enforced. If a sexually transmitted disease is present then testing may be requested by the doctor. Needlestick injuries are the exception although the voluntary aspect of the test is still applicable. All women are tested anonymously for HIV and for syphilis.

All sites had clinics with long queues of patients waiting to be attended to. Introducing VCT into this setting is a challenging exercise primarily due to the lack of space, counsellor posts and time available for such activity in addition to the already heavy demands on staff. Counsellors have to find space where they can talk confidentially and privately when conducting their interviews and this often poses an obstacle to optimum delivery of service.

Although all sites had available rooms for one counsellor, any additional counselling staff had to rotate with other staff when they vacated their offices. At Eshowe the room used by the part-time counsellor was shared with another counsellor dealing with TB patients. At KwaDabeka one counsellor used an office when the part-time specialist had completed his clinic.

Of the four sites only Addington Hospital had laboratory facilities available to deal with HIV testing. At the other sites the time taken to receive test results is lengthy and costly. Patients have to return for another appointment to be given post-test counselling with their results. Although this does give the patient time to internalise the pre-test counselling messages it is costly for them to spend another day away from work or find bus and taxi fares to make the return trip.

## 5.2 Counselling Evaluation

There were 8 questions on the evaluation form and the questions were posed to women who had undergone counselling in the clinics.

A sample of the some of the responses by the women follows;

**Q1. Did the counsellor spend enough time with you during the counselling session?**

The counsellor was helpful, kind and understanding. Everything was explained to me thoroughly and I learned new things especially about the symptoms of HIV.

**Q2. Were you treated with courtesy and respect?**

I was well respected, seated and greeted kindly.

**Q3. Did you feel comfortable talking to the counsellor?**

The counsellor was patient with me when I asked questions.

I would have preferred a female counsellor for sensitive issues.

(Two of the sites had male counsellors for female clinic attendees).

**Q4. Were you satisfied with the counselling you received?**

The counsellor helped me to accept my situation and to understand.

**Q5. Were you satisfied with the measures taken to ensure your privacy?**

I was comfortable and in a quiet place.

**Q 6. Would you recommend the services at this health facility to someone else?**

In response to this question the women replied that they would tell their friends about the health facility because they were treated with dignity and kindness.

**Q7. What do you think is not functioning well at the clinic/hospital?**

The long waiting in queues and the hospital fees. Waiting for a long time to talk to the counsellors was another problem mentioned. The necessity for return visits incurred extra costs for the patients which they complained about.

**Q8. What could be improved?**

More counselling and education are needed. Ongoing counselling and information about how to care for our child should the results of the HIV test be positive.

Medications are only given to last one week. This means that travel to the hospital or clinic each week is necessary. This is costly and when someone is sick and weak from continuous acute diarrhoea or something it is extremely difficult to travel.

Others mentioned cheaper hospital fees. Another request was for the provision of beds for people who cannot travel far distances every day.

Thematic analysis of the responses by the women to the evaluation of the counselling questionnaire revealed that the way in which the women are treated can be a predictor of uptake of VCT. Genuine kindness and respect were highly regarded by the women and this empathetic attitude brought out a positive attitude towards the counselling procedure. The words "education" and "understanding" were repeated frequently and it was apparent that the women did want to understand the messages around HIV but they needed more exposure to the educational themes embodied in the counselling interaction.

Several comments can be made with regard to the replies to the counsellor evaluation questionnaires.

The women stated that as a consequence of being treated kindly and with dignity they would recommend the health facility to their friends. This affirms the theory of a rising consciousness amongst associated communities.

The comment that the counsellor was patient shows there is a history of a level of intimidation and the women appreciate time being taken to help them understand. It was evident that the women felt uncomfortable being counselled about intimate sexual matters by a male counsellor. This is a normal phenomenon amongst all race groups and their preferences should be respected. Undoubtedly this relates to the lack of funding for dedicated counsellor posts. It is not acceptable to slot nurses who are juggling busy work schedules into the role of counsellor even though they may have undertaken a brief course on HIV. Counselling is a skilled and demanding intervention. The male counsellors at both hospital sites could be gainfully employed counselling male patients and in training roles for other counsellors rather than interfacing directly with the women. If the level of counselling is in any way superficial it will negate the benefits to be gained from the intervention.

Many of the rural women attending clinics have had little formal secondary education and therefore may not be able to read and



understand English. Some of the health messages about HIV are in English and there are few opportunities for educating women in isolated communities, so the counselling opportunity is exceptionally important in broadening the understanding about HIV amongst the women attending clinics.

The clients expressed difficulty in returning to collect prescriptions when they are sick and weak. Difficulties in meeting costs of transport for return visits were seen as another determinant for uptake of results and follow-up counselling visits. Although services are free for pregnant women and children under 6 years there are often other expenses which prevent clients from returning to the clinics. Particularly in rural communities transport is costly as distances are frequently far and with limited income taxi fares are hard to find. The mobile clinics can alleviate this problem to a degree but there needs to be co-ordination between the service providers because information about the client is usually filed at the clinic where first contact was made.

The shortage of counsellor posts, was seen as a serious drawback to VCT as well as dedicated office space with adequate privacy for counselling. The sensitive nature of dealing with HIV dictates the type of environment that is necessary for optimum delivery of service.

### 5.3 Clinic Attendees

The results of the survey questionnaires follow. The original intention was to compare the responses of the women at four individual sites but it was found that the women formed a homogenous group with little differentiation in the between site statistics gathered, therefore the full cohort from all four sites were treated as one group. The final cohort comprised of 112 women and this was due to logistical problems in the field. Eight men were also interviewed which made up the full quota of 120 persons but these interviews were withdrawn because the focus of this study was on women only.

The results of the questionnaire are displayed in tables using percentage scores and missing statistics are recorded. As this was primarily a qualitative study there was no attempt to prove statistical significance. The percentage scores represent an indication of how the women interviewed responded to the questionnaire concerning the subject of HIV and the intervention of VCT.

**Table 1 Sociodemographic characteristics of the women**

<b>Characteristics</b>	<b>Clinic Attendees (n = 112)</b>
1. Age (in years) M (Mean) R (Range)	29 15 - 60
	%
2. Marital Status Married Divorced Single Widowed	21.4 0.0 78.6 0.0
3. Employment Employed Unemployed Partner employed Partner unemployed Missing	24.1 74.1 62.5 23.2 3.6
4. Education Never attended Primary 1-4 Primary 5-8 Secondary >8 Tertiary	8.0 19.6 25.9 42.9 3.6
5. Number of children 0 1 2 3 4 5 6 7 8	18.8 31.3 23.2 11.6 8.0 2.7 2.7 0.9 0.9

The women attending the four antenatal clinic sites were mainly aged 18-35 years with a mean of 29 years. The findings showed that the majority of the women were single 78.6% and there were no divorcees or widows amongst the 112 women interviewed. Unemployed was high at 74.1% and partner employment was 62.5%. The levels of education were low with 53.5% having less than a secondary level of education, and only 3.6% having attended any tertiary level education.

Eighteen point eight percent (18.8%) of the women had not had a child yet while 31.3% had one child and 23.2% had two children. The balance of 26.8% of the women had three or more children. These statistics are of significance when planning future educational intervention programmes.

