The effect of voluntary counselling and testing and a negative HIV result on risk behaviour: a qualitative longitudinal study in a Zambian mining community

Dr Janet Precious Banda Sikasote
Own Work Declaration

I do hereby declare that the work submitted in this thesis is my own original work and has not been submitted for any other award. Contributions from others have been acknowledged.

Signed: [Signature]

Date: 26 May 2010
Dedication

In memory of my late father, Lightson Chenjelani Banda and brother, Chenjelani Gabriel Banda.

To my family:

My husband, Chomba Chinyungu Sikasote, for taking care of our boys and our home during the many months I was away and for your steadfast love, support and faith in my abilities. I couldn’t have done it without you.

My four babies, Nataizya, Khondwani, Koozya and Teza who had to make do without mum – I pray that through this work and that of others you may be spared the pain and suffering that is now our lot.

My mother, Beauty Banda, my sisters, Jacqueline and Chileshe and my brothers, Ernest, Wilson and Stanley, you have been a source of inspiration to me spurring me on to higher heights even when I do not think I am capable of achieving those heights. Thank you, mum for setting the bar so high.

To my adopted family in Edinburgh — Maria, Pota, Mebeelo and Tendai — I could never find the words to express my appreciation for providing me with a “home away from home”. Thank you.
Overview of Thesis

This thesis presents and discusses findings of a study examining the relationship between voluntary counselling and testing (VCT) for human immunodeficiency virus (HIV) infection, receipt of a negative result and subsequent sexual behaviour, and the needs of HIV-negative people from the perspective of people testing HIV-negative in an urban mining area in Zambia.

The first acquired immune deficiency syndrome (AIDS) case in Zambia was reported in 1984 (Bayley, 1984) and by the end of 2007, 1.1 million people were living with HIV. AIDS was a terminal illness until 1996 when the availability of highly active antiretroviral therapy (HAART) converted it to a chronic controllable one. There is as yet no cure or vaccine for HIV infection and prevention remains the primary means of control (NAC, 2006b, CDC, 2006, UNAIDS, 2007).

VCT is a key component of most national HIV/AIDS control programmes (Denison et al., 2008, Meiberg et al., 2008, NAC, 2006a, Sheon, 2004, UNAIDS, 1999a). The Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organisation (WHO) policy statement on HIV testing states that “among the interventions which play a pivotal role both in treatment and in prevention, HIV testing and counselling stands out as paramount.” The policy encourages expanded access to VCT services (UNAIDS and WHO, 2004).

HIV Counselling and testing is said to encourage the initiation and maintenance of safer sexual behaviour preventing the transmission or
acquisition of HIV (CDC, 1987, Crampin and Damisoni, 2001, Kamb et al., 1998, The Voluntary HIV-1 Counselling and Testing Efficacy Study Group, 2000, UNAIDS, 2000, Denison et al., 2008). However, emphasis on identifying HIV-infected people so as to meet treatment targets has led to underdevelopment of the preventive role of VCT and support services for people testing negative. The question addressed by this thesis arose out of a noted bias of post-VCT support and care services for those testing HIV-positive compared to those testing HIV-negative.

The thesis situates the study in terms of the evolution and current status of the HIV/AIDS epidemic, current literature, geographical location and environment. Through a review of the relevant HIV VCT literature the thesis demonstrates gaps in knowledge on: (1) the interaction between VCT, receipt of an HIV-negative result and sexual behaviour; and (2) the felt support needs of people testing HIV-negative.

Using data generated from a qualitative longitudinal study, the thesis presents and discusses the HIV test decision making process, the effects of counselling and testing on HIV knowledge, attitudes to risk and subsequent behaviour and the felt support needs of people testing HIV-negative at four health-facility affiliated VCT centres in Zambia. The thesis proposes:

1. an explanatory framework of the relationship between voluntary counselling, receipt of a negative result and sexual behaviour
2. post-test support options for people testing HIV-negative

The thesis concludes by discussing the implications of the study findings for VCT policy, service and practice, training and research.
The thesis is presented in eleven chapters. Each chapter begins with an introductory section which aims to provide a link to the preceding chapter(s) — except for the ‘background’ and ‘conclusions and recommendations’ chapters (1 and 11) — and a brief overview of the chapter contents. The first four chapters essentially provide the various contextual settings of this study: historical, theoretical and geographical.

Chapter 1 provides the historical context of the study covering study conceptualisation, justification, evolution of the HIV/AIDS pandemic and the international response. This chapter also provides basic information on HIV, VCT, human behaviour and health behaviour change theories. This information provides the background for the statement of the key issue to be explored, and research questions and aims which are presented in the same chapter. The chapter concludes with a brief introduction to qualitative longitudinal research and the limitations of the study in terms of its claims to generalisability.

Chapter 2 opens with a presentation of the background literature on behaviour change and health promotion theories that inform HIV/AIDS intervention programmes and a discussion of their limitations. The impact of the availability of anti-retroviral therapy (ART) on HIV risk behaviour is then discussed followed by a brief history of the development of VCT, a discussion of its cost-effectiveness as an HIV prevention strategy in comparison to other strategies, its acceptability and its effectiveness in encouraging initiation and maintenance of behaviour change.
Chapter 3 presents and discusses the findings of a focussed systematic review conducted to investigate the relationship between HIV voluntary counselling, receipt of a negative test result and sexual risk behaviour.

Chapter 4 presents the physical context of the study locating it in a low income, developing, and politically stable sub-Saharan African country in a region with the highest HIV prevalence rates in the world. After a brief description of the geographical, historical, political, economical, socio-cultural, and health service country context, this chapter presents an overview of the national HIV/AIDS epidemic and national response including VCT programme and guidelines.

Chapter 5 lays out the methods employed in answering the research questions. The chapter is presented in 13 sections. Section 1 provides a link to the previous chapter and an overview of chapter contents. Section 2 provides background information on qualitative research and discusses issues of rigour. Section 3 discusses the rationale for using a qualitative approach, and section 4 presents the philosophical issues pertinent to the conduct of qualitative research and the philosophy that informed the conduct of this study. Section 5 discusses the selective use of behaviour change theories in this study. Section 6 provides the rationales for the selection of the methods of data generation: semi-structured interviews and focus group discussions. Section 7 provides the specific local context of the study with a description of the study sites and the VCT service as it is provided at these sites. Section 8 discusses the process of recruitment of the study participants and the sampling method and section 9 goes on to discuss the conduct of the interviews and focus group discussions and the lessons learnt therein. Section 10 follows with a discussion on how the data were managed and
analysed. Section 11 presents a discussion of the ethics of research in general and qualitative research in particular and section 12 discusses the researcher’s position and role in the generation and analysis of qualitative data. Section 13 provides a succinct conclusion to the chapter.

The findings are then presented in Chapters 6 – 9.

**Chapter 6** provides context in terms of participant characteristics and participation rates and presents an overview of chapters 7–9 which present the findings in relation to the aims. The findings are presented according to the identified themes within the findings related to each aim.

**Chapter 7** presents findings related to how people came to identify themselves as at risk and the factors positively or negatively impacting the HIV test decision making process.

**Chapter 8** presents the influence of counselling and the negative result on HIV/AIDS related knowledge, perceptions and attitude and **Chapter 9** concludes the findings chapters with a presentation of the findings reflecting the experience of life post-test, its challenges, and the felt support needs of the respondents.

**Chapter 10**, the discussion, begins with a reflexive account of my position in the study and its influence on the findings and then goes on to discuss the study strengths and limitations. This background provides the context for the discussion of the findings. These are discussed and interpreted relating them to currently available literature and developments in VCT.
Chapter 11 is the final chapter of this thesis. This chapter begins by discussing the implications of the findings for policy relating to VCT and HIV prevention, the practice of VCT and the training of counsellors, and for future research. The chapter concludes the thesis with a presentation of the key findings and recommendations.
Abstract

Background: Countries in sub-Saharan Africa are scaling up access to Voluntary Counselling and Testing (VCT) services as a strategy for HIV prevention, treatment, care and support. The international and national push to achieve targets for anti-retroviral therapy scale up has emphasised VCT as an entry point to treatment, with follow-up mostly directed at those who test positive. Yet over 60% of those testing are HIV negative. Limited understanding of how HIV voluntary counselling and testing, and receipt of a negative result impact on sexual behaviour has resulted in underdeveloped support for those testing HIV negative.

Aims: To gain the perspective of those who have tested HIV-negative on the following: (1) the decision making process that precedes attendance for voluntary counselling and testing; (2) how voluntary counselling and a negative test result influence sexual behavioural intentions and reported subsequent behaviour; and (3) support systems and networks that would enhance the respondent’s ability to remain HIV negative.

Method: Qualitative longitudinal study utilising semi-structured interviews, six months apart, with people who have tested negative and three one-off focus group discussions with counsellors. Participants were purposively sampled from VCT centres in two mining towns in Zambia. Interviews were digitally recorded, transcribed verbatim and analysed thematically with the aid of the qualitative data analysis software, Nvivo7. Cross-sectional analysis of all data sets was conducted and paired transcripts were analysed longitudinally to assess change over time.

Results: Forty-two HIV-negative people were interviewed, with thirty-one returning for the follow-up interview (74% return rate). VCT was perceived as “testing for HIV”. Before attending VCT most participants had gone
through a protracted period of angst, resulting in a resolution to reduce number of partners, use condoms or abstain from sex. Counselling affirmed life choices, rather than initiating them. Although perception of the risk of HIV increased, misconceptions about HIV transmission persisted post-counselling. The negative test result provided impetus and resolve to implement or maintain life change. Themes identified were: (1) recognising personal susceptibility to HIV infection; (2) emotional and cognitive engagement with the problem of testing; (3) a driving need to know status (regardless of test result); and (4) empowerment and being in control providing the ability to plan for the future. Analysis of post-test support needs revealed two further themes: (1) reinforcement of behaviour change through additional knowledge, supportive networks, and life-skills training; and (2) access to recreational activities.

There was no reported post-test increase in unsafe sexual behaviour among those that returned for the follow-up interview. Focus group findings reinforced those from interviews.

**Conclusions:** This study has shown that in this population of people who tested HIV-negative:

1. the majority made life changes before attending VCT and used VCT to know their status
2. counselling consolidated pre-test decisions about risk behaviour and testing provided motivation to adopt safer behaviour and to maintain previous low- or no-risk behaviour and
3. there is a felt need for post-testing recreational activities, further HIV/AIDS education and participation in HIV prevention activities
Recommendations include: (1) the promotion of community-based interactive one-to-one and group information, education and communication (IEC) (to aid understanding and progression to the point where testing appears to be of optimum benefit); (2) referral to post-test support options such as support groups and inclusion on a text messaging list should be made available; and (3) post-test intervention strategies, for example, provision of result-specific IEC materials and active involvement in prevention activities should be developed and evaluated.
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<td>ABCs</td>
<td>Abstinence, Be Faithful, use Condoms</td>
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<td>AIDS</td>
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<td>ANC</td>
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<td>Food and Drug Administration</td>
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<td>GRZ</td>
<td>Government of the Republic of Zambia</td>
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<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
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<td>HBM</td>
<td>Health Belief Model</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>IEC</td>
<td>Information, Education and Communication</td>
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<td>IMB</td>
<td>Information-Motivation-Behavioural Skills model</td>
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<td>KCM</td>
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<td>MOH</td>
<td>Ministry of Health</td>
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<td>MSM</td>
<td>Men who have Sex with Men</td>
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<td>National AIDS Council</td>
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<td>NASF</td>
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<td><em>Pneumocystis Carinii</em> Pneumonia</td>
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<td>Social Cognitive Theory</td>
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<td>VCT</td>
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1.1 Introduction

In this chapter I present a brief background to the conception of this study to give the reader an idea of why and how I came to the decision to do this particular study and not any other. I will also take the reader through a brief history of the overall study area so that the present scenario in which this study is set can be better appreciated. To facilitate understanding of issues that will be raised in the thesis I provide some information on the Human Immunodeficiency Virus (HIV), Voluntary Counselling and Testing (VCT), qualitative longitudinal research and behaviour change. I will end the chapter with a discussion of the issue that this thesis addresses, the research question and the limitations of this study.

Why the interest

To me, the HIV epidemic is a very personal one having lost many close family members and friends to the disease with many more living with it. This is generally the experience of the majority of people in countries most affected by the pandemic (Central Statistical Office, Ministry of Health and MEASURE Evaluation, 2002, Macintyre, Brown and Sosler, 2001, Palekar et al., 2008).

My earliest experience with the disease was very early on in the epidemic when a sick relative was nursed in our home. Nothing could be done for him and his mother could just watch and grieve as he slowly died. I next came in contact with HIV and the Acquired Immune Deficiency Syndrome (AIDS) a couple of years later, in medical school, when the Medical wards suddenly began to fill with these patients who were extremely emaciated, just seemed to melt away and nothing much could be done for them. This experience of
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helplessness in the face of such need dented my faith in clinical medicine and kindled my interest in the prevention of disease rather than its cure.

Some years later I was managing the Community Medicine department of a large mining company in the Copperbelt Province of Zambia and it was during one of the HIV/AIDS programme meetings that the seed of this research study was sown. We realised that the majority of people testing were negative and we wondered what was happening to these people after they had tested. We had a “post-test package” for those testing positive but practically nothing, for those testing negative. We had no idea whether the VCT process they had been through was helping them maintain their HIV negative status or not, and what, if any, further support they would wish to have.

A perusal of the literature seemed to show that VCT was not very effective at eliciting desired sexual behaviour change in people testing negative, increasing my interest in this particular area of HIV prevention.

A couple of months later, the personal experience of undergoing VCT for HIV, further increased my interest in the relationship between a negative result and subsequent sexual behaviour. When the opportunity for a PhD came my way I realised I could use it to finally pursue my interest and at the same time hopefully contribute to the fight against HIV/AIDS.

1.2 Causative agent

HIV causes AIDS. HIV was first discovered by French scientists in May 1983. They named it lymphadenopathy-associated virus or LAV. A year later scientists in America identified a virus they believed could be the cause of AIDS and named it human T-lymphotropic virus type III or HTLV-III. It was
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later established that these two viruses were one and the same and in 1986 the International Committee on the Taxonomy of Viruses re-named it Human Immunodeficiency Virus (HIV) (Anon, 1986, AVERT, 2009, Coffin et al., 1986). There are two types of HIV, HIV-1 and HIV-2. HIV-2 is rare and is mostly restricted to West Africa (Mortimer, 1997). Nine subtypes of HIV-1 have been described. The most common sub-type in the West is subtype B which differs from the subtypes found in Africa and Asia (Wainberg, 2004).

The exact origins of the virus are not known but it is generally agreed that HIV is a recent infection in human beings which was probably acquired from African monkeys. Viruses which could be precursors of the HIV have been identified in these monkeys (Pratt, 1995).

HIV belongs to a group of slow viruses with a long incubation period. The virus incorporates itself into the cells of the hosts’ immune system and destroys them as it multiplies (Mortimer, 1997). It is transmitted from one person to another through the receipt of contaminated blood, sharing of contaminated needles, and from mother to child either during pregnancy, delivery or through breast milk. Sexual intercourse is the main route of transmission (Adler, 1997, Pratt, 1995).

On infection with the virus, a person’s immune system begins to produce antibodies which can be detected in the blood about two to twelve weeks later. The period from infection to when the antibodies can be detected is known as the “window period”. The majority of infected people will remain asymptomatic for a number of years following infection. During this period the immune system is still able to keep the virus at bay and protect the
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individual from various other infections and such a person does not yet have the disease, AIDS.

However, with time the viral load in the body increases and since the virus destroys cells that are part of the immune system as it multiplies, the CD4 T lymphocytes, the ability of the body to protect itself against infections diminishes. This finally leads to a situation where the infected person has such a weakened immune system that they eventually succumb to infections that they would normally have been able to fight off. They are then said to have developed AIDS (Murray and Johnson, 1996).

The definition for the diagnosis of AIDS in a person varies according to the diagnostic facilities available in a country or health facility. The definitions are based on laboratory tests for HIV, CD4 levels, the presence of defined diagnostic diseases and specified combinations of particular clinical signs of the disease (CDC, 1992, WHO, 1994).

1.3 The history of AIDS

On 5 June 1981, the first case study detailing an unusual cluster of pneumonia cases among gay men alerted the world to AIDS (BBC News, 2006.)

AIDS first came to the attention of the public in 1981 when the Centers for Disease Control and Prevention (CDC) Atlanta, USA, published a report of a rare type of pneumonia, Pneumocystis Carinii Pneumonia (PCP), with no apparent underlying cause in five previously healthy men in Los Angeles. All five were active homosexuals and at that time PCP was known to be an opportunistic infection affecting individuals with a severely compromised immune system (CDC, 1981).
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At about the same time eight cases of a much more aggressive form of Kaposi’s sarcoma, a rare relatively benign cancer usually seen in older people, were seen in young homosexual men in New York (Hymes et al., 1981).

Infection of human beings with HIV prior to 1981 has been documented using sero-archaeological studies. These studies suggest that the epidemic may have started in the mid- to late 1970s. It is estimated that during this time, when the disease was unknown, 100 000-300 000 people may have become infected (Mann, 1989).

AIDS was defined in 1982 and the modes of transmission were identified in the same year (UNAIDS, 2006a, CDC, 1982). Before 1982, the disease was referred to as gay-related immunodeficiency disease or GRID (Merson et al., 2008).


The first community-based responses to the epidemic were organised by groups of infected individuals and their carers. In 1982, groups in San Francisco distributed pamphlets about Kaposi’s sarcoma and how to avoid infection with whatever it was that was causing AIDS. In the same year two publications that are now accredited with having invented “safe sex” were issued by two other groups. These groups increased in number and geographical representation. They became more organised and active in
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providing care, support and promoting prevention. They were also very active in advocating for a more active response from health care providers, scientists and politicians (Merson et al., 2008).

The use of condoms and sexual education for the youth was met with resistance from religious groups and faith based organisations providing care for HIV infected people. This was seen as actively promoting promiscuity (Merson et al., 2008).

In April 1985 the first international Conference on AIDS was held in Atlanta heralding an era of global mobilisation against the epidemic (Mann, 1989) which would only truly take off about fifteen years later.

During 1985 and 1986 denial and discrimination, fuelled by the stigma that became attached to individuals and to countries reporting cases of AIDS, characterised the response to the epidemic hampering the sharing of scientific information. In addition the needs of developing countries were largely ignored (Mann, 1989, Merson et al., 2008) resulting in delays in responding to the epidemic with resultant disastrous consequences (Merson et al., 2008).

The first blood test for HIV became available in 1985 and affected countries began implementing routine testing of all blood donations effectively reducing the number of infections through contaminated blood (Merson et al., 2008, CDC, 2006).

The WHO Global Programme on AIDS (GPA) was launched in 1987, six years into the epidemic. The GPA developed a Global AIDS Strategy providing much needed guidelines for the prevention and control of
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HIV/AIDS at the local, national and international level. The objectives of the Global Strategy were: to prevent new HIV infections; to reduce HIV/AIDS related morbidity and mortality; and to unite national and international efforts against AIDS (Mann, 1989).

In the late 1980s various organisations and Governments began to provide support to HIV prevention and control efforts in developing countries. With support from these donors and from GPA almost all developing countries had established national HIV/AIDS control programmes by the early 1990s (Merson et al., 2008).

In October 1987 AIDS became the first disease ever debated at the United Nations (UN) General Assembly (Mann, 1989) and in 1988 a world summit of ministers of health was held in London to discuss a common strategy against the disease focussing on prevention. The summit was attended by a record number of ministers and resulted in the London Declaration on AIDS (World Summit of Ministers of Health, 1988) urging urgent action to implement the WHO’s Global AIDS Strategy. The declaration galvanised prevention and control efforts in affected countries (Mann and Kay, 1991).

Since the development of the first drug for the treatment of AIDS in 1987, more drugs with different mechanisms of action were developed and combinations of these were tested for their effectiveness in controlling the virus. Studies reporting on the effectiveness of the combination therapy “highly active antiretroviral therapy” (HAART), at the 11th International AIDS Conference in 1996 (Merson et al., 2008) led to an era of treatment optimism with dramatic improvement in the treatment outcomes for people
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with AIDS. The disease was no longer a terminal disease but a chronic controllable one.

However, this brought new problems in as far as access to these drugs for people in the most affected areas of the world was concerned. The drugs were far too expensive for the Governments and infected individuals of the affected developing countries. This led to a movement advocating for supply of affordable drugs to these countries. The 13th International AIDS Conference held in Durban, South Africa in 2000, is credited with raising international awareness about the scale of Africa’s AIDS epidemic and death toll emphasising the need for accessible and affordable drugs (Merson et al., 2008). Finally, four years after effective treatment had become available infected individuals in poorer regions of the world could access antiretroviral drugs. Drug prices were reduced and the Doha declaration facilitated access to the drugs by removing barriers imposed by the World Trade Organisation Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS Agreement) (World Trade Organisation, 2001).

The WHO’s GPA was replaced by the Joint United Nations Programme on HIV/AIDS, UNAIDS, on 1 January 1996. UNAIDS’ mandate is to mobilise, coordinate and lead an expanded, multisectoral approach to the pandemic (Merson et al., 2008, UNAIDS, 1999d)

Meanwhile the epidemic was worsening in sub-Saharan Africa, Latin America and the Caribbean and was exploding in parts of Asia and Eastern Europe (UNAIDS, 1997b)
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However, there were some notable successes in reversing or slowing the spread of the epidemic in some developing countries such as Uganda, Thailand, Senegal and Brazil. These success stories have been attributed to successful behavioural change interventions facilitated by community participation and strong political leadership (UNAIDS, 2001a).

The importance of prevention in the fight against the epidemic was again brought to the fore with reports of problems with anti-HIV drugs and failed vaccine trials at the 12th International AIDS conference in 1998 (Schoofs, 1998, Altman, 1998).

Recognition of the threat that HIV posed to global development and security, led to an increased commitment to prevention with increased funding. In January 2000 the UN Security Council deliberated on the security implications of the pandemic (UN, 2000a). This is the first time that a health issue had ever been discussed at the UN Security Council (Merson et al., 2008).

At the dawn of the new millennium the United Nations General Assembly announced eight key goals – the Millennium Development Goals – as part of its Millennium Declaration. Goal number six directly addresses the HIV pandemic as it aims to halt and begin reversing the spread of HIV/AIDS, malaria and TB by 2015 (UN, 2000b).

Twenty years into the pandemic estimates stood at 40 million infected with HIV worldwide, and it was reported that AIDS was now the leading cause of death in sub-Saharan Africa and was the fourth biggest killer worldwide (UNAIDS and WHO, 2001).
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The first ever UN meeting to be devoted to a public health issue, the UN General Assembly Special Session — UNGASS — on HIV and AIDS was held in June 2001 (Merson et al., 2008). Representatives of 189 UN member states signed a declaration of commitment on HIV and AIDS stipulating targets for HIV prevention programmes in affected countries and funds to be made available by donor governments. They also pledged to reduce HIV prevalence in young people aged 15-24 by 25% in the most affected countries by 2005, and globally by 2010 (UN, 2001, NAC/MOH, 2008). The declaration stimulated political commitment and funding resulting in a global comprehensive approach to HIV. However, whereas progress towards indicators has been encouraging in some target areas and countries, more needs to be done in order to realise the targets set at this meeting (UN, 2005, UN, 2008).