All the women were from low socio-economic circumstances

**Table 2 Knowledge about HIV transmission**

<b>Questions</b>	<b>Responses (n=112) %</b>
6. HIV is a virus which causes AIDS Agree Disagree Unsure	85.7 0.9 13.4
7. A person can have HIV and look well Agree Disagree Unsure	84.8 3.6 11.6
8. Married people can get HIV infection Agree Disagree Unsure	91.1 3.6 5.4
9. If one has HIV one can transmit the virus True False Unsure	97.3 2.7 -

**Table 2a** (Knowledge about HIV transmission continued)

Questions	Responses (n=112) %
10. How can someone be infected with HIV?	
a. by hugging someone who has HIV or AIDS Agree Disagree Unsure	5.4 83.0 11.6
b. by sharing razors with someone who has HIV Agree Disagree Unsure	95.5 0.9 3.6
c. by being transfused with contaminated blood Agree Disagree Unsure	100.0 - -
d. by having an injection with non-sterile material Agree Disagree Unsure	97.3 2.7 -
e. by kissing someone who has HIV or AIDS Agree Disagree Unsure	11.6 76.8 11.6
f. by mosquito bite Agree Disagree Unsure	59.8 16.1 24.1
g by sharing toothbrushes Agree Disagree Unsure	83.0 8.0 8.9
h. .by sharing clothes Agree Disagree Unsure	5.4 87.5 7.1
i. by having unprotected sex (without condoms) with someone who has HIV or AIDS one can become infected with HIV? Agree Disagree Unsure	100.0 - -

**Table 2b** (knowledge about HIV transmission continued)

11. Can a baby be infected by his/her mother who has HIV?	
Yes	84.8
No	3.6
Perhaps	6.3
Don't know	5.4
12 An HIV seropositive mother can infect her baby by:	
a kissing her baby	
Agree	1.8
Disagree	94.6
Unsure	3.6
b hugging her baby	
Agree	.9
Disagree	98.2
Unsure	.9
c during pregnancy	
Agree	66.1
Disagree	28.6
Unsure	5.4
d when giving birth	
Agree	46.4
Disagree	34.8
Unsure	17.9
Missing	.9
e bottlefeeding	
Agree	4.5
Disagree	86.6
Unsure	5.4
Missing	3.6
f breastfeeding	
Agree	69.6
Disagree	21.4
Unsure	8.0
Missing	.9

Table 2 shows that the results concerning knowledge about HIV transmission were good. Despite the low levels of education it was apparent that the subject of HIV/AIDS is now becoming more openly discussed and the women learn from the media and each other while attending the clinics.

Of the women who responded to questions 6 and 7, more than 84% agreed that HIV is a virus which causes AIDS and that a person can have HIV and look well. The majority who answered questions 8 and 9 (91.1% and 97.3%) agreed that married people can contract HIV infection and knew that if one has HIV one can transmit the virus.

Knowledge about how HIV transmission occurs was good with only questions 10e and f causing some concern. When being asked whether infection can occur by kissing someone who has HIV or AIDS 11.6% thought it could and another 11.6% were unsure. However the women did ask what type of kissing was meant which shows a discernment and comprehension of the likelihood of transmission.

Question 10f which asked whether infection could occur by a mosquito bite was wrongly answered by 59.8% who agreed that it could. The balance of the women disagreed that it could cause infection (16.1%) and the rest (24.1%) were unsure. This highlights the misconceptions



and fears that people live with concerning HIV/AIDS.

The full cohort answered questions 10(c) and 10(l) correctly. This is significant because question 10 (c) stated that infection can occur when contaminated blood is transfused and question 10(l) stated that by having unprotected sex (without condoms) with an HIV infected person one can become infected with HIV. Although they are aware of this fact the difficulty arises when they have to negotiate safe sexual practices with their partners.

In Table 2b, 84.8% of the women agreed that a baby can be infected by his/her mother who has HIV. Only 66.1% of the women thought that an HIV positive mother could infect her baby during pregnancy, 28.6% disagreed and 5.4% were unsure.

Most of the women (86.6%) believed that an HIV seropositive mother cannot infect her baby by bottle feeding but 4.5% thought it was possible and 5.4% were unsure. Of the women (69.6%) thought that an HIV seropositive mother could infect her baby by breastfeeding and 21.4% disagreed, while the remainder (8.0%) were unsure.

**Table 3 Attitudes towards HIV/AIDS persons and perception of risk of HIV transmission**

Questions	Responses (n=112) %
13. People with AIDS should receive more support from the community Agree Disagree Unsure	93.8 2.7 3.6
14. Would you be willing/not willing to take care of a family member with AIDS? Willing Not willing Don't know	96.4 .9 1.8
15. Have you personally known anyone who is HIV infected or has AIDS? Yes No Missing	23.2 75.9 .9
16. What do you think are your chances of getting the AIDS virus? Would you say that there is: No chance Moderate chance Good chance Already infected Don't know No answer	5.4 31.3 34.8 .9 26.8 .9

The response to question 13 showed that 93.8% of the women agreed that people with AIDS should receive more support from the community. Question 14 asked whether the women would be willing or unwilling to take care of a family member with AIDS and 96.4% stated that they would be willing to. The interviewer bias may have been the reason for the high affirmative reply to this question as respondents sometimes

feel it is culturally correct to give the reply they feel is correct rather than what they actually believe.

The response to question 15 showed that only 23.2% of the women said they had known anyone who is HIV infected or has AIDS, 75.9% said that hadn't known anyone with this virus. Many of the people who are ill and dying with HIV/AIDS prefer to say they are ill from other diseases because of the way in which they are discriminated against and stigmatised, even by their own family members.

The answers to question 16 listed different categories of the chances a person has of contracting the AIDS virus. The results showed that 31.3% of the women thought they had only a moderate chance and 34.8% said they had a good chance of contracting HIV. The number who stated that they don't know what their chances of contracting the disease are (26.8%) illustrates the level of ignorance about this virus. Only 0.9% (one person) acknowledged they were already infected.

**Table 4 Attitudes to HIV testing**

Questions	Responses (n = 112) %
18. Would you be willing to have an HIV test if you were given the chance?	
Yes	62.5
No	28.6
Perhaps	3.6
Don't know	0.9
Afraid	4.5
Missing	0.8
19. Is there any benefit in knowing your HIV status?	
Yes	30.4
No	58.0
Don't know	6.3
Missing	5.4
20. Benefits of knowing your HIV status;	
a I could choose to conceive or not	
agree	27.7
missing	72.3
b I can live positively being HIV+	
agree	26.8
missing	73.2
c I can eat a better balanced diet	
agree	23.2
missing	76.8
d I can seek medical care if I get sick	
agree	27.7
missing	72.3
e I will stop having unprotected sex so that I don't transmit the virus to someone else	
agree	29.5
missing	70.5
f I can plan for the future of my children	
agree	16.1
missing	83.9

**Table 4a** (Attitudes to testing continued)

Questions	Responses (n = 112) %
<p>21 Are there disadvantages in knowing your own HIV status?</p> <p>Yes No Don't know Missing</p>	<p>32.1 55.4 5.4 7.1</p>
<p>22 Negative factors of knowing status;</p> <p>a No hope I will die Agree Missing</p> <p>b My husband will reject me Agree Missing</p> <p>c The community will reject me Agree Missing</p> <p>d I will feel ashamed. True Missing</p> <p>e I will not be able to share this burden.  True Missing</p> <p>f I will live in fear of my children becoming orphans.  True Missing</p>	<p>%</p> <p>17.0 83.0</p> <p>9.8 90.2</p> <p>16.1 83.9</p> <p>18.8 81.3</p> <p>12.5 87.5</p> <p>13.4 86.6</p>
<p>23. Have you ever had an HIV test?</p> <p>Yes No Missing</p>	<p>21.4 75.9 2.7</p>

**Table 4b** (Attitudes to testing continued)

Questions	Responses (n=112) %
24 Did you come back to receive the results? Yes No Missing	17.0 7.1 75.9
25 After having done the test what would you say about your reaction? Relief Acceptance Missing	9.8 0.9 89.3
26 Here are some reasons for taking the test: a I was concerned about risks for my baby Agree Missing  b I was concerned about my health True Missing  c I felt at risk of being infected True Missing  d I was persuaded by my family or friends Agree Missing  e A doctor or midwife advised me to Agree Missing  f Because it was offered to me Agree Missing	8.0 92.0  15.2 84.8  5.4 94.6  2.7 97.3  8.0 92.0  8.0 92.0
27 Here are some reasons people give for not taking the test. a I don't want to know my HIV status Agree Missing  b I am worried that I might be HIV+ True Missing  c It was never offered to me Agree Missing  d I have been in a faithful relationship for a long time True Missing  e I always use condoms True Missing  f I have no partner, no more sexual relations Agree Missing	17.0 83.0  15.2 84.8  8.0 92.0  10.7 89.3  4.5 95.5  2.7 97.3

Table 4, 4a and 4b cover questions 18-27 which deal with attitudes to HIV testing. The results show that 62.5% of the women would be willing to take an HIV test if they were given the opportunity to have one and 28.6% said they would not while 4.5% said they would be afraid to take one. Only 30.4% of the women thought there would be any benefit from knowing their status, and 58% said they didn't think there would be. In the prevailing cultural climate this response is understandable.

Question 20 a - f enumerates the missing statistics. They are missing because the women chose not to answer the questions. To question 20a only 27.7% of the women agreed that one of the benefits of knowing your HIV status meant that they could choose to conceive or not. However in South Africa the fact that 31 (27.7%) of the women actually thought they could take the decision of whether or not to conceive themselves is encouraging and shows that gradual empowerment is taking place amongst African women who are from low socio-economic cultural backgrounds.