In the same year the Global Fund to Fight AIDS, Tuberculosis and Malaria was set up to support countries in developing and implementing HIV/AIDS prevention programmes (Feachem and Sabot, 2007).

In 2002 a rapid HIV test using whole blood from a finger prick was approved by the U.S. Food and Drug Administration (FDA) making it possible for more widespread use and for people to receive their results on the same day (FDA, 2002).

In December 2002 the US Agency for International Development (USAID) affirmed support for the “ABC” (Abstinence, Being faithful and Condom use) approach to preventing sexual transmission of HIV/AIDS, based on the strategies used in Uganda (USAID, 2002a).
In January 2003, the US President’s Emergency Plan for AIDS Relief, PEPFAR, was announced with a pledge of $15 billion, over the next five years, to HIV/AIDS prevention, treatment, care and support programmes in Africa and the Caribbean with the aim of preventing seven million new HIV infections and providing treatment for at least two million people (Office of the U.S. Global AIDS Coordinator, 2004). This programme focussed on the fifteen countries with 80% of all people requiring treatment. PEPFAR has been particularly successful in helping recipient countries scale up antiretroviral treatment and prevention of mother-to-child transmission programmes and provide community outreach activities. Its success in prevention has been limited by its narrow approach focussing on individual sexual behaviour change and advocating abstinence and mutual faithfulness rather than the use of condoms (Merson et al., 2008, U.S. Government Accountability Office, 2006).

A new initiative to reduce the incidence of HIV infections was announced by CDC in April 2003. Unlike previous prevention efforts, Advancing HIV Prevention (AHP) was targeted at HIV-positive people. It proposed making HIV testing a routine part of medical care and increasing available resources for partner tracing (CDC, 2003).

At the end of May 2005, a quarter century since the first AIDS case, a UNAIDS comprehensive report on the epidemic showed that although the number of people living with HIV was still on the increase, there was evidence of declines in Kenya, as well as urban areas of Burkina Faso, Haiti, Thailand and four states in India (UNAIDS, 2006b, Global HIV Prevention Working Group, 2007). The report also highlighted that although funding for the response to AIDS in low- to middle-income countries had risen from $300
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Million in 1996 to $8.3 billion it still fell short of what would be needed for meaningful action and of the $18.1 billion that would be required in 2007, only $10 billion was likely to be available (UNAIDS, 2006b).

Apart from financial constraints in scaling up HIV/AIDS prevention and control programmes, developing countries were also facing a critical shortage of health care workers to provide the service. The XVI International AIDS Conference focussed on acceleration of expansion of antiretroviral treatment worldwide and, in particular, how to deal with the shortage of healthcare workers in the hardest hit countries (KaiserNetwork.org, 2006, WHO, 2006). Routine HIV testing was also debated, the WHO and others suggested that a wider uptake of this approach would increase take-up of treatment and help counter stigma (Csete, 2006, De Cock, 2006).

In September 2006 the CDC issued new guidelines recommending routine HIV testing for all adults and adolescents attending Healthcare services. The new recommendations did away with some barriers to implementing routine testing such as the requirement for signed consent before testing and prevention counselling. It was hoped that more general use of this approach which had proved highly successful in prevention of mother to child transmission (PMTCT) of HIV, would help to reduce the rate of new infections and increase the number of people receiving treatment before becoming too ill (CDC, 2006).

By the end of 2006 circumcision was added to the toolbox of HIV prevention interventions. Two trials in Africa had conclusively shown that male circumcision is effective in preventing the transmission of HIV to males (Bailey et al., 2007, Gray et al., 2007, National Institutes of Health, 2006).
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However, this generated concerns about the gender bias of this intervention which favours male protection with unclear direct prevention benefit for females (Berer, 2008, AIDS Vaccine Advocacy Coalition, 2008).

The year 2007 began with another disappointing failed microbicide trial (Polydex Pharmaceuticals Ltd, 2007) dashing hopes for a prevention method that would be controlled by women who make up close to 60% of those infected in sub-Saharan countries (UNAIDS, 2006b).

In 2008 UNAIDS announced a drop in the estimates of the global burden of HIV. The reduction was mostly attributed to improved surveillance techniques but some of it was also due to a drop in prevalence in some areas including Sub-Saharan Africa. It was now estimated that 33.2 million people worldwide were living with the virus down from the 39.5 million estimate made in 2006. This year also saw, for the first time, a decline in global AIDS deaths from 2.3 million in 2005 to 2.1 million (UNAIDS and WHO, 2007).

1.4 Disease burden

Twenty-seven years into the epidemic, AIDS continues to challenge all of our efforts. Twenty-five million worldwide have died of AIDS-related causes (UNAIDS, 2008a). The pandemic has brought untold misery and hardship to millions, has overburdened the economies and health systems of developing countries and is arresting or reversing political and socioeconomic gains of the past decade in health, education, agriculture and other sectors in Africa (Shah, 2006, The Nairobi Declaration, 2000, United Nations Development Programme, 2003).
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According to UNAIDS estimates, in 2007, 2.7 million people became newly infected with the virus. In low- and middle-income countries the number of infected people requiring treatment outstrips supply and globally, for every two people who start taking antiretroviral drugs, another five become newly infected (UNAIDS, 2008a). These statistics emphasise the need for prevention of new infections.

Although only one tenth of the world population live in sub-Saharan Africa, it is home to about two-thirds of all HIV infected people worldwide and accounted for 75% of global AIDS deaths in 2007 (UNAIDS, 2008a).

In Zambia, a country in sub-Saharan Africa with a 2008 projected population of 12.5 million (Central Statistical Office), one in every seven adults aged between 15 and 49 is infected with HIV (Central Statistical Office et al., 2009).

Heterosexual contact is the predominant mode of transmission accounting for 80% of new infections (NAC, 2006c).

With the scale up of access to HAART, more infected people are surviving longer, increasing the prevalence of HIV/AIDS. In the absence of a cure or a vaccine and to ensure sustainability of the scale-up programme, prevention must be the primary focus of control (NAC, 2006c, UNAIDS, 2008a).

### 1.5 Voluntary counselling and testing

Counselling for HIV was formalised in 1987 with the publication of the ‘Public Health Service Guidelines for Counselling and Antibody Testing to Prevent HIV Infection and AIDS’ (CDC, 1993). HIV tests are based on the detection of antibodies to the virus in the serum and other body fluids. These tests have high sensitivity and specificity meaning that false negative results
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are very rare therefore any one of the tests may be used to exclude infection. However, in the case of a positive result a confirmatory test is required (Loveday, 1996).

The test must be voluntary in order to protect people from being tested against their will. Counselling and informed testing are necessary because of the life-threatening nature of the disease and the potential for harmful social and psychological consequences especially those following a positive result (WHO, 2002). A third principle underlying VCT is confidentiality. This has been necessitated by the stigma attached to the condition which often leads to negative consequences for infected individuals (WHO, 2002, UNAIDS and WHO, 2004).

By its very nature VCT is client-initiated. VCT is defined as:

A confidential dialogue between a person and a care provider aimed at enabling the person to cope with stress and make personal decisions related to HIV/AIDS. The counselling process includes an evaluation of personal risk of HIV transmission and facilitation of preventive behaviour (UNAIDS, 2000b)

According to UNAIDS guidelines the VCT process should consist of pre-test, post-test and follow-up counselling.

In the pre-test counselling the counsellor prepares the client for the test by explaining what an HIV test is, correcting any misconceptions about the disease and providing information about the disease transmission and prevention depending on the clients’ level of knowledge. The clients “personal risk profile” may also be discussed.
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Post-test counselling must be done to help both negative and positive clients understand their result and draw up a risk reduction plan to avoid transmission or acquisition of the virus.

According to the guidelines follow-up counselling should be offered to sero-positive people to provide ongoing care and support and should also be offered to those who may not be infected but are affected, “such as the family and friends of those living with HIV” (UNAIDS, 2000b: p5).

The personalised counselling and knowledge of HIV status are believed to provide motivation for individuals to adopt behaviours that will prevent transmission of the virus by influencing knowledge of HIV risk reduction, attitudes and beliefs (Fig 1.1) (Denison et al., 2008).
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Figure 1.1: VCT components and outcomes

Decision to seek testing

Pre-test counselling:
- The test process
- Implications of testing
- Risk assessment
- Risk prevention
- Coping strategies

Prevention counselling

Decision to test and informed consent

Yes, HIV test is performed

Post-test counselling
- Test result given, risk reduction reinforced, discussion about disclosure
- HIV-Positive: + Emotional support, discussion about onward referral

Individual psycho-social outcomes:
- Increase knowledge, change attitudes & beliefs, improve self-efficacy

Relational level outcomes:
- Disclosure to sexual partners & families, partner testing, increase social support

Community level outcomes:
- Disclosure to communities, reduce stigma & increase demand for VCT

Individual behavioural outcomes:
- HIV infected & uninfected clients - safer sexual practices and behaviour. HIV infected clients – access care, support and treatment
- Reduced HIV/STD transmission
- Improved health
- Reduced unintended pregnancies
- Reduced HIV transmission to infants

Source: (Denison et al., 2008, UNAIDS, 2000b)
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VCT is considered a pivotal intervention for both treatment and prevention of HIV/AIDS (UNAIDS and WHO, 2004).

The goals of VCT are:

1. Prevention of HIV transmission
2. Prevention of HIV acquisition
3. Early and appropriate uptake of services for both HIV negative and HIV-positive people
4. Societal benefits such as normalisation of HIV and promoting awareness
5. Counselling for adherence (UNAIDS, 2001b)

Zambia has prioritised the prevention of new HIV infections and VCT is among the key interventions in the 2006-2010 Zambian National HIV and AIDS Strategic Framework (NAC, 2006a).

1.6 HIV testing scenarios

HIV testing is not only at the initiative of the individual. Health care providers may also initiate testing for HIV. This is referred to as provider-initiated HIV testing and includes opt-out testing and mandatory testing.

In opt-out testing the individual is offered the test and retains the right to accept or refuse testing:

- Diagnostic HIV testing is indicated whenever a person has clinical signs and symptoms suggestive of HIV/AIDS and testing is necessary for diagnosis and management. This includes all tuberculosis patients.
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- A routine offer to test is made to all pregnant women to facilitate prevention of mother-to-child transmission of the virus; all patients being treated for a sexually transmitted infection; and any patient seen in any health facility located in an area where HIV prevalence is ≥ 1% and treatment is available.

Mandatory screening of any potential donor of blood or any other bodily fluid or organ is required to avoid transmission of the infection to the recipient (UNAIDS and WHO, 2004, WHO and UNAIDS, 2007).

In order to achieve the target of universal access to HIV treatment, care and support, WHO and UNAIDS recommend the expansion of diagnostic and opt-out testing in order to capture those individuals that would not otherwise present for HIV testing (WHO and UNAIDS, 2007).

1.7  Behaviour change

According to the Compact Oxford Dictionary, the noun “behaviour” is defined as “the way in which someone behaves” with the verb “behave” being defined as “act in a specified way”.

Health behaviours are those behaviours that are related to a person’s health status (Ogden, 2007). Therefore, health behaviour is the way in which someone behaves in relation to their health status.

These behaviours will impact on a person’s health by for example determining whether or not they get a particular disease, if and when they seek VCT and how well they adhere to the offered advice.
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Understanding how health related behaviour can be changed and the development of effective interventions to achieve desired behaviour change continues to be of prime importance in the bid to reduce disease and death in susceptible populations (Albarracin et al., 2005).

Various social science theories have been developed to try and explain how people change their behaviour. These theories have also been used to design interventions. The most common theories used in understanding and responding to AIDS related behaviours will be discussed in chapter 2.

Continued spread of HIV is primarily dependent on individual behaviour and the current poor prospects for a cure or vaccine mean that our only hope of turning the tide and winning the battle is through behaviour change. Behaviour change is a complex process. The highly personal and intimate nature of the behaviour surrounding transmission of HIV makes it even more difficult to understand the underlying processes and development of effective health behaviour change interventions (Albarracin et al., 2005).

In 1992, at the request of the National Institutes of Health, USA, a group of behavioural scientists met with the purpose of developing a model that could be used to explain and guide change in AIDS-related behaviour (Fishbein et al., 2001). They created a behaviour change framework comprising eight variables representing almost all mainstream behaviour change theories. The eight variables are:

1. Strong intentions to perform the behaviour
2. No environmental constraints hindering performance of the behaviour
3. Possession of the necessary skills to perform the behaviour
4. Advantages of performing the behaviour outweigh disadvantages
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5. Perceived social pressure to perform behaviour outweighs pressure not to perform behaviour
6. Behaviour is consistent with individual’s personal standards
7. Positive emotional response to performing the behaviour
8. Confidence in ability to perform the behaviour (self-efficacy)

Defining HIV as a “problem of individual behaviour” has resulted in prevention and control efforts that have largely overlooked the social context in which HIV transmission occurs, disregarding the social determinants of health which impact on prevention (Mann and Tarantola, 1996, p.xxxiii). The above framework attempts to take this wider context into consideration in the second and fifth points.

1.7.1 Highly active antiretroviral therapy and behaviour change
With the advent in 1996 of HAART, AIDS has been converted from a fatal disease to a chronic controllable illness. This has given rise to concerns that the obvious improvement in health status of infected individuals and reduction in viral load may lead to complacency about prevention, due to a perceived reduction in risk of transmitting or acquiring the infection (Remien and Smith, 2000). This may then lead to increased transmission rates compounded by the increased number of surviving healthy HIV-positive individuals.

1.8 Problem statement

Unless we take urgent steps to intensify HIV prevention we will fail to sustain the gains of the past few years, and universal access will simply be a noble aspiration. Peter Piot, UNAIDS Executive Director 2008
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The effectiveness of VCT in reducing HIV incidence at population level is dependent on the number of people testing (Glick, 2005, Hogan and Salomon, 2005). In accordance with UNAIDS and WHO recommendations, countries in sub-Saharan Africa are scaling up access to VCT services as a strategy for prevention of HIV spread and as an entry point for care and support (UNAIDS and WHO, 2004, Denison et al., 2008, Campbell et al., 1997, Department of Health, 2007, Kipp, Kabagambe and Konde-Lule, 2002, NAC, 2006a).

One of the aims of VCT is sexual behaviour change (UNAIDS, 2001b, CDC, 2001). However, a review of available literature shows inconsistency in the effectiveness of VCT in producing the anticipated change in sexual behaviour. While VCT for HIV may have some impact on sexual behaviour change in those testing positive, it has little or no impact in those testing negative with some studies showing an increase in risky behaviour in this group. These differences may reflect shortcomings in the provision of VCT for HIV negative individuals (Corbett et al., 2007, Fernyak et al., 2002, Leaity et al., 2000) or may reflect the influence of the test result rather than the counselling and testing (C&T) on behaviour (Amaro et al., 2005). It is not well understood how voluntary counselling and a negative HIV result impact on subsequent sexual behaviour.

In addition, in the bid to provide available treatment to as many as possible and achieve national and international targets, greater emphasis has been placed on VCT as an entry point to treatment, care and support for those testing positive (Phillips and Coates, 1995, Horton and Das, 2008, Denison et al., 2008, Amaro et al., 2005). This has resulted in an inadequate response to the needs of HIV negative people. Post-test support for people testing
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negative is in most cases limited to an offer of follow-up counselling if desired by the client.

A number of qualitative studies have been conducted exploring the HIV-test decision making process, perceptions of HIV C&T and psychological effects of HIV counselling and negative test results (Flowers, Duncan and Knussen, 2003, Lupton, McCarthy and Chapman, 1995, Ransom et al., 2005, Siegel et al., 1989, Kipp, Kabagambe and Konde-Lule, 2002, Maman et al., 2001, Worthington and Myers, 2003, Taegtmeyer et al., 2006) However, none of these studies focussed on a holistic examination of the process from when a person first starts to think about attending VCT to HIV risk behaviour post test (cf Solomon et al., 2004).

The scale up of VCT provides an opportunity to influence behaviour on an individual basis with more people than any other prevention programme (Weinhardt et al., 1999). The majority of those who will test will be negative. Therefore, understanding the effect VCT and an HIV negative result have on the process of sexual behaviour change and how this effect is mediated, would facilitate the development of a more effective VCT intervention for the majority (Corbett et al., 2007, Sherr et al., 2007).

Most HIV prevention programmes in developing countries rely on donor support and a significant proportion of these funds are going towards the provision of VCT (UNAIDS, 2008b). As pointed out by Phillips and Coates (1995), these funds are not unlimited and therefore, it is essential that VCT provides the maximum possible benefit:

*We certainly need ...more information on how to make C&T a useful primary prevention strategy so that the experience can motivate the maximum*
number of people to protect themselves and others from the virus. The resources for HIV prevention are not unlimited ... Thus such research is essential in order to ensure that the resources are used as wisely as possible to the maximum benefit of as many people as possible (Phillips and Coates, 1995).

1.8.1 **Main research question**

I therefore set out to gain an understanding, from the perspective of heterosexual HIV negative people, of the influence of VCT and the receipt of an HIV negative result on attitudes, intentions and self-reported sexual behaviour, and the felt support needs of people living with an HIV negative result in an urban mining area in Zambia.

**This study is about:**

1. understanding what it is that drives people to go for a test - their experience of going through this decision-making process, facilitators and inhibitors (understanding where they are coming from would allow interpretation of the influence of the VCT process in the appropriate context)

2. attempting to understand how VCT influences the attitudes and intentions of a person who discovers they are negative during the process (culminating in implementation or not of sexual behaviour change)

3. learning about people’s experiences of living with and trying to maintain a negative status (what motivates people to practice safer sexual behaviour, what supports their efforts and what are their felt needs)

4. determining if VCT delivery needs to be modified in any way to achieve the desired goal of sexual behaviour change

5. making recommendations for the enhancement of VCT services.
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1.8.2 Aims

The aim of this study was to gain the perspectives of people who are HIV negative on:

1) how voluntary counselling and a negative result influence their attitudes, intentions and subsequent sexual behaviour and

2) support systems and networks that would enhance participants’ ability to remain HIV negative

However, during the course of the study it became clear that there was an additional area that seemed to be exerting a marked effect on the influence of VCT on subsequent self-reported sexual behaviour and deserved to be investigated in its own right. Some of the people interviewed progressed through an unexpectedly protracted period of angst before presenting for VCT and initiated self-protection measures before finally coming to the decision to test. Various factors within their environment either facilitated or hindered this process.

The open-ended nature of the design of qualitative research allows for the identification and further investigation of concepts found to be relevant during the course of the research thereby necessitating a change in focus; “qualitative research is open to the possibility that the research question may have to change during the research process” (Willig, 2004: p19).

In order to allow for the interpretation, in context, of the influence of voluntary counselling and a negative result, it was necessary first of all, to understand what it is that drives people to go for a test and the factors facilitating and restraining the decision making process. The opening questions of the interview were therefore focussed on understanding this
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area. Being open-ended these questions were able to draw in-depth responses from the participants. Initial analysis of the data drew attention to the pivotal role that this phase appeared to be playing in determining the influence of VCT and the negative result on subsequent self-reported sexual behaviour. Further data generation and analysis supported this finding and hence a third objective was developed re-aligning the major focus of the study to three areas instead of the original two:

3) To gain an understanding of the decision making process that precedes VCT attendance and its role in moderating the influence of VCT on subsequent sexual behaviour

Addressing the first and third objectives provides a clearer understanding of how VCT exerts its influence on subsequent sexual behaviour in this group of participants. This understanding coupled with findings answering the second objective then provide for a more holistic approach to the identification of areas requiring modification or improvement in order to enhance the effectiveness of VCT in achieving and maintaining desired sexual behaviour change.

1.8.3 Specific objectives

In order to guide the gathering of data that would fulfil the aims of the study specific objectives were developed:

1. To determine the factors influencing the decision to test for HIV
2. To determine how the counselling process influences knowledge of and attitude to risk of HIV acquisition
3. To determine how the negative result influences attitude to risk of HIV acquisition
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4. To determine the influence of the counselling process and a negative result on sexual risk behaviour

5. To determine the influence of the counselling process and a negative result on subsequent HIV testing behaviour

6. To determine if and how HIV/AIDS prevention messages influence attitudes to testing and risk of HIV acquisition

7. To determine whether the availability of ARVs influences attitudes to sexual risk taking behaviour

8. To determine the unmet needs of HIV negative people

9. To identify ways in which the current programme appears to be successful

10. To identify gaps in current programme and suggest recommendations for its enhancement

The specific objectives were then operationalised into questions that formed the basis of the interview guide:

1. What factors influence the decision to test for HIV?

2. What influence does the counselling process have on knowledge of and attitude to risk of HIV acquisition?

3. What influence does the negative result have on attitude to risk of HIV acquisition?

4. What influence does the counselling process and negative result have on sexual risk behaviour?

5. What influence does the counselling process and negative result have on subsequent HIV testing behaviour?

6. In what way do the prevention messages around HIV/AIDS influence the attitude to testing and risk of HIV acquisition?
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7. Does the availability of ARVs influence the attitude to sexual risk-taking behaviour?
8. What are the perceived needs of HIV negative people?
9. In what ways does the current programme appear to be successful?
10. How can it be enhanced so as to strengthen its ability to achieve the desired change in sexual behaviour to reduce transmission of HIV?

1.9 Qualitative longitudinal approach

Qualitative research is particularly suited to answering questions in areas which are not well understood. It provides the opportunity for the discovery of new explanations for puzzling phenomena that the investigators may never have thought of (Barbour, 2008, Britten, 1995, Mays and Pope, 1995, Richards and Morse, 2007, Willig, 2004).

A longitudinal approach allows for the study of a process or state over time and provides for comparison of data collected at baseline to that collected at a later point in time. It is the ideal method for studying a person’s experience of change over time (Flick, 2006, Saldana, 2003).

Qualitative longitudinal research is only just emerging as a methodology within qualitative medical research (Neale and Flowerdew as cited by Holland, Thomson and Henderson, 2006: p189) although longitudinal qualitative research has been conducted within certain research communities for decades, for example, anthropologists (Holland, Thomson and Henderson, 2006).

1.10 Study limitations

This study was conducted in a limited geographical area with its own peculiar context in terms of culture, social, health and economic activities
and structures, and a specific group of people. Therefore, no claims to generalisability of the study findings outside this particular context are made.

1.11 Conclusion

International and national response has always lagged behind the HIV/AIDS epidemic. A cure or vaccine has proved as elusive as the origins of the virus; prevention has therefore remained the cornerstone of the response to the epidemic.

From the very beginning HIV and AIDS have been associated with stigmatised behaviours and groups of people leading to denial at both personal and national level. This further compounded the problem by delaying preventive action and resulted in poorly controlled epidemics in most developing countries especially in sub-Saharan Africa.

The advent of HARRT in 1996 served to draw attention from prevention to treatment. However, reports of problems with anti-HIV drugs including the problem of demand outstripping supply, failed vaccine trials, epidemics emerging in new areas, and recognition of the threat posed by HIV to global development and security refocused attention on prevention of new infections.

Although most developing countries are scaling up VCT as both a primary and secondary prevention strategy, its effectiveness as a primary prevention strategy has been questioned.

The availability of affordable treatment in developing countries and the desire to provide treatment to as many as possible has again resulted in
shifting attention from prevention to treatment. Hence, the needs of people testing negative have been largely ignored or sidelined.