The response to question 20b which stated that a person can live positively being HIV+ was similar to 20a with 26.8% agreeing that this would be a possibility. The response to question 20c and d concerning diet and medical care was answered with 23.2% and 27.7% agreeing. These questions are difficult to pose to women who are challenged on

many levels, both financially and culturally, and reflect the peculiar situation where health professionals draw up questionnaires in First World countries where intentions are good but the sensitivity to the position of the women is sometimes lacking.

The result of question 20e which asked whether a person would stop having unprotected sex so that the virus isn't transmitted to someone else was 29.5%. Only 16.1% felt that they could plan for the future of their children if they knew their HIV status.

Table 4a looked at the disadvantages of knowing your HIV status and the negative factors associated with that knowledge. The response to question 21 showed that 32.1% of the women thought there were disadvantages to knowing their HIV status while 55.4% stated there weren't any. In view of the fact that only 23.2% of the women said they knew anyone who was HIV positive this result is understandable and may change when HIV comes closer to home and more of a reality in their lives.

The response to question 22a that if they knew their HIV status there would be no hope and they thought they would die 17.0% agreed. However in reply to question 22b only 9.8% said their husband would reject them. Although most of the women were single in this cohort the



relationships between partners are often considered to be the same as a common law arrangement where there is agreement similar to that of marriage.

Question 22c showed that 16.1% of the women thought their community would reject them if they were HIV positive and 18.8% said they would feel ashamed and 12.5% said they would not be able to share this burden with anyone. These sentiments are very real to the women and reflect the perceived attitude of both the community and themselves. The negative self-efficacy and a sense that they will be condemned is a strong feeling which must be counteracted during counselling sessions.

Only 13.4% responded to 22f and said they will live in fear of their children becoming orphans. This could be due to the fact that the women have not given the subject of HIV much consideration because it is something someone else has and never the person concerned. This is true of all race groups and emphasises the need for individuals to grasp the reality of the situation that HIV is no respecter of persons whatever their socio-economic background.

In response to question 23 only 21.4% of the women had ever had an HIV test and in Table 4b question 24 showed that 17% returned for their results. Question 25 showed that 9.8% of those who had returned for

their results felt relief and only 0.9% said they felt a sense of acceptance about it.

Questions 26 and 27 deal with reasons for taking a test and reasons people give for not taking a test. The scores on both these questions were very low but this is because as yet there is no policy in place where testing is routinely offered. In response to question 27 a and b 17.0% said they didn't want to know their HIV status and 15.2% said they were worried they might be HIV+. One good reason for being tested is to offer relief and instruction regarding their health and sexual practices to those who turn out to be negative and also to provide coping mechanisms and instructions to those who test positive.

The response to question 27d was 10.7% and e was 4.5% and to f was 2.7%. It is important to explain to women that even though they no longer have a partner and profess to have no more sexual relations, the fact is they could still be HIV positive and in future they might be involved in another relationship.

**Table 5 Decisions concerning the test and HIV**

Questions	Response (n = 112) %
28 I would take an HIV test if noone except for the AIDS counsellor knew Agree Disagree Unsure Afraid Not a problem Missing	59.8 24.1 5.4 1.8 0.9 8.0
29 I would take an HIV test if noone else would know the results of the HIV test except for the AIDS counsellor Agree Disagree Unsure Afraid Not a problem Missing	58.9 20.5 3.6 2.7 0.9 13.4
30 I don't know about the HIV test so I need more information Agree Disagree Unsure Missing	67.0 13.4 1.8 17.9
31 The decision to take an HIV test is not mine alone Agree Disagree Unsure Missing	18.8 44.6 1.8 34.8
32 Counselling and HIV testing should be offered every time people come to the hospital Agree Disagree Unsure Missing	77.7 11.6 3.6 7.1
33 The decision should be left to you to ask for counselling and testing when you come to hospital Agree Disagree Unsure Missing	83.9 5.4 1.8 8.9

(Table 5 Decisions concerning the test and HIV continued)

34 Among the following health services which one is the most appropriate place where women could have the chance to ask for or to be offered a test for HIV.	
ANC	18.8
Family Planning	3.6
>5 Clinic	4.5
STD	.9
OPD	19.6
Special Counselling & Testing Centre	31.3
Anywhere	16.1
Schools	.9
Missing	4.3
35 In my community people with HIV are supported and I would not be afraid to take the test	
Agree	22.3
Disagree	55.4
Unsure	19.6
Afraid	1.8
Missing	0.9

Table 5 covers decisions concerning the test and HIV. The response to question 28 in this section, about testing if only the AIDS counsellor was aware that it was being taken, was 58.9%, which confirms that confidentiality is a prime determinant of the likelihood that the women will take a test. Similarly 58.9% said they would take the test if no one knew the results except the AIDS counsellor.

In reply to question 30, 67% admitted they didn't know enough about the test so they needed more information. Only 18.8% said that the decision to take an HIV test was not theirs alone. The women agreed in response to question 32, (77.7%) that counselling and HIV testing should be offered every time people come to the hospital. The choice of the most appropriate place where women could seek or be offered testing was divided into four main categories. The highest preference of 30.8% was for a special counselling and testing centre, 17.5% were happy with the ANC and 19.2% chose the OPD clinic. Any venue would be acceptable to 21.7% of the women.

In response to question 35 the women were in agreement (93.8%) that people with AIDS should receive more support from the community.

**Table 6      Attitudes towards partners and HIV testing**

<b>Questions</b>	<b>Responses (n=112) %</b>
<p>36 In a couple both husband and wife should receive counselling together and take HIV test together.</p> <p>Agree Disagree Unsure Missing</p>	<p>76.8 13.4 6.3 3.6</p>
<p>37 In a couple only one partner has to take the test in order to know the HIV status of both partners</p> <p>Agree Disagree Unsure Missing</p>	<p>13.4 82.1 1.8 2.7</p>
<p>38 If my partner knows my HIV status he will support me.</p> <p>Agree Disagree Unsure Missing</p>	<p>28.6 14.3 52.7 4.5</p>
<p>39 My partner should be informed and decide for me if I can take the test.</p> <p>Agree Disagree Unsure Missing</p>	<p>6.3 87.5 1.8 4.5</p>

In reply to question 36 the majority of the women (76.8%) believed that both a husband and wife should receive counselling and testing together. The difficulty with this result is that single women do not have the same influence over their partners as their married counterparts do, even if they have children and are in a longstanding and permanent relationship with their partner.

The response to question 37 showed that most of the women (82.1%) were aware that in a couple both partners have to undergo a test in order to know their individual status.

The response to question 38 showed that only 28.6% of the women were confident that their partner would support them if he knew their HIV status and 14.2% disagreed and said they wouldn't. Another 52.7% stated that they were unsure whether their partner would support them.

In response to question 39 the majority of the women 87.5% felt they should decide for themselves whether or not they should take a test.

### **5.3.1 Additional comments by the women interviewed**

In addition to the questionnaire the women were given the opportunity to make comments about anything to do with HIV that they would like to share.

Some direct quotes of responses by the women interviewed follow;

"At the clinic there is not enough information given about HIV"

"The reason why I prefer to keep my status a secret is that a girl did a live broadcast on TV who was then killed by the community in KwaMashu"

"We need more educating on awareness as there are many people who still don't believe that HIV/AIDS is killing us"

"I personally would take a blood test at the hospital, but for the sake of other poor people it should be done at schools, as most people don't have money for transport to get to hospitals and clinics"

"In my community I wish all people would accept HIV/AIDS and stop pointing fingers at one another. I am very scared to be exposed"



"Blood tests should be done all over to protect us and our children.  
Schools, mobile clinics and hospitals"

"I have a good chance of getting HIV/AIDS as I cannot trust my husband.  
I don't go with him wherever he goes. It troubles me alot. No  
community support whatsoever"

"I learned alot about HIV/AIDS from the TV - Take 5 and Scanto. We  
don't have any support groups community or church"

"We don't have a problem in my community, everyone worries about  
himself/herself, if you die you just die, no one cares anymore"

"I don't think my partner would support me, when something worries him  
he drinks alot and gets abusive"

"I have never seen anyone with HIV/AIDS only people who tell me that  
someone has died from HIV"

"I disagree that both partners should be counselled together as we are  
two individuals"



"I don't even want to think of taking a blood test. I will not be able to tell anyone, as it is a vulgar thing to be HIV positive. People in Inanda don't care about HIV/AIDS"

"I am scared what will happen to my children. In Hluhluwe I have not seen or heard of anyone who is HIV positive"

"The fact is HIV positive or not I am still going to die, I will never tell the community".

A thematic analysis of these statements in line with the grounded theoretical perspective shows that the women have many misgivings about the whole issue of HIV/AIDS, particularly in a hospital clinic setting, where they are often subjected to adverse experiences. There is a strong feeling of self-condemnation and uncertainty surrounding an HIV positive result. There was also evidence that there is still a sense of denial, mystery and mystique surrounding HIV/AIDS. The influence of the witchdoctors and traditional medicine was apparent from the expressed fears of community response to people living with HIV/AIDS.

The comment that the women have never seen anyone with HIV before is confirmed by the response to question 15 in which 75.9% of the women stated they had never known anyone with HIV or AIDS, they only heard that someone had died of AIDS after the event. This response

illustrates the complexity of confronting the problem in communities where it is estimated that prevalence rates are as high as 35% but the actual residents of the communities are unaware of the situation. This is in communities where according to evidence given by members interviewed there are often as many as seven funerals on weekends which belies the fact that the women are unaware of people having HIV in their communities. Those dying with HIV/AIDS in these communities are still shrouded in secrecy because of the discrimination the families would suffer if the real cause were made known. This situation is likely to change dramatically when HIV testing becomes part of the routine hospital experience, and more people reach the terminal stage in their communities.

In general the women were very negative about their communities. The responses were similar for all the sites, the women spoke about the communities where they lived which were Inanda, Hluhluwe and Clermont and there was a general consensus that HIV is still very much in the closet and a feared disease.

The telling response one woman gave that HIV positive or not she is still going to die and she will never tell the community was mirrored by the statement of the woman who said she would rather die alone than disclose her status. This reveals that she believes her community is

hostile and uncaring, a circumstance which has to be bridged by infiltration and sharing of knowledge about the natural and real causes of the disease.

There was a perception amongst the women that HIV/AIDS is a vulgar thing, something to feel ashamed about and an illness that cannot be shared with anyone else, not even close family or partners. The anxiety expressed by one woman who said she was scared about what will happen to her children illustrates the depth of the associated problems of getting an HIV positive diagnosis.

One of the women who was only married for one year and still lives with her in-laws in a rural environment told the counsellor that she knows that she is positive as well as her husband and their baby. The husband is supportive to herself and the infant and understands the situation but they are afraid to tell his parents because they fear they will blame the woman and chase her away.

Another challenge for the women is that even though they are aware of the perceived threat of contracting HIV it does not mean they feel capable of protecting themselves or of ensuring their partner uses any form of protection during sexual intercourse. Several women stated that they believe their partners would leave them for other women if they disclosed

their status and acted on the information they received during the counselling concerning safer sex practices. The woman who expressed her anxiety that she doesn't go with her husband everywhere so even if she herself is cautious she is still at risk.

A serious problem experienced by the women associated with lack of financial resources is that as HIV/AIDS begins to remove the adult population, as seen in the chimney diagrams (Anderson, 2000), there is a sense that the elderly will become even more vulnerable in terms of being direct custodians of their grandchildren.

The responses confided by the women to the counsellor when in a confidential setting were heartfelt and they were a sad reflection of the reality of living with HIV in some South African communities. An analogy to the pervasive negative social malaise in respect of HIV, evidenced by the attitude of the women interviewed, can be made to the famous story 'The Plague' by Albert Camus. He wrote about the plague which occurred in Oran in the 1940's and which for Camus symbolised the German occupation of France (Camus, 1947). Similarly the ravages of apartheid perpetrated through the racist policies of the previous 'white oligarchy' which for years destroyed the dignity and social fabric of life for many black citizens in South Africa can be witnessed through the poverty and despair wrought by HIV on an already demoralised and vulnerable

marginalised sector of our society, namely the women and children living in many of the rural communities.

#### **5.4 Community Representatives**

A diverse range of interviews and community visits were carried out to investigate what is taking place regarding HIV/AIDS in different community settings.

##### **5.4.1 Interview with Mrs Dudu Ntshangase**

[Wednesday 21 June 2000]

The first interview was held with Mrs Dudu Ntshangase a secondary school principal at Gwebusha School in a rural area near Eshowe in KwaZulu/Natal. Mrs Ntshangase met with me at Eshowe hospital primarily because she was genuinely concerned about what the community is going to do to tackle the HIV/AIDS problem. She told me there was a need for lifeskills guidance for school children which she proposed could be incorporated into the school curriculum.

One suggestion she made was for community nurses to act as role models to the children and their parents and she believed that more information was necessary because of the misinformation that is expressed through fear in the community. Her personal opinion was that this fear was seen as artificial and not based on truth. In addition to the

community nurses she stated the need for community field workers and clinic health care workers who could inform children about primary health care.

Dudu was interested to know what medicine Mercy (Makhalamela an AIDS activist) took - another role model who has been outspoken about her HIV positive status. These PLWA's have a wide influence and other women respect and look to them for advice.

Dudu felt that the government projects a poor example to the people and more brainstorming needs to be undertaken to find creative solutions to deal with HIV. She said the high rate of unemployment in the community was serious and only about 20% of the children were able to pay school fees. Many of the children were hungry and as a result could not concentrate at school.

Dudu impressed me with her willingness to discuss matters which concerned her. She considered the media messages were rather distorted. She asked why all the pilot tests were necessary in the health forum and whether there are clear objectives for dealing with the pandemic.

One barrier Dudu mentioned concerning the counselling procedure was that the men are unwilling to protect themselves and women don't question their rights. She thought that young men must respect themselves. There is also a lack of understanding and men think women are promiscuous if they ask a man to use a condom.

Dudu told me about some Italian people working at Mbonglewane who are using innovative strategies to educate local communities about HIV. She said they slaughter a cow and provide Zulu beer and invite the community to a social gathering then deliver talks about AIDS.

A closing remark Dudu made illustrated the depth of thought she had given the subject of HIV and its consequences. She asked if Thabo Mbeki's child was HIV positive what would he do?

#### **5.4.2. Interview with Edward Masondo**

[Thursday 22 June 2000]

In Eshowe, Edward Masondo is another community outreach person working with the Tugela AIDS programme. He and his colleagues visit companies in KwaZulu/Natal and educate workers on their rights and labour issues in relation to HIV. Unfortunately he has battled to get funding despite the fact that the programme does exceptionally pro-active



work in the community. He visits police establishments, youth in schools, Amakhozi, CBO's as well as church organisations.

#### **5.4.3 Interview with Nyami Mbhele**

[Thursday 24 August, 2000]

At KwaDabeka the Claremont Community Resource Centre headed by Nyami Mbhele, a paralegal worker, the focus is on helping individuals to access grants and providing homecare visits. She said that the community confronted by AIDS feel a sense of hopelessness. Women frequently end up looking after numerous children, several of whom are not their own, and some of whom are often HIV positive. However Nyami stated that people were willing to foster children if they received a grant even though it was insufficient to support the child. The government have increased the grants since the time of this interview but as Nyami pointed out the access to such assistance should be made easier for those in need.

Nyami also recounted the hardships faced by PLWA's and stated the frequent weekend funerals, as many as seven per day on some Saturdays, as evidence that the disease is already taking its toll.

#### **5.4.4 Interview with Sister Mthalane**

[Wednesday 28 June, 2000]

Sr Mthalane of St Mary's Hospital is a community worker who holds workshops, to educate traditional healers and other community groups, in hygienic methods of practice and this shows an encouraging attitude of embracing all sectors in the community to fight this disease. Vegetable garden projects were common enterprises to improve nutrition and Sr Mthalane demonstrated a technique, which she discovered in the township, of mixing paper shavings with the soil to retain water. She felt that it was important that information was a two-way mediated process whereby people learn from each other and respect their different cultural methods.

#### **5.4.5 Extraneous field trips by the researcher**

[Made during August- September, 2000]

The other extraneous field trips were informative and it was encouraging to see the different strategies being employed to combat HIV. At **Mosvold Hospital** patients were instructed about HIV via video produced by "Doctors for Life" and this was seen as an excellent example of how to use hospital in-patient time constructively. Patients are a captive audience and the novelty of seeing a video in their own language was appreciated.