In most developing countries, VCT is largely a donor-supported programme. Ensuring that VCT provides maximum benefit at minimum cost is therefore in the interests of both donors and recipients. Gaining an understanding of how VCT influences behaviour and the felt needs of those testing HIV-negative, who comprise the majority of those testing, would provide useful information for the enhancement of VCT services.
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2.1 Introduction

The previous chapter provided a background to the problem being studied and introduced the various concepts that will be referred to in this thesis. This chapter presents these concepts in more detail.

The chapter begins with a discussion of behaviour and behaviour change and the various behaviour change models that have been developed to try and predict, explain and influence human behaviour. The present literature on health promotion and education in relation to HIV is described followed by a brief review of the literature on the influence of antiretroviral drugs (ARVs) on sexual behaviour. The chapter closes with a discussion of the current literature on the acceptability, cost-effectiveness and effectiveness of voluntary counselling and testing (VCT).

2.2 Human behaviour

HIV prevention presents challenges “for the discovery of health behaviour change techniques and for the understanding of the theoretical processes that underlie such change” (Albarracin et al., 2005).

2.2.1 Understanding human behaviour

Prevention remains the cornerstone of the response to the HIV pandemic. As Fishbein (2000) so aptly puts it in his paper on the role of theory in HIV prevention “AIDS is first and foremost a consequence of behaviour. It is not who one is, but what one does, that determines whether he or she will expose themselves or others to HIV” (my emphasis). He goes on to state that in recent years there has been growing recognition of the significant role that behavioural science theory and research can play in public health. It is impossible to develop effective behaviour change interventions if there is no clear understanding of the determinants of behaviour and how it can be
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changed. We can appreciate the underlying determinants of human behaviour through the discipline that studies human behaviour, namely psychology. In presenting this section I have relied quite heavily on Ajzen’s book, “Attitudes, personality, and behaviour” (Ajzen, 1988)

Human beings have always had the need to understand their behaviour and explain it. “It is the goal of many researchers interested in health behaviour to understand both the determinants of health behaviours and the process of health behaviour change” (Noar and Zimmerman, 2005). Individual human behaviour has been ascribed to stable underlying traits or attitudes. The assumption made is that people are inherently predisposed to behaving in a particular manner. This is referred to as the dispositional explanation of behaviour (Ajzen, 1988). It uses the concepts of personality traits and attitudes.

Ajzen (1988) defines a personality trait as “a characteristic of an individual that exerts pervasive influence on a broad range of trait-relevant responses”. For example if a man is seen out with a different woman every other week he is labelled a “womaniser”, if he makes negative comments about women he is said to be “sexist”. A large number of traits, such as extroversion, introversion, agreeableness and conscientiousness, have been identified and more are still being added to the list.

“Attitude” has been defined as “a disposition to respond favourably or unfavourably to an object, person, institution, or event” (Ajzen, 1988). The distinctive characteristic of an attitude is its evaluative nature. A person’s evaluation of the pros and cons of anything — an object, a person, an activity, a service — leads to either a positive or a negative attitude towards that item.
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For example, if a person believes that use of a condom will detract from his sexual pleasure, he will have a negative attitude towards condoms. Attitudes can either be favourable, unfavourable or neutral. They are based on the beliefs that an individual holds about an object.

Beliefs are formed either through direct experience, inference or information gathered about the object. An individual may have a negative attitude towards condoms if they have heard from others that they do not protect against the HIV virus, they burst or they reduce sexual pleasure. A negative attitude may equally develop from personal experience of these adverse events.

Intentions are said to flow from attitudes and, in the case of the individual described above, it might be expected that he would be unlikely to use condoms particularly as intentions can reasonably be expected to translate into actions.

In terms of predicting behaviour, intentions have been found to correlate well with actual performance of the behaviour (Ajzen, 1988). This correlation is particularly strong in the case of volitional behaviours, that is, behaviours that are generally under the control of the individual. The correlation is not as strong with behaviours that are dependent on factors beyond the individual’s control. These factors may be internal to the individual such as knowledge and skill on how to use a condom, or they may be external such as when performance of behaviour depends on the cooperation of another person, as is the case in condom use.
Attitudes are more amenable to change as new information, changing the beliefs informing the attitude, becomes available. On the other hand personality traits are much more resistant to change.

The relationship between personality traits, attitudes and intentions, and behaviour is not as straightforward as outlined above. Various other factors determine whether a behavioural intention actually translates into performance of the behaviour. It has been shown, for example, that there is an “intention-behaviour gap” which may be due to factors beyond an individual’s control (Ogden, 2007). An individual may intend to perform a particular behaviour but be unable to do so because of the influence of another individual. For example, one partner in a sexual relationship may have intentions of using a condom but if the power dynamics in that relationship are such that sexual decisions are made by the other partner, this individual will find it very difficult to carry out their intention if the dominant partner is opposed to the use of condoms.

In general, an individual’s behaviour will be consistent with their underlying personality traits and attitudes; however, individual behaviour acts depend to a great extent on the context (Ajzen, 1988).

2.2.2 Behaviour change theories

A variety of theories have been proposed in the attempt to understand, explain and predict human behaviour. It is generally agreed that theoretically based interventions are more likely to be successful than those based on informal concepts and logic (Kelly et al., 1993, DiClemente and Peterson, 1994). As Kelly et al. (1993) point out, the task confronting the behavioural sciences is to develop theory-based intervention programmes to
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reduce ‘risky’ and increase ‘healthy’ behaviours. Theory driven interventions have been found to be successful in diverse health promotion activities such as bicycle helmet use (Hendrickson and Becker, 1998), health promotion for older adults (Lach et al., 2004) and physical activity (Van Sluijs et al., 2005).

Since the transmission of HIV is facilitated by behavioural factors, behaviour change theories are the basis for most HIV prevention interventions worldwide and a variety of theories have been adopted. The explanations for behaviour change provided by the different theories provide useful insight for the development of interventions (Johns Hopkins AIDS Service, 1997-2004).

Most interventions do not use one theory in its entirety. Programmes have been developed using one or more constructs from one or more theories depending on the context in which the programme is to be implemented (UNAIDS, 1999c).

A systematic review by Lyles et al (2007) examined the effectiveness of AIDS risk reduction interventions implemented in the U.S. from 2000-2004. The interventions were theory driven, utilising different behaviour change theories. The review did not identify any one single behaviour change model as being the best but found that studies utilising different theoretical underpinnings were equally effective.

Albarracin et al (2005) conducted a comprehensive systematic review of studies published over an 18 year period from 1985-2005. The aim of the meta-analysis was “to synthesise research on the effects of ... interventions conducted since the beginning of the HIV epidemic and compare the reality of intervention effectiveness with theoretical proposals about the nature of
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effective interventions”. They included only those studies that assessed condom use as the main outcome. The authors recommend the selective use of relevant constructs from the individual theories depending on the demographics of the target population, risk profile and social-cultural context.

Following is a brief description of the behaviour change theories that have had the most influence in HIV prevention programmes (Kalichman, 1998, UNAIDS, 1999c).

Theory of reasoned action

Fishbein and Ajzen’s theory of reasoned action (TRA), introduced in 1967, and developed further over the years, is based on the premise that people are usually quite rational and use logical reasoning when engaging in a particular behaviour. The theory also assumes that the behaviour in question is under volitional control (Ajzen, 1988, Ajzen and Fishbein, 1980).

According to this theory (Fig 2.1), intentions are the immediate determinants of behaviour and these intentions are the product of an individual’s attitude towards the behaviour and their perception of the social pressure to engage or not to engage in the behaviour (subjective norm). The theory further proposes that attitudes and subjective norms are the products of behavioural beliefs and normative beliefs (respectively) held by the individual.

Behavioural beliefs are beliefs about outcomes of particular behaviours whereas normative beliefs are the beliefs held by an individual about whether or not other people, who are important to them, would want them to implement the behaviour.
The theory of planned behaviour (TPB) is a progression from the theory of reasoned action and was developed to address the issue of behaviour over which one has incomplete volitional control (Ajzen, 1988). This theory adds a third antecedent to intentions, that of perceived behavioural control. Perceived behavioural control is determined by the individual’s beliefs about their ability to perform a particular behaviour with the resources available to them (control beliefs) (Fig 2.2). The theory states that perceived behavioural control can directly influence behaviour even without intention of performing the behaviour.
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Figure 2.2: Theory of Planned behaviour (TPB)

[Diagram showing the Theory of Planned Behaviour (TPB) with nodes for Behavioural beliefs, Normative beliefs, Control beliefs, Attitude towards behaviour, Subjective norm, Intention, Perceived behavioural control, and Behaviour.]

Source: Adapted from Ajzen, 1988

Social cognitive (or learning) theory

The social cognitive theory (SCT) was developed by Bandura in 1977. The theory explains human behaviour as a continuous interplay between behaviours, environmental influences, attitudes and beliefs (Fig 2.3). A central tenet of this theory is self-efficacy, that is, people will only engage in a particular behaviour if they believe that they are capable of implementing the behaviour. Achievement of expected outcomes serves to reinforce self-efficacy and continued performance of the behaviour (Bandura, 1977b).

Figure 2.3: Social Cognitive Theory

[Diagram showing the Social Cognitive Theory with nodes for P (Intrapersonal factors: cognitive, internal [affective, biological]), B (Behaviour), and E (External environment).]

Source: Kalichman, S.C., 1998
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**Stages-of-change model**

The transtheoretical model of behaviour change more commonly known as the stages-of-change model (SOC) (Ogden, 2007) was developed by Diclemente and Prochaska (1982) to study smoking cessation in self-quitters and those in therapy. According to this model people go through five stages in the process of changing behaviour:

1. **Pre-contemplation**: not aware of risk, no intention of changing
2. **Contemplation**: aware of risk, thinking about changing
3. **Preparation**: making some changes
4. **Action**: change consistently performed for less than six months
5. **Maintenance**: new behaviour is sustained for six months or more

Figure 2.4: Stages of change model

![Stages of change model diagram]

Source: Adapted from Kalichman, S.C., 1998
An individual does not progress through these stages in a linear manner but rather in a cyclical manner. For example a person may be at the preparation stage then move back to the contemplation stage. This is referred to as regression. People may also regress or relapse from the action or maintenance stage to an earlier stage, a phenomenon known as “the revolving door schema” (Ogden, 2007: p22).

Health belief model

The health belief model (HBM) (Rosenstock, Strecher and Becker, 1994) was initially developed in the 1950s in an attempt to explain the poor participation in health screening and prevention programmes. It has undergone further developments over the years. According to this model health behaviour is determined by an interaction between socio-demographic characteristics (educational level in particular), knowledge and attitudes.

The model states that an individual will take action to protect their health if they believe that:

1. they are susceptible to the condition
2. the health condition is serious
3. an available course of action will reduce their susceptibility to or the severity of the condition
4. the perceived benefits of the preventive action outweigh the anticipated barriers
5. cues to action which may be internal (experiencing a symptom suggestive of the health condition) or external (witnessing the death or illness of a relative or friend due to the health condition)
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6. they are able to perform the required action or behaviour (added by Bandura in 1977)

Figure 2.5: Components of the Health Belief Model

Beliefs about perceived threats and outcome expectancies are thought to incite readiness for action, thereby acting as triggers for behaviour.

Therefore, changes in belief systems are expected to lead to changes in behaviour. Findings from research suggest that the applicability of the HBM to HIV risk reduction depends on whether the individual recognises their susceptibility to infection, their perceptions of the actions required to reduce risk, cues from the environment and motivation to reduce risk (Kalichman, 1998).
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Models specific to HIV prevention

AIDS risk reduction model
The AIDS risk reduction model (ARRM) was developed in 1990 to specifically address HIV/AIDS sexual behaviour change. It is a three-stage model incorporating elements of the Health Belief Model, “efficacy” theory, emotional influences and interpersonal processes (Catania, Kegeles and Coates, 1990). The theory describes the process involved in changing HIV risk behaviour.