At **Mnguzi Hospital** there is a dedicated community health worker who holds training sessions to instruct and empower other health workers. These are fledgling initiatives in regard to HIV but are gaining ground and the provision of vehicles and resources for rural communities is one step in the right direction.

At **Tugela Ferry the Church of Scotland Hospital** has an impressive home-based care strategy in place with a sophisticated survey system used to locate patients. The health workers identify patient homes and network together with a supervisor in the hospital to coordinate the necessary health services. Dedicated buildings for community enterprises have been sponsored by outside funders at this hospital and these will be used for nutrition clinics and other health related services.

This concludes the findings section of the research project.

## **CHAPTER SIX**

### **6. PSYCHOSOCIAL ANALYSIS OF POSSIBILITIES AND LIMITATIONS OF VCT**

Chapter six examines the implications of the findings and provides a psychosocial analysis of limitations and possibilities of VCT.

In countries where HIV prevalence is high and where there are numerous deaths attributed to AIDS, it is common for many to develop feelings of hopelessness and a misperception that behaviour change is futile. In these settings, the power of positive behaviour change messages may be reinforced by effective HIV counselling and testing services. For example, even in Uganda, where HIV prevalence is high, approximately 75% of tested clients learn that they are still uninfected. Anecdotal evidence from counsellors suggests that for many of these clients, learning that they are not infected displaces the sense of futility and is a powerful motivator to behaviour change (Campbell, Marum, Alwano-Edyegu et al, 1997: 99).

The reality faced by service providers and policymakers is that dealing with the social and psychological dimensions of this disease is extraordinarily complex and difficult. A greater understanding is needed regarding the dialectic between social and psychological factors to

facilitate more sophisticated and effective approaches to intervention in risk-reducing life-style behaviours (Perkel, 1992). In South Africa where VCT is only just becoming appreciated as a viable means of preventive care the onus will be on the service providers to impart a positive attitude towards the procedure as illustrated by the above example.

Attitudes play a critical role in any environment but particularly in South Africa where the aftermath of the apartheid years will be felt for many years, especially by those African people who were subjected to discrimination and inferior health service treatment compared to other race groups. For African women to be able to trust and relate comfortably with health service providers there must be a genuine feeling of concern and empathy towards them on the part of the service providers. The idea of anyone actually being interested or concerned about what happens to another person who tests positive for HIV will be a new experience in a health care setting for many of those undergoing VCT.

This issue of testing for HIV is a complex one and as was stated in a paper by Cartoux et al (1998) the National AIDS control programmes should investigate means to combat discrimination and enhance medical management for HIV-infected persons in order to encourage access to prevention and care via HIV testing, particularly for pregnant women.

The choice of counsellors who will be trained to deliver the service is a key factor in the likely success of VCT as a preventive and empowering intervention. The aspect of language and personal prejudice towards HIV will have to be considered seriously as well as characteristic traits of empathy and good communication skills. The appreciation expressed by the women who evaluated the counselling process highlighted the above issues. (See page 81 response to Q2).

Far more trained counselling staff are required to deal with the large numbers of clinic attendees. Counselling is an intervention which cannot be rushed and clinic attendees raise many questions which need answering. The issue of burnout for counselling staff is another factor which limits the number of patients a counsellor can handle during a day. (See page 82 Q7 which relates to the long queues and lengthy waiting time to see the counsellors).

The introduction of the new rapid testing techniques should alleviate the problem of return visits for patients, provided there is quality control in the training of those handling the counselling aspects of the testing procedure. Ongoing counselling strategies are also essential to assist patients who are facing very real difficulties in handling their seropositive status.

The lack of dedicated office space is not conducive to good staff morale, and comfortable surroundings with complete privacy are essential for the staff and clients to feel confident and have the ability to communicate effectively.

The breastfeeding discourse taking place in academic circles is complicated by diverse viewpoints as seen in two research letters published recently. Coutsoudis et al (2001: 655) challenged the findings of a study by Nduati et al (2000) which stated that breastfeeding by HIV-infected women was associated with a higher maternal mortality rate than that observed in mothers who formula fed. They supported the view that counselling to HIV-infected women should be based on current recommendations of UNAIDS "amplified to the extent suggested recently by us with regard to exclusive breastfeeding" (Coutsoudis et al, 2001).

In the same issue of the AIDS journal a research letter by van der Perre et al (2001: 659) stated that short antiretroviral monotherapy may be sufficient to prevent some MTCT, but it may also not be potent enough to result in a viral rebound at interruption of treatment, and increases the odds of breastfeeding transmission of HIV. Therefore the introduction of antiretroviral drugs will necessitate more changes to be made to existing policies regarding feeding practices.

In reply to the research letter by Coutoudis et al (2001) two other authors responded separately (Forsyth, 2001 and Walker et al, 2001) that they felt that policy recommendations could not be made on the basis of the current study and Forsyth (2001) in his letter stated that "I am particularly concerned that this study might delay making formula available to those countries and areas where this is considered a reasonable alternative [to breastfeeding]".

These debates illustrate that the academics are not in agreement about feeding policies which translates into confusion and difficulties for policy recommendations. Since the women being counselled must feel confident that the counsellor is able to give them the best possible information in order for them to make informed choices there should be a framework for updating counsellor skills and current information as an integral component of the employment contracts for counsellors.

The response by most of the women interviewed that they would be willing to undergo VCT is encouraging because if VCT became a normal part of routine visits to a hospital or clinic the majority who said they would be willing to take a test would inevitably influence others they talked to and interacted with in different community settings.



Any programmes being initiated to tackle preventive measures aimed at reducing HIV infection rates must take into consideration the psychosocial and cultural context of those undergoing the procedure. Since taking an HIV test and being informed that the result is positive can be a traumatic experience the way in which the process is handled is of paramount importance. It is obvious that there will be no positive outcomes for those willing to undergo the process unless a holistic and comprehensive strategy is in place to provide the psychological support and ongoing counselling and advice necessary to cushion the blow and give clients a way of dealing with whatever circumstances they find themselves in.

The need for quality control in counselling is essential. This is time-consuming and costly but for maximum benefit to be gained from VCT it is another compulsory dimension of the integrated programme. Specific training programmes with broader understanding of primary health care goals should undergird the basic educational and preventive messages embodied in the intervention. If a person knows their status it can help them to address different aspects of their lives as cited in the HIV Continuum of Care Model (van Praag & Baggailey, 1999).

Attitudes are difficult to change and since the power is in the hands of those providing services it is imperative that the whole process of VCT is

given due consideration by those implementing it prior to its introduction into the health service. In this way the multifactoral benefits contained in the WHO model for VCT to be used as an entrypoint for HIV prevention and care will be appreciated and internalised by the health workers whose responsibility it will be to share their knowledge and skills with those undergoing the procedure.

The findings from this study showed that there is a definite apathy amongst service providers towards the issue of HIV testing and this could be a limitation of the successful application of the intervention of VCT. This is in some ways understandable due to the budget constraints and the constant stream of media coverage painting very negative and bleak pictures. In addition "AIDS politics" have always been a part of South Africa's AIDS history (Whiteside and Sunter, 2002: 121) and the confusion displayed amongst the government hierarchy has added to the dilemma and brought about a difficult climate in which to introduce intervention programmes.

As stated by Perkel and Strebel (1991) sexual practices are notoriously difficult to change. This is not to say that it is not worth trying because any educational message can bring about empowerment, and knowledge does take time to be digested and understood. The relief experienced by those who test negative for HIV can provide a catalyst for change in

sexual behaviour and empower women to protect themselves against infection.

The ANC Health Plan succinctly describes the necessary change in the medical culture. "PHC is not just a cheaper, simpler approach to the delivery of health care, nor is it simply basic health interventions. It is a concept which is changing the medical culture. Previously this was centred around health professionals, where the community - the patients - were the passive recipients of health services and the doctors and health professionals alone were the dispensers of health" (ANC Health Plan, 1994:181).

Concerning the concept of intersectoral strategies and community participation the ANC health plan stated that, "the government would integrate efforts by all sectors, organisations and individuals to make socioeconomic development sustainable and humane, ensuring a sound environmental basis for health" (ANC Health Plan, 1994:185).

Finally in this document the ANC stated the need for outreach education and health promotion and prevention programmes which would be run in schools and work-places (ANC Health Plan, 1994).