The process begins with people recognising that their behaviour puts them at risk of contracting HIV. They then make a commitment to changing the behaviour in question. In making a commitment people may need to decide whether the behaviour(s) can be changed and if the benefits outweigh the costs or disadvantages. Lastly efforts are made to secure solutions through self-help or help from others such as peers or professional services. This process is not unidirectional. People may change decisions made earlier and take a different course of action or no action at all (Catania, Kegeles and Coates, 1990).
The various stages in this process are influenced by hypothesised factors such as aversive emotions, social factors and self-efficacy.

**Information-Motivation-Behavioural skills model**

The Information-Motivation-Behavioural Skills (IMB) Model was developed by Fisher and Fisher (1992) to provide an explanation for HIV risk reduction behaviour (Kalichman, 1998). Through an analysis of successful HIV prevention strategies Fisher and Fisher discovered that most successful programmes included information, motivation and skills building components.
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They therefore proposed three fundamental determinants of AIDS-risk reduction:

1. **Information** on AIDS transmission and methods of prevention
2. **Motivation** to change AIDS-risk behaviour
3. **Behavioural skills** for performing the preventive behaviour

Figure 2.7: The Information-Motivation-Behavioural Skills (IMB) Model

Source: Fisher and Fisher, 1992

The assumption is that “AIDS-risk reduction information and motivation work largely through AIDS-risk reduction behavioural skills to affect AIDS-risk reduction behavioural change” (Fisher and Fisher, 1992). In situations where the behavioural actions are relatively simple and do not require much skill, information and motivation alone may have a direct effect on behaviour.

### 2.2.3 Limitations of behaviour change theories

Although it is generally said or implied that these theories were developed in the West and may not be applicable to other cultures or countries (UNAIDS, 1999c, Fishbein, 2000), I tend to concur with Fishbein (2000) who argues that these models are not culture specific if properly applied. All the variables in a model can be found in almost any culture or population and the relative importance of each in the model will vary as a function of both the behaviour...
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and the population being studied. The models require an understanding of the behaviour from the perspective of the population being studied. Therefore, it is necessary to take into account the socio-cultural context and elicit the perceptions of the study population about the behaviour under study before applying any particular model to that specific behaviour in that population. The systematic review by Albarracin et al (2005) (see p38) assessed the generalisation of interventions across minority and majority populations. They found that in samples with more people of African descent the most effective interventions were those employing active strategies such as behavioural skills training and HIV counselling and testing (C&T) whereas passive interventions such as condom provision were more effective for European populations.

Only two of these models were developed specifically for AIDS; these were the AIDS risk reduction model and Information-Motivation-Behavioural Skills Model (Kalichman, 1998). The rest were developed to provide predictions and explanations for behaviour including health-related behavioural problems, such as the SOC model for smoking cessation (DiClemente and Prochaska, 1982) and the HBM for participation in screening programmes (Rosenstock, Strecher and Becker, 1994).

The SOC model is more of a descriptive than an explanatory model as it seeks to present “the structure of the process of intentional change” (Prochaska, DiClemente and Norcross 1992).

Although all these models are considered to be socio-cognitive models, they differ as to the extent they actually consider the influence of the social context on behaviour. The TRA, TPB and SCT are considered to be more
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socio-cognitive than the HBM and ARRM (Ogden, 2007). In general, models of individual behaviour change fail to take into account socio-cultural and environmental issues and the context in which sexual interactions occur (UNAIDS, 1999c, Logan, Cole and Leukefeld, 2002). This then means that these theories cannot on their own provide a full explanation of behaviours such as sexual health behaviour which are influenced by various other factors within the socio-cultural, economic and political environment in which individuals live and interact. Indeed, none of these models could provide an adequate framework for the explanation of the findings of this study.

These theories are quite similar to each other (Kalichman, 1998) and have many concepts in common though they use different terminology, for example, behavioural beliefs (TRA), benefits and barriers (HBM) and outcome expectancies (SCT).

An attempt was made to create an integrated theory of health behaviour in 1991 by the National Institutes of Health (NIH), USA. A theorists’ workshop was organised by the NIH with the purpose of identifying the core determinants of health behaviour which would be of particular relevance to HIV prevention research and development of HIV prevention interventions. They identified eight variables representing almost all the major behaviour change theories: intention, environmental constraints, skills, anticipated outcomes (or attitude), norms, self-standards, emotion, and self-efficacy (see section 1.7) (Fishbein et al., 2001). However, this group did not propose a common set of terminology (Noar and Zimmerman, 2005) nor did they reach consensus on how these variables interact or work together to influence behaviour although they did agree, in general, that intentions are the most
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proximal to behaviour (Fishbein et al., 2001). The validity of the selected core determinants of behaviour have been questioned by Noar and Zimmerman (2005), underscoring the major difficulty that any attempt at developing an integrated approach would face.

Apart from individual-focused behaviour change models social theories and models have also been used to develop HIV prevention programmes. This arose out of the recognition that the determinants of sexual behaviour go beyond the individual and require changes at the community, national and international level (UNAIDS, 1999c). These theories include the diffusion of innovation theory (Rogers, 1995) which posits that people are more likely to adopt new ideas if they get favourable evaluations of it from people they respect; social influence or social inoculation model – based on the concept that young people engage in behaviours partly because of peer pressure (Marion and McCabe, 1990); social network theory which views individual behaviour through relationships (Borgatti et al., 2009); and the theory of gender and power, a social structural theory, which addresses the wider social and environmental issues surrounding women (Connell, 1987).

2.2.4 Why do people engage in unhealthy behaviour?

Weinstein (Weinstein, 1982, Weinstein, 1987) suggested that people continue to engage in unhealthy or risky behaviour because of unrealistic optimism. People have a tendency to underestimate their risk of acquiring a particular health condition. This is due to an inaccurate assessment of their level of risk or susceptibility which, according to Weinstein, is due to selective focus. People generally tend to focus more on their risk-avoidance or healthy behaviour than on their unhealthy behaviour and also on others’ unhealthy rather than healthy behaviours. Therefore, people will be unrealistically
optimistic if they focus on the times they use condoms comparing to the times they perceive that others do not use condoms.

A study by Hoppe and Ogden (1996, cited in Ogden, 2007) asked one group of participants to focus on their risk-increasing (“unsafe sex”) or risk-reducing (“safe sex”) behaviour and assessed the effect of this on their unrealistic optimism for risk of acquiring HIV. They found that by encouraging participants to focus on their own healthy behaviour they felt more unrealistically optimistic, rating themselves to be at less risk than others whom they perceived to be at more risk than themselves. These findings suggest that assessment of self-risk is not a rational process (Ogden, 2007). Weinstein also suggests that people will tend to have an unrealistic perception of their own risk to a health problem if it is a problem they would have expected to have appeared but has not and if it is one that is preventable by actions they can take (Weinstein, 1987). Both these suppositions apply to HIV/AIDS — if a person had exposed themselves to risk previously, due to the long incubation period, they may start to think they are not at risk of getting the infection and believe their actions protected them.

2.2.5 HIV beliefs and practices, and stigma in Zambia

Lay beliefs about the cause of an illness will determine the health-seeking behaviour of individuals (Bowling 1997, Ogden 2007). If people believe that a disease is caused by supernatural means, such as witchcraft, they will first seek help from traditional healers rather than the formal health sector. Such a belief will also absolve the person of any responsibility for the illness and they will therefore not take heed of advised protective measures.
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Joffe and Bettega (2003) found that of sixty youths that were interviewed in a study on the representation of AIDS in Zambia, two-thirds believed that AIDS originated in the West due to “deviant” sexual practises such as bestiality and anal sex. More than a quarter attributed the origin of AIDS to scientific experiments in Western laboratories and a third believed that AIDS is a “punishment from God for people’s immoral behaviour”.

Misconceptions about the transmission of HIV are still quite prevalent in Zambia (Central Statistical Office, Ministry of Health (MOH), Tropical Diseases Research Centre (TDRC) et al. 2009). The two most common misconceptions are that HIV can be transmitted by mosquito bites and by supernatural means (witchcraft).

In Zambia, as elsewhere in Africa, women tend to be held responsible for the transmission of the virus, as mothers, prostitutes, young girls and single women engaging in transactional sex – exchanging sex for some material benefit (Baylies and Bujra 2000, Bond, Chase and Aggleton 2002, Joffe and Bettega 2003, Longfield, Cramer and Sachingongu 2003). The Tonga of the Southern Province associate AIDS with Kahungo, a traditional disease caused by coming into sexual contact with a woman who has not yet undergone a traditional cleansing ceremony after a miscarriage or an abortion. Mogensen (1997) suggests that the Tonga use the concept of Kahungo to make sense of AIDS as a disease that has come about due to a disregard of traditional norms and values. Responsibility for the spread of AIDS is also attributed to HIV positive people who are believed to deliberately infect others so that they are not the only ones suffering (Joffe and Bettega 2003, Grant, Logie, Masura et al. 2008).
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Men are generally absolved of responsibility in the spread of HIV because it is believed that men cannot control their natural desire for sex (Joffe and Bettega 2003), hence it is up to the women and girls to dress appropriately and conduct themselves in a manner that will not entice men. In the case of Kahungo, the woman and her relatives must ensure that she is cleansed in order to protect any future partner(s).

In a study on young men’s risk for STIs and HIV in Zambia, Longfield, Cramer and Sachingongu (2003) conducted thirty in-depth interviews with randomly selected male out-of-school youths between the ages of 15 and 19 years. Complementary interviews were also conducted with female youths. In addition to witchcraft, many participants in this study associated HIV infection with menstruation and weak blood. Most relied on outward appearances to judge if a person was infected or not “despite knowing that a healthy-looking person can be infected with HIV”. People who were considered to be unhygienic, careless (not using condoms) and sexually promiscuous were perceived to be at greatest risk for HIV. Most participants believed that a single sexual encounter with an HIV-infected person would inevitably result in infection.

Most people are aware that there are two phases to the illness and that if one is treated early their chances of survival are higher. However, some do not differentiate between “HIV-infection” and “AIDS”. Shingles, chronic diarrhoea, weight loss, hair and skin colour changes, and pulmonary tuberculosis are the most common signs and symptoms associated with HIV-infection or AIDS (Bond, Chase and Aggleton 2002, Longfield, Cramer and Sachingongu 2003).
Zambia is a predominantly Christian country (50-75%) (CIA 2009) with churches condemning immoral behavior and viewing HIV/AIDS as a punishment from God (Bond, Chase and Aggleton 2002). Association of HIV infection with undesirable moral attributes has led to stigma being attached to infection with HIV since a person who becomes infected has only themselves to blame (Longfield, Cramer and Sachingongu 2003). Such stigma can lead to denial and fear of diagnosis and hence reluctance to test. Ascribing the symptoms of AIDS to witchcraft may be in response to perceived stigma since one cannot be blamed for having been bewitched but can be blamed for having AIDS (Bond, Chase and Aggleton 2002).

A study on stigma, HIV/AIDS and prevention of mother-to-child transmission of HIV in Zambia by Bond, Chase and Aggleton (2002) found that stigma was pervasive at all levels of society; the family, community, schools, churches and health facilities. This study found that stigma was experienced in its most extreme forms in health care facilities and households where infected individuals were subjected to verbal abuse, isolation and even neglect. Married women expected to be divorced or abused if they shared their positive status with their husbands whereas HIV-positive men expected support from their wives. However, participants in this study noted that levels of stigma appeared to be reducing.

This is in line with the findings from the 2007 ZDHS. The ZDHS assesses stigma by asking respondents whether they would want it to remain a secret if a family member became HIV-positive, whether they would be willing to care for a relative with AIDS in their own household, whether a worker with AIDS should be allowed to continue working, and whether they would buy vegetables from an HIV-positive seller (Central Statistical Office, Central
Board of Health and ORC Macro 2003). The number of people expressing more accepting attitudes to the four situations has been increasing. In 2007, 95% of both male and female respondents were willing to take care of an HIV-positive relative compared to 92% females and 90% males in 2001 and 67% males and 73% females were willing to buy vegetables from an infected vendor compared to 39% females and 48% males in 2001.