These intentions are noble and admirable but as this research project found the delivery of such high ideals is far from being realised. Although there are encouraging inroads being made by dedicated health professionals they are unfortunately sporadic and isolated instances. The need for a complete comprehensive, holistic and all encompassing strategy which is evolved by interaction between communities and service providers is of paramount importance for the onslaught dictated by the rising prevalence rates of HIV infection.

An article entitled, "Cheaper Drugs alone will not defeat HIV/AIDS" which appeared in the Sunday Independent of 18 March 2001 stated, "the only effective weapons [against HIV] currently are education, awareness programmes and behaviour modification". A recently published report - on the 'Impact of VCT' summarising studies from sub-Saharan Africa affirmed two important points that this study has found and they are that although there are difficulties for both men and women, women in particular find it difficult to practice safer sex (or negotiate with their sexual partners to use safer sex methods) following VCT and secondly that most studies in this geographic region have been carried out when VCT services are initially set up and longer-term [more in-depth] analyses would be valuable (UNAIDS, 2001: 15). The research in this thesis has endeavoured to address some of these issues.

In conclusion it is abundantly clear that VCT is a beneficial intervention for prevention and education about HIV. The relevance of the counselling and testing will only be measured when the strategies embrace a much broader spectrum of society, but the Department of Health is now employing a more proactive policy in initiating rapid-testing facilities, home-based care and community health worker models. It is important to understand that no intervention can stand alone, however successful the application, but must be engendered in a comprehensive, holistic package as illustrated by the HIV Continuum of Care Models. In the same vein the networking and cumulative energy of NGO's, religious groups and health professionals will all be needed to find sustainable solutions for those living with HIV and those at risk of becoming infected.

It is a sad indictment that anyone, of any race or creed, should choose to "die alone" rather than be able to seek succour and care from others. South Africa with all it's rich cultural heritage, resources and advantages, compared to other countries on this continent, must dig deep and search for acceptable solutions, to gain credibility when the word "democracy" is discharged, particularly in the health arena.

## **CHAPTER SEVEN**

### **7. RECOMMENDATIONS**

The following recommendations include suggested solutions in an attempt to address some of the difficulties currently being experienced in the health service sector. The dissemination of the findings conclude the thesis.

1. The first and most important recommendation is that a more comprehensive and holistic strategic plan should be implemented by the Department of Health aimed at introducing VCT in different settings simultaneously.
2. If the budget constraints preclude universal implementation of VCT then the minimum recommendation is that VCT should be introduced in antenatal clinics and communicable disease clinics simultaneously to ensure that males and females are offered the same options.
3. Health workers and service providers should be offered VCT in an effort to give them first hand experience of the procedure and the emotional trauma which can be linked to the results. Update opportunities for best practice in line with current knowledge for counsellors should be written into service contracts

4. VCT programmes must be launched in work places, such as factories and businesses, where both males and females can undergo the counselling and educational component of the testing procedure.
5. Adolescents should be targeted for educational programmes and VCT, aimed at empowering them to make informed choices regarding their sexual relationships.

**In line with these recommendations (for 3, 4, and 5) a Core Counselling Concepts programme could be initiated. Workshops should be held to promote the benefits to be gained from the intervention of VCT and also for updating the latest policies recommended by the academic community. Attitudes of service providers towards the intervention are of significance if VCT is to accomplish the goal of empowerment and integration which is the aim of the WHO recommended model.**

**(The idea behind producing a Core Counselling Concepts model is to define in simple terms, the essence of the counselling and educational messages embodied in the VCT process. Ultimately this tool will be used as a manual for health workers, business employees and school teachers amongst others and it could be translated into different languages for easy reference by lay counsellors).**

6. Qualified health workers who have in-depth training of counselling techniques should act as mentors and quality controllers to assist with the many situations which may arise when lay counsellors are faced with handling complex issues beyond the scope of their experience.

**To combat this inexperience it is recommended that a webpage be designed and initiated detailing all aspects of the VCT intervention. Ideally this webpage would be available for health workers at their hospital and clinic sites to augment and consolidate their training. Topics such as bereavement counselling, health messages and follow-up support may not have been discussed in their training. Usually only pre and post-test counselling issues are covered.**

7. At a community level hospital personnel should be encouraged to forge linkages via their social workers and counsellors with relevant partners, such as religious groupings and schools amongst others, to assist in the improvement of understanding about HIV and VCT. This would also create infrastructure for more care and support for individuals both affected and infected by HIV.



8. Looking at the bigger picture key players in business and identified role players in the major cities should be canvassed to address the issues which HIV/AIDS will play in the future. They must be invited and encouraged to participate in finding solutions to the problems which will arise from illness and the resulting mortality to their workforce.

One suggestion to deal with 7 and 8 is to initiate a networking system which identifies and links specific institutions with a view to forming a supportive catchment for those seeking care, and specifically home-based care during terminal stages of the disease. The primary target would be religious institutions which need to be canvassed to participate in and sponsor this type of networking enterprise. Religious groups operate in most communities and a new model of best practice could be implemented and piloted in one specific area. Key AIDS workers such as Edward Masondo of the Tugela AIDS Programme and Nyami Mbhele of Claremont Community Resource Centre are examples of people strategically placed for assisting in this type of study. The local knowledge that community workers share is a valuable resource and it must be used in finding networking models.

9. It is recommended that investigations are conducted into the improvement of subsidies offered to people willing to care for orphaned children. There are many unemployed women in the townships who could be gainfully employed caring for others, either children or adults. This would have to be linked to the networking system where infrastructures would be built up to ensure that checks and balances are in place.
10. Suitable testing and counselling sites need to be explored in-depth. More than thirty percent of the women interviewed in this study supported the view that specific VCT centres were the preferred place to attend for VCT.

#### **7.1 Dissemination of findings**

An article will be submitted for publication to a relevant international journal detailing the findings of this research as a means of disseminating the findings. In addition a final report with an executive summary of the main findings was submitted to Health System's Trust during February 2001 and an article was written for their Update publication in November 2000 which should be circulated to health professionals and health workers in South Africa.

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UNIVERSITY OF NATAL  
FACULTY OF MEDICINE  
MEMORANDUM

<b>TO:</b> Ms MH Ross Department of Paediatrics Faculty of Medicine	<b>FROM:</b> Mrs Anita Walker Postgraduate Administration Faculty of Medicine
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8 June 2000

PROTOCOL: Voluntary counselling and testing as a beneficial tool in the health care delivery system. M Ross. Paediatrics/Sociology. Ref E058/00

The Ethics Committee considered the abovementioned application and made various recommendations.

These recommendations have been addressed in your memo of 8 June 2000 and the protocol was approved on 8 June 2000.

  
PP Anita Walker  
Postgraduate Administration  
Aw/ethics/ross.6

## VCT RESEARCH QUESTIONNAIRE

MRoss/99-2000

## Profile of Clinics/Hospitals

## 1. Profile of hospital and environment

- Function
- Area
- Community profile
- HIV prevalence
- Organogram - staff

## 2. Role and function of staff

- Qualifications
- Specific HIV/AIDS training?
- Adequate staffing
- Type of counselling
  - categories: group/individual
  - pre- post- test
  - follow-up counselling
  - mental health referral facility

## 3. General

- Is there adequate counselling space available?
- Privacy?
- Views on the issue of HIV/AIDS?
- Budget constraints?

HST RESEARCH QUESTIONNAIRE  
KAP SURVEY WHO

Evaluation of Counselling

1. Did the counsellor spend enough time with you during the counselling session?

.....

2. Were you treated with courtesy and respect?

.....

3. Did you feel comfortable talking to the counsellor?

.....

4. Were you satisfied with the counselling you received?

.....

5. Were you satisfied with the measures taken to ensure your privacy?

.....

6. Would you recommend the services at this health facility to someone else?

.....

7. What do you think is not functioning well at the clinic/hospital?

.....

8. What could be improved?

.....

### Ukuhlaziya isimo sokuSizwa (Evaluation of Counselling)

1. Umsizi wakho uchithe isikhathi esanele ngenkathi ekusiza>  
.....
2. Waphatheka kahle nangenhlonipho?  
.....
3. Wawuzizwa ukhululekile ngenkathi ukhuluma noMsizi wakho?  
.....
4. Waneliswa ngosizo owalutholayo?  
.....
5. Waneliswa ngemizamo yokuqikelela ukusizwa ngasese ngaphandle kokuba nabanye abantu abakhona?  
.....
6. Ungamtshela yini omunye umuntu ngosizo lwalo mtholampilo?  
.....
7. Yini obona sengathi akuhambi kahle kulo mtholampilo/isibhedlela?  
.....
8. Yini engenziwa ukuze isimo sibe ngcono?  
.....