This finding is further supported by Denison et al’s (2008) study in Ndola, Zambia, which assessed the role of family and friends in the HIV-test decision-making process of adolescents. The authors of this study found that intention to test was associated with having discussed testing with a family member, sex partner or friend (and a history of having indulged in sex).

Stigma is more prevalent in rural than urban areas and has been ascribed to lack of knowledge and understanding about HIV and AIDS (Bond, Chase and Aggleton 2002, Central Statistical Office, Central Board of Health and ORC Macro 2003, Central Statistical Office, Ministry of Health (MOH), Tropical Diseases Research Centre (TDRC) et al. 2009).

2.3 Health education and health promotion

Health education and promotion have been central to the response to the HIV epidemic. These terms are defined as below:

Health education:

An educational activity involving some form of communication designed to improve knowledge and develop skills which are conducive to health (Nutbeam, 1986).
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Traditionally health education has been concerned mainly with changing the behaviour and hence health of individuals. According to Nutbeam, it is a “potentially effective strategy” to use in diseases that are related to personal behaviours (Nutbeam, 1986).

Health promotion:

A core strategy to improve health and wellbeing, and reduce health inequities, and in so doing help achieve international and national health goals e.g. Millennium Development Goals. Implementing health promotion creates fairer societies that enable people to lead lives that they value by increasing their control over their health and the necessary resources for wellbeing. (The Nairobi Call to Action, 2009).

Health promotion is a relatively new strategy – within the health and social fields – for the promotion of health (Nutbeam, 1986, Nutbeam and Blakey, 1990). The “perceived failures of health education” in influencing health behaviour and an improved understanding of the various factors that influence health led to the formal development of the new strategy at the first International Conference on Health Promotion held in Ottawa on 21 November, 1986 (Nutbeam and Blakey, 1990, Ottawa Charter for Health Promotion, 1986). The Ottawa Charter called for the development and implementation of health promotion strategies in all countries to facilitate realisation of the Alma-ata vision of “Health For All by the year 2000” (Declaration of Alma-Ata, 1978).

The World Health Organisation (WHO) defines health as “a state of complete physical, mental and social well-being, and not merely the absence of disease
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or infirmity” (WHO, 1946). There have been calls for a re-definition of “health” with critics arguing that it is utopian and unattainable by most people (Awofeso, 2005, Nutbeam, 1986, Saracci, 1997). Within health promotion, rather than an objective to be attained, “health is seen as a resource for everyday life” (Ottawa Charter for Health Promotion, 1986).

A central concept of health promotion is the idea that health is determined by the socio-ecological environment: both the ways and the conditions of living are important in the pursuit of health. Personal empowerment and communal action are fundamental to the health promotion concept (Ottawa Charter for Health Promotion, 1986).

The Bangkok Charter for Health Promotion in a Globalized World (2005) affirmed the Ottawa Charter laying particular emphasis on addressing inequities in health. The charter also called on all countries to “make the promotion of health a requirement of good corporate practice”.

A recurrent theme in the International Conferences on Health Promotion, which was the focus of the 7th Global Conference on Health Promotion held in Nairobi, Kenya, in October 2009, is the need to close the implementation gap between knowledge and action. The Nairobi Call to Action (2009) states that “health promotion has demonstrated its effectiveness and return on investment at local, regional, national and international levels” and calls for the development of a Global Health Promotion Strategy to expedite global implementation of proven approaches to health promotion.

Health education and health promotion are “closely interlinked” (Nutbeam, 1986). Health promotion cannot be possible without the involvement of an informed public, hence health education – directed at individuals,
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communities, groups and organisations – plays a central role in raising awareness about the environmental, social and economic causes of health and ill health (Nutbeam, 1986).

2.3.1 Approaches to health promotion

Naidoo and Wills (2000) describe five approaches to health promotion which differ in terms of what they aim to achieve, how they go about achieving their stated aims and how the interventions are evaluated:

- The medical or preventive approach targets populations or groups at risk and aims to prevent disease, prevent the progression of disease, and limit disability and discomfort. These objectives are met through such activities as immunisations, screening for diseases and rehabilitation.
- The behaviour change approach targets the individual and attempts to influence behaviour through individual or mass means of education.
- The educational approach, while employing similar methods to that of the behaviour change approach, does not aim to influence change in any particular direction but to provide information and skills which allow the client to make their own choice.
- The empowerment approach seeks to provide individuals or communities with the ability to identify and address their own health needs.
- The social change approach is more radical and aims to promote health by influencing the social, economic and physical context of the lived environment of people and communities so that “the healthy choice” becomes “the easier choice” (Naidoo and Wills, 2000: p102).

Apart from the empowerment approach all these are what are termed ‘top-down’ approaches which make the assumption that the health professional is...
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the ‘expert’ who knows what health status needs to be attained and how to attain it. In contrast the empowerment approach endeavours to provide individuals and communities with the means by which they can make their own choices about what is important for them and how to achieve desired health goals — the ‘bottom-up’ approach.

The approaches that seek to change individual behaviour have utilised some of the health behaviour change models presented in section 2.2.2 (Beattie, 1991).

2.3.2 Theories of health promotion

There is no consensus in the health promotion field on what comprises health promotion (Beattie, 1991, Naidoo and Wills, 2000). A number of health promotion theories have been proposed.

A model that is widely accepted by health care workers is one developed by Tannahill (Downie, Fyfe and Tannahill, 1990). Tannahill presents health promotion as being composed of three overlapping fields: health education (communication), health prevention (medical interventions) and health protection (legislative).

Figure 2.8: A model of health promotion

Source: Downie, Fyfe and Tannahill, 1990
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This is a descriptive rather than an explanatory model. Tannahill identifies seven areas within health promotion. Preventive (1) and health education (5) approaches have been referred to in section 2.3.1. Health protection (6) utilises legislation to safeguard health. Preventive health education (2) uses education to influence lifestyle and the utilisation of available preventive services. Preventive health protection (3) uses legislation to reduce occurrence of disease or disability. Health education for preventive health protection (4) aims to garner community support for protective legislation through education. Health education aimed at positive health protection (7) similarly raises awareness for health protection measures.

Caplan & Holland (1990) use two dimensions of theories about society and epistemology (the nature of knowledge) to propose four models of health promotion. Theories about society are placed along a vertical continuum ranging from those concerned with issues of power imbalance, oppression and discrimination – radical theories, to those that view society in terms of how it is organised to serve the interests of all its members. The nature of knowledge is placed along a horizontal continuum from subjectivist to objectivist. This conceptualisation generates four models of health promotion:
Beattie (1991) also suggests four models of health promotion. Similar to the conceptualisation used by Caplan and Holland he uses two dimensions: a dimension of “mode of intervention” ranging from authoritative to negotiated and a dimension relating to the primary target of the intervention, ranging from the individual to the whole community and environment:
Tones (Tones and Tilford, 1994) presents a model that reflects how health education can contribute to health promotion through empowerment of individuals and communities:

**Figure 2.10: Strategies of health promotion**

<table>
<thead>
<tr>
<th>MODE OF INTERVENTION</th>
<th>HEALTH PERSUASION</th>
<th>LEGISLATIVE ACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>AUTHORITATIVE</td>
<td>To persuade or encourage people to adopt healthier lifestyles</td>
<td>To protect the population by making healthier choices more available</td>
</tr>
<tr>
<td></td>
<td>Practitioner is in the role of expert or ‘prescriber’</td>
<td>Practitioner is in the role of ‘custodian’ knowing what will improve the nation’s health</td>
</tr>
<tr>
<td></td>
<td>Conservative political ideology</td>
<td>Reformist political ideology</td>
</tr>
<tr>
<td></td>
<td>Activities include advice and information</td>
<td>Activities include policy work, lobbying</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FOCUS OF INTERVENTION</th>
<th>INDIVIDUAL</th>
<th>COLLECTIVE</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERSONAL COUNSELLING</td>
<td>To empower individuals to have the skills and confidence to take more control over their health</td>
<td>To enfranchise or emancipate groups and communities so they recognize what they have in common and how social factors influence their lives</td>
</tr>
<tr>
<td></td>
<td>Practitioner is in the role of ‘counsellor’ working with people’s self-defined needs</td>
<td>Practitioner is in the role of ‘advocate’</td>
</tr>
<tr>
<td></td>
<td>Libertarian or humanist political ideology</td>
<td>Radical political ideology</td>
</tr>
<tr>
<td></td>
<td>Activities include counselling and education</td>
<td>Activities include community development and action</td>
</tr>
</tbody>
</table>

Source: Modified from Beattie, 1991, Naidoo & Wills, 2000
Health education—with the objective of increasing knowledge and changing attitudes—has been used as a primary tool in the prevention of HIV (Nutbeam et al., 1989). Mass media campaigns have played a central role in the response to the epidemic from very early on (Bertrand et al., 2006, Rigby et al., 1989, Nutbeam et al., 1989). These have tended to focus on the general public rather than any specific risk group (Bertrand et al., 2006). Bertrand et al (2006) define mass media interventions as:

any programs or other planned efforts that disseminate messages to produce awareness or behaviour change among an intended population through channels that reach a broad audience.
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Such channels include radio, TV and print media including posters, billboards and pamphlets (Bertrand et al., 2006).

The early campaigns focussed on raising awareness about HIV and as a consequence awareness in most countries is quite high (Lupton, McCarthy and Chapman, 1995). However, as evidenced by various studies, information alone is not sufficient to prompt behaviour change and though knowledge levels may be high this does not necessarily translate into safer behaviour (Becker and Joseph, 1988, Adamchak, Mbizvo and Tawanda, 1990, Konde-Lule, Berkley and Downing, 1989, Lindan et al., 1991). Australia and the United Kingdom launched mass media education campaigns based on fear-inducing messages — the “grim reaper” and “Don’t die of ignorance” respectively — which were found to have had little or no effect on sexual behaviour (Rigby et al., 1989, Nutbeam et al., 1989).

The focus of mass media campaigns has evolved with time from the initial awareness-raising campaigns through the behaviour change campaigns of the late 1980s and the 1990s to the present more comprehensive campaigns covering prevention, treatment, care and support (Bertrand et al., 2006). Bertrand and colleagues provide a framework which is useful in understanding how mass media communication, for HIV-risk behaviour change, are expected to achieve their intended outcome (Fig 2.12).

In this framework mass media interventions are expected to affect knowledge, attitudes and self-efficacy — within the social, cultural, political, legal and economic context — thereby influencing behaviour (Bertrand et al., 2006).
Of the twenty four studies included in a systematic review by Bertrand et al (2006) — assessing the effectiveness of mass communication programmes in developing countries — five used television, seven radio and twelve small media (posters, pamphlets, audio programming, dramas and puppet shows) with or without face-to-face communication. Between 1990 and 2004 there was a shift towards evaluation of programmes using media designed to reach larger audiences. More than 70% (10/13) of the evaluations published between 1990 and 1999 focussed on small media and a similar percentage (8/11) of those published from 2004 onwards focussed on radio and television. They found that of the seven outcomes they were assessing there were significant effects on only two; knowledge of HIV transmission and reduction in high-risk sexual behaviour such as multiple sexual partners, casual sex, sex with a ‘sugar daddy’ (also known as "cross-generational sex")
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—a sexual relationship between a young woman and man at least ten years older) or commercial sex worker. The other outcomes were: perceived personal risk of contracting HIV; self-efficacy to negotiate condom use or protect oneself; discussion with others about HIV/AIDS or condom use; abstinence from sexual relations; and condom use. Twelve of the studies were from Africa (two from Zambia), seven from Asia and five from Latin America and the Caribbean. The authors advise caution in interpreting the results due to the weak designs of most of the studies and the non-representation of the comprehensive mass media programmes that are currently being implemented which use a variety of media within the same programme hence targeting various subgroups within the population.