HST RESEARCH QUESTIONNAIRE  
KAP SURVEY WHO

Appendix D

1 WOMEN

DATE: RESPONDENT:

HOSPITAL/CLINIC:

INFANT: YES/NO AGE:

VILLAGE:

*Background*

No	Questions	coding categories	
1	How old are you?	Age	
2	What is your marital status?	Married 1 Divorced 2 Single 3 Widowed 4	
3	Are you employed?  Is your partner employed?	Yes 1 No 2 Yes 1 No 2	
4	Up to what level/standard did you attend school ..... ..... .....	If never attended 0 Primary 1-4 1 Primary 5-8 2 Secondary >8 3 Tertiary 4	
5	How many children (alive) do you have?	Number:	



*Knowledge on HIV transmission*

6	HIV is a virus which causes AIDS	Agree 1 Disagree 2 Unsure 3	
7	A person can have HIV and look well	Agree 1 Disagree 2 Unsure 3	
8	Married people can get HIV infection	True 1 False 2 Unsure 3	
9	If one has HIV one can transmit the virus	True 1 False 2 Unsure 3	

Filter Q9 If True

If false/unsure -->

10

13

10	How can someone be infected with HIV? For each statement, say if you agree, disagree or are unsure.  Agree 1 Disagree 2 Unsure 3	-By hugging someone who has HIV or AIDS - - - -by sharing razors with someone who has HIV - - - -by being transfused with contaminated blood -by having an injection with non-sterile material -by kissing someone who has HIV or AIDS -by mosquito bite -by sharing toothbrushes -by sharing clothes -by having unprotected sex (without condoms) with someone who has HIV or AIDS	
11	Can a baby be infected by his/her mother who has HIV?	Yes 1 No 2 Perhaps 3 Don't know 4	

Filter question 11

If yes and perhaps  
Q 12

If no or don't know  
Q 13

12	By which ways can a woman infect her baby? Read option and tick accordingly	-By kissing her baby .....	2
	Agree 1	-By hugging her baby .....	2
	Disagree 2	-during pregnancy, .....	1
	Unsure 3	-when giving birth .....	1
		-by bottle feeding .....	2
		-when breastfeeding .....	1
		-others, specify .....	
		.....	
		.....	

*Attitudes towards HIV/AIDS persons and perception of risk of HIV transmission*

13	People with AIDS should receive more support from the community	Agree 1	1
		Disagree 2	
		Unsure 3	
14	Would you be willing /not willing to take care of a family member with AIDS?	Willing 1	1
		Not willing 2	
		Don't know 3	
15	Have you personally known anyone who is HIV infected or has AIDS?	Yes 1	1
		No 2	
16	What do you think are your chances of getting the AIDS virus? Would you say that there is:	No chance 1	
		Moderate chance 2	
		Good chance 3	
		Already infected 4	4
		Don't know 5	
		No answer 6	

18	Would you be willing to have an HIV test if you were given the chance?	Yes No Perhaps Don't know	
19	Is there any benefit in knowing your HIV status	Yes No Don't know	

If yes – 20

if no or don't know -- 21

20	<p>What are the benefits of knowing your HIV status?</p> <p>Open-ended question with possible answers listed. Tick those that apply.</p>	<p>Being HIV negative means that</p> <p>Being HIV + means that:</p> <ul style="list-style-type: none"> <li>- I could choose to conceive or not</li> <li>- I can live positively being HIV+</li> <li>- I can eat a better balanced diet</li> <li>- I can seek medical care if I get sick</li> <li>- I will stop having unprotected sex so that I don't transmit the virus to someone else</li> <li>- I can plan for the future of my children</li> <li>- others, specify.....</li> </ul>	<p>✓</p> <p>✓</p> <p>✓</p>
21	<p>Are there disadvantages in knowing your own HIV status?</p>	<p>Yes 1</p> <p>No 2</p> <p>Don't know 3</p>	

Filter question 21

If yes 22

If no or don't know – 23

22	What are the disadvantages of knowing your HIV status  <i>Open-ended questions with possible answers listed. Tick those that apply.</i>	-There is no hope I will die ..... -My husband will reject me ..... -the community will reject me ..... - I will feel ashamed..... -I will not be able to share this burden with anyone..... -I will live in fear of my children becoming orphans..... -it is better not to know..... -other, specify.....	
23	Have you ever had an HIV test?	Yes 1 No 2	

Filter question 23

If yes...24

If no .....27

24	Did you come back to receive the results?	Yes 1 No 2	
25	After having done the test what would you say about your reaction?		
26	Here are some reasons given for taking the test?  <i>Tick those that apply to you.</i>	-I was concerned about risks for my baby -I was concerned about my health -I felt at risk of being infected -I was persuaded by family or friends -a doctor or midwife advised me to -because it was offered to me -other, specify...	Skip to 28

Skip to 28

27	<p>Here are some reasons people give for not taking the test?</p> <p><i>Tick those that apply to you.</i></p>	<p>-I don't want to know my HIV status</p> <p>-I am worried that I might be HIV+</p> <p>-It was never offered to me</p> <p>-I have been in a faithful relationship for a long time</p> <p>-I always use condoms</p> <p>-I have no partner, no more sexual relations</p>	
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### Decisions of whether or not to take the HIV test

28	I would take an HIV test if noone else would know that I took the test except for the AIDS counsellor	<p>Agree 1</p> <p>Disagree 2</p> <p>Unsure 3</p>	
29	I would take an HIV test if noone else would know the results of the HIV test except for the AIDS counsellor	<p>Agree 1</p> <p>Disagree 2</p> <p>Unsure 3</p>	
30	I don't know about the HIV test so I <del>know</del> <sup>need</sup> more information	<p>Agree 1</p> <p>Disagree 2</p> <p>Unsure 3</p>	
31	The decision to take an HIV test is not mine alone	<p>Agree 1</p> <p>Disagree 2</p> <p>Unsure 3</p>	
32	Counselling and HIV testing should be offered every time people come to the hospital	<p>Agree 1</p> <p>Disagree 2</p> <p>Unsure 3</p>	
33	The decision should be left to you to ask for counselling and HIV testing when you come to the hospital	<p>Agree 1</p> <p>Disagree 2</p> <p>Unsure 3</p>	
34	<p>Among the following health services which one is the most appropriate place where women could have the chance to ask for or to be offered a test for HIV</p> <p><i>Tick next to one you would choose</i></p>	<p>ANC</p> <p>Family planning</p> <p>&gt;5 clinic</p> <p>STD clinic</p> <p>OPD Clinic</p> <p>Special Counselling and testing Centre</p> <p>Nowhere</p> <p>Other, specify</p>	

35	In my community people with HIV are supported and I would not be afraid to take the test	Agree Disagree Unsure	1 2 3	
36	In a couple both husband and wife should receive counselling at the same time and take the HIV test together	Agree Disagree Unsure	1 2 3	
37	In a couple only one partner has to take the test in order to know the HIV status of both partners	Agree Disagree Unsure	1 2 3	
38	If my partner knows my HIV status he will support me	Agree Disagree Unsure	1 2 3	
39	My partner should be informed and decide for me if I can take the test	Agree Disagree Unsure	1 2 3	

USUKU: OBUZWAYO:

ISIBHEDLELA/UMTHOLAMPILO:      INGANE: YEBO/CHA      UBUDALA:

INDAWO:

**Umlando**

No	Imibuzo	uphawu lomkhakha	
1	Uneminyaka emingaki yobudala?	Ubudala	
2	Ushadile?	Ushadile      1 Uhlukanisile      2 Uhlala wedwa      3 Ungumfelwa      4	
3	Uqashiwe?  Uqashiwe umaqondana wakho?	Yebo 1 Cha 2 Yebo 1 Cha 2	
4	Ufunde wagcina kuliphi izinga esikoleni? ..... ..... ..... .....	Uma ungakaze ufunde      0 Esikoleni esiphansi 1-4      1 Esikoleni esiphansi 5-8      2 Esekhondari > 8      3 Imfundo ephakeme      4	

5      Unabantwana abangaki (abaphilayo)?

Inombolo:

**IMIBUZO NGOCWANINGO LWE- HST  
KAP UPHENYO NGOMUNTU**

**1 OWESIFAZANE**

**Ulwazi ngokuthathelana ngegciwane le-HIV**

No.	Questions	uphawu lomkhakha	
6	Igciwane le-HIV lidala ingculazi	Uyavuma 1 Uyaphika 2 Awunaqiniso 3	
7	Umuntu angaba negciwane abukeke kahle	Uyavuma 1 Uyaphika 2 Awunaqiniso 3	
8	Abantu abashadile bangalithola igciwane	Iqiniso 1 Amanga 2 Anginaqiniso 3	
9	Uma umuntu enegciwane le-HIV angalidlulisela phambili	Iqiniso 1 Amanga 2 Anginaqiniso 3	

Sef umbuzo 9 Uma kuyiqiniso

Uma kungamanga/ungenaqiniso .....>



10	<p>Umuntu angalithola kanjani igciwane le-HIV? Emazwini abekiwe yisho ukuthi uyavuma, uyaphika noma awunaqiniso.</p> <p>Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3</p>	<p>-Ngokwanga umuntu onegciwane le-HIV -ngokusebenzisa amaleza omuntu onegciwane le-HIV -ukuxhubana kwamagazi akhungethwe yigciwane le-HIV -ukujovwa ngomjovo osuke wasebenza nongahlanziwe -ukuqabula umuntu onegciwane le-HIV noma ingculazi -ukulunywa wumiyane -ukusebenziselana ngezixubho -ukugqokelana izimpahla -ukulala nomuntu onegciwane le-HIV noma ingculazi okungavikelekile (ngaphandle kwejazi lomkhwenyana)</p>	
11	<p>Ingane ingaba nalo igciwane uma unina enalo?</p>	<p>Yebo 1 Cha 2 Mhlawumbe 3 Angazi 4</p>	

**Sefa umbuzo 11**

**Uma kunguYebo kanye nomhlawumbe**

**Umbuzo 12**

**Uma kunguCha noma angazi**

**Umbuzo 13**

12	Yiziphi izindlela umuntu wesifazane angathelela ngazo ingane yakhe? Funda izimpendulo bese ufaka uphawu lokuvuma lapho kudingeke khona Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3	-Ukuqabula ingane yakhe -ukwanga ingane yakhe -ngenkathi ekhulelwe, -ngenkathi ebeletha -ngokuncelisa ngebhodlela -ngenkathi encelisa -ngezinye izindlela, chaza ..... .....	
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**Indlela abantu abamukela ngayo abantu abahlaselwe yi-HIV/AIDS nokusabela ubungozi bokuthola igciwane le-HIV**

13	Abantu abanegciwane le-HIV kufanele banakekelwe kakhulu emphakathini	Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3	
14	Ungakujabulela noma ngeke ukujabulele ukunakekela ilungu lomndeneni onengculazi?	Ngingakujabulela 1 Ngeke ngikujabulele 2 Angazi 3	
15	Ukhona umuntu omaziyo wena ngokwakho onegciwane le-HIV noma ohlaselwe yingculazi?	Yebo 1 Cha 2	
16	Uma ucabanga angakanani amathuba okuthola ingculazi? Ungasho ukuthi:	awekho 1 mancane 2 mahle 3 senginayo vele 4 angazi 5 anginampendulo 6	

Uvo lwabantu ngokuhlola i-HIV

18	Ungathanda ukuhlola i-HIV uma ungase unikezwe ithuba	Yebo 1 Cha 2 Mhlawumbe 3 Angazi 4	
19	Kuyakusiza ukwazi ukuthi unalo igciwane le-HIV?	Yebo 1 Cha 2 Angazi	

Sefa umbuzo 19

Uma kungu Yebo .....20

Uma kunguCha noma Angazi .....21

20	Kukusiza ngani ukwazi ukuthi unengculazi?	<p>Ukungabi nengculazi - kusho ukuthi</p> <p>Ukuba nengculazi + kusho ukuthi:</p> <ul style="list-style-type: none"> <li>-ngingakhetha ukuthatha isisu noma ngingasithathi</li> <li>-ngingaphila impilo emnandi uma ngazi ukuthi nginengculazi</li> <li>-ngingadla ukudla okunempilo</li> <li>-ngingafuna usizo lokunakekelwa ngokwezempilo uma kwenzeka ngigule</li> <li>-ngingayeka ukulala nomuntu ngaphandle kokufaka ijazi lomkhwenyana ukuze ngingamtheleli ngegciwane</li> <li>-ngingahlelela ikusasa labantwana bami</li> <li>-okunye, chaza .....</li> </ul>	
21	Zikhona yini izingqinamba zokwazi ukuthi unengculazi	Yebo 1 Cha 2 Angazi 3	

Sefa umbuzo 21

Uma kunguYebo 22

Uma kungu Cha noma Angazi .....23

22	Kubi ngani ukwazi ukuthi unengculazi?	-Alikho ithemba ngizofa... -umyeni wami uzongilahla <u>-umphakathi uzongilahla</u> -ngizoba namahloni -akekho ozongithwalisa lomthwalo -ngizohlala novalo lokuthi abantwana bami bazoba yizintandane -kungcono ukwazi -okunye, chaza.....	
23	Usuke wahlolwa ingculazi?	Yebo 1 Cha 2	

Sefa umbuzo 23

Uma impendulo kunguYebo .....24

Uma kungu Cha.....27

24	Wabuye ukuzolanda imiphumela yokuhlolwa?	Yebo 1 Cha 2	
25	Emva kokohlolwa ungathi wazizwa unjani?		
26	Nazi ezinye zezizathu ezikhona zokuhlola igazi	-ngangithinteke ngobungozi bengane yami -ngangithenteke ngempilo yami -ngazizwa ngingaphephile ngenxa yokuba negciwane -nganxenxwa wumndeni noma abangane -ngayalelwa ngudokotela noma umbelethisi -ngoba nganikwa ithuba -okunye, chaza.....	

27	Nazi ezinye zezizathu ezenza abantu abathile bangalahloli igazi?	-angifuni ukwazi ukuthi nginengculazi -ngiphatheke kabi ukuthi ngingase ngibe nengculazi -angikaze nginikwe ithuba -bengithembekile isikhathi eside -ngisebenzisa ijazi lomkhwenyana njalo -anginamaqondana, angilali namuntu	
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**Izinqumo ngokuhlola igazi noma ukungahloli igciwane le-HIV**

28	Ngizohlola igazi uma kuzoba yimfihlo yami ngaphandle komsizi we-Aids	Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3	
29	Ngizohlola igazi uma imiphumela izoba yimfihlo yami nomsizi we-Aids	Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3	
30	Angazi lutho ngokuhlola igazi ngakho ngifuna ulwazi olunzulu ngokuhlola igazi	Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3	
31	Isinqumo sokuhlola igazi akusona esami kuphela	Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3	
32	Umzamo wokusiza abanengculazi kanye nokuhlola igazi kufanele kuhlale kukhona ngaso sonke isikhathi uma abantu beze esibhedlela	Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3	
33	Isinqumo sokubonana noMsizi wabantu abanengculazi kufanele kube ngesakho kanye ukuhlola igazi uma ufika esibhedlela	Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3	

34	Kulezi zidingo ezilandelayo yiziphi ezifanelekile kubantu besifazane abangazithola uma bedinga usizo lokuhlola igazi	ANC Ukuhlela umndeni >5 umtholampilo STD - emasokeni OPD umtholampilo Ukusizwa mayelana nengculazi kanye nesikhungo sokuhlola igazi Akukho lutho okunye, chaza	
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35	Emphakathini wabantu bakithi abanengculazi bayanakekelwa ngakho angesabi ukuhlola igazi	Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3	
36	Kubantu abaganene bobabili umyeni nonkosikazi kufanele basizwe kanye kanye ukuze bahlolwe igaze bendawonye	Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3	
37	Kubantu abaganene kufanele abe munye ohlola igazi ukuze kwazeke ukuthi bobabili abanayo yini ingculazi	Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3	
38	Uma engihlezi naye- umaqondana azi ukuthi nginegciwane le-HIV uzongisekela	Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3	
39	Umaqondana wami kufanele aziswe bese engithathela isinqumo sokuthi ngihlola igazi	Ngiyavuma 1 Ngiyaphika 2 Anginaqiniso 3	