2.3.3 Health education and health promotion programmes in Zambia

The Zambia National HIV and AIDS Strategic Framework identifies six priority action areas (NAC, 2006a). The first one of these is the intensification of HIV prevention. Zambia introduced an HIV and AIDS education programme early in the epidemic with the aim of controlling the spread of the virus by providing people with information about how it is transmitted and about prevention (Central Statistical Office, Ministry of Health and MEASURE Evaluation, 2002). Like the campaigns in some developed countries, the Zambian “Before and After” mass media health education campaign employed fear-inducing messages with its’ posters and billboards depicting extreme changes in physical appearance after developing AIDS. There appears to be paucity of studies assessing the effectiveness of this campaign.

Behaviour change communication— “the strategic use of communication to promote positive health outcomes” (AED: Center for Global Health
Communication and Marketing, 2005-2009) — plays a central role in the prevention programme. Various Information, Education and Communication (IEC) strategies such as mass media, small media, counselling and peer education, are used to reach different target groups within the community. HIV prevention messages are centred on the ABC (abstain, be faithful, use condoms) approach. This approach has been credited with increasing the age of sexual debut and reducing casual sex among youths aged 15-24 years (NAC, 2006a). Median age at first sex increased from 16.5 years in 2000 and 2003 to 18.5 years in 2005. The 2005 Zambia Sexual Behaviour Survey\(^1\) (ZSBS) recorded additional positive sexual risk behaviour changes; reduction in number of sexual partners among the male youth (12% in 2000 to 6% in 2005) but not among females (from 2% in 2000 to 3% in 2005); increase in percentage of never-married adolescents who had never had sex from 39% in 1998 to 64% in 2005 among females and from 57% in 1998 to 69% in 2005 among males (Central Statistical Office, Ministry of Health and MEASURE Evaluation, 2006). The ABC approach has also been credited with Uganda’s success in reducing HIV prevalence (Kirby, 2008).

The Zambia National HIV prevention programme appears to have made some headway in changing sexual behaviour and attitude (Fylkesnes et al., 2001, Agha, 2002, Sandoy et al., 2006, Bloom et al., 2000, Slaymaker and

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\(^1\) The 2005 ZSBS utilised a nationally representative probability cluster-based household sample. A questionnaire based on one designed by the Joint United Nations Programme on HIV and AIDS (UNAIDS) was administered to all eligible adults in selected households (15-49 year old females and 15-59 year old males). A total of 2,244 households were located and the survey achieved a response rate of 93%.
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Buckner, 2004). The Fylkesnes et al (2001) study used data from both ante-natal clinic surveillance sites and population-based surveys and reported the results separately; both showed a positive trend in behaviour change. Sandoy et al (2006) used data from ante-natal clinic surveillance sites and Agha (2002), Bloom et al (2000) and Slaymaker and Buckner (2004) used data from population-based surveys. Showing the same effect with data from different sources increases confidence in the findings (Fylkesnes et al., 2001).

However, the impact of this change in behaviour and attitude on HIV prevalence seems to be slight — from 16% in 2001/2002 to 14% in 2007 (Central Statistical Office et al., 2009).

2.4 Anti-retroviral therapy and sexual behaviour change

With the advent of Highly Active Antiretroviral Therapy (HAART), a combination of anti-HIV drugs, in 1996 AIDS has been converted from a fatal disease to a chronic controllable illness (Amaro et al., 2005, Lohse et al., 2007) allowing infected people to live longer healthier lives (Murri, 2005, Horizons Program, 2005).

The introduction of ARVs appears to have resulted in increased uptake of VCT, attributable to the impression that people are more willing to test because there is assistance available for those testing positive. In Zambia, HIV test-uptake increased with the introduction of free ARVs (NAC, 2006c) and in Khayelitsha, South Africa, the uptake of VCT increased from less than 1 000 tests in 1998 to more than 12 000 in 2002 after ARVs were introduced (WHO, 2003a). Following the provision of ARVs, a fivefold increase in the number of HIV tests performed was also noted in a community in Tutume District, Botswana (Warwick, 2006).
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Treatment with HAART leads to remarkable improvement in health and this has given rise to concerns that the obvious improvement in health status of infected individuals and reduction in viral load may lead to complacency about prevention, due to a perceived reduction in risk of transmitting or acquiring the infection (Remien et al., 2005, Kravcik et al., 1998, Dilley, Woods and McFarland, 1997, Wilson et al., 2004). However, akin to the literature on VCT effectiveness, there appears not to be a clear consensus on the influence of HAART on risky sexual behaviour (Bunnell et al., 2006, Remien et al., 2005).

A meta-analysis of 25 English language studies from January 1996 to August 2003 (Crepaz, Hart and Marks, 2004) found no significant difference in the prevalence of unprotected sex in HIV-positive people on HAART and those not on HAART. However, beliefs that HAART and undetectable viral loads protect against transmitting HIV were associated with unsafe sex in both HIV-positive and HIV-negative people. The availability of HAART also reduced concerns about engaging in unprotected sex. Fourteen of these studies were conducted in the United States, two each in France and the UK, one each in the Netherlands, Switzerland and Australia, one was a multisite study (UK, France, Australia and Canada), one was a multicentre study in the USA and no location was indicated for one. More than fifty percent of the studies were with men who have sex with men (MSM).

Remien et al (2005) conducted a cross-sectional study of 456 HIV-positive MSM in San Francisco and New York City. The authors found no “evidence of a widespread increase in sexual risk behaviour associated with the use of HAART”. They found that the men on HAART who engaged in unprotected
anal sex (less than 25%) had a lower perception of risk for transmitting HIV or worsening their own health.

In a study conducted at the Taipei City Sexually Transmitted Disease (STD) Control Centre in Taiwan, Chen et al (2006) reported no difference in levels of unprotected sex in HIV positive people on HAART and those not on HAART. They concluded that their study had found no evidence to suggest that HAART encouraged unsafe sex. A limitation of this study was that they did not elicit participant perceptions of the effect of HAART on HIV transmission. Their findings may just mean that there is an overall reduced perception of the seriousness of infection with HIV because of the availability of HAART.

A study with a similar drawback was conducted by Wilson et al (2004) in the USA. The investigators collected data from 1,168 women—enrolled in a multi-centre longitudinal cohort study—who had been on HAART between January 1996 to January 2001. This study also investigated the relationship between CD4 cell counts and viral load, and sexual behaviours. They reported increased levels of unprotected vaginal sex post-HAART compared to pre-HAART and reduction in number of sexual partners. Since these findings were unrelated to CD4 cell count levels and viral load—and, therefore, to actual improvements in physical health—the authors suggested that perceptions of HAART benefits may be influencing sexual behaviour in these women. While they acknowledge that the study was limited by not having sought “specific information regarding psychological factors and beliefs that may have influenced risk behaviour”, they support their suggestion by reference to a previous study conducted in another subgroup
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of the same cohort. This study found that after starting HAART women were less worried about using condoms or believed that they were less infectious.

Bunnell et al (2006) followed a cohort of 926 HIV positive individuals in Uganda from May 2003 to December 2004. They provided home-based antiretroviral therapy (ART), prevention counselling and VCT for household members. Participants were followed up every three months and 815 were included in the final analysis. They documented a 70% reduction in risky sex. They argued that integrated ART and prevention programmes can reduce transmission of HIV.

2.5 Voluntary counselling and testing

2.5.1 History

When the HIV antibody test became available in 1985 the United States Government moved quickly to protect the nation’s blood and blood products supply. HIV testing facilities were introduced in blood donor facilities and this attracted high risk individuals seeking to obtain a free HIV test. This increased influx of potentially infected blood donors posed a risk to the blood supply. HIV testing centres were therefore provided in other sites such as primary health care facilities and STD clinics (Kalichman, 1998, CDC, 2006). At this time there was no treatment for HIV or any other support that could be offered apart from palliative care and psychological support.

Counselling or information-giving was necessitated by the terminal nature of the diagnosis and its potential for adverse psychological reactions (Miller and Madge, 1996, Sheon, 2004, CDC, 2006).
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Many countries expressed initial interest in the test for the purpose of mandatory screening. This was successfully thwarted by the WHO Global Programme on AIDS redirecting attention to prevention (Mann and Kay, 1991).

Counselling initially focussed on detection of those infected so as to limit transmission of the virus and to provide support (Mann, 1989, CDC, 1985a, Miller and Madge, 1996) and consisted of information giving and advice (CDC, 1985b, Sheon, 2004).

Later in 1985 the US Centres for Disease Control and Prevention (CDC) issued guidelines on the prevention of peri-natal transmission of HIV extending counselling to include negative pregnant women or women who might become pregnant (CDC, 1985a).

In an attempt to interrupt the transmission of HIV by encouraging C&T in persons in high risk groups, the CDC issued further guidelines in 1986. They recommended that individuals in these groups must be counselled and offered voluntary HIV testing whenever they attend a health care facility (CDC, 1986). These guidelines highlighted the importance of maintaining confidentiality (due to the stigma around the disease that was rife at this time). The groups identified as being at high risk were: homosexual and bisexual men; IV drug abusers; persons with clinical or laboratory evidence of infection; persons born in countries where heterosexual transmission was thought to play a major role; male or female prostitutes and their sex partners; sex partners of infected persons or persons at increased risk; all persons with haemophilia who had received clotting-factor products; and newborn infants of high-risk or infected mothers (CDC, 1986).
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Counselling formally became a part of HIV testing, in 1987 (Kalichman, 1998, CDC, 2006) when the CDC issued new guidelines making HIV C&T a priority prevention strategy and extending the target group to include all women of child bearing age who may have been exposed to infection with HIV, persons planning marriage and all persons admitted to hospitals or attending health facilities for medical check-ups or treatment and prisoners (CDC, 1987). These guidelines widened the net providing for contact with an increasing number of individuals who were more likely to be negative and therefore focussing some attention on the uninfected individual.

The 1987 guidelines emphasised behaviour change as an expected outcome from HIV C&T (CDC, 1987, CDC, 2006). Due to pressure from evaluative research consistently showing unfavourable VCT outcomes, the CDC developed a client-centred model based on the stages of change behaviour model (CDC, 1993, Sheon, 2004). The new guidelines, issued in 1994, encouraged a client-centred approach including the negotiation of a risk-reduction plan with each client (CDC, 2006). As mentioned earlier (section 1.5) the purpose of this approach was to encourage behaviour that would limit the spread of the virus and identify individuals requiring treatment, care and support for HIV infection.

The emphasis on behaviour change as an outcome of HIV C&T has made C&T the cornerstone of comprehensive HIV prevention programmes and it is now the most widely available and most frequently used HIV prevention service in the world (Kalichman, 1998, Denison et al., 2008).

VCT has not always enjoyed the popularity that it has now especially in developing countries. In the 1990s there was resistance to the introduction of
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VCT in developing countries due to the perception that scarce resources could be better invested in interventions that had been shown to be more effective (Campbell et al., 1997). In an attempt to get sceptical policy makers and programme managers on board, UNAIDS issued technical guidelines in 1998 highlighting evidence of VCT effectiveness and explaining what VCT entails and its benefits (UNAIDS, 1997a).

With the advent of HAART in 1996 the global focus shifted from prevention to treatment. This was exacerbated by the ensuing discrepancy in access to treatment with the countries needing it the most not being able to access it due to cost. This firmly put the spotlight on treatment and getting it to the people that needed it the most (Merson et al., 2008). Once treatment was made available for this group of individuals it was then necessary to ensure that as many as possible could access it, hence UNAIDS’ 3-by-5 initiative which aimed to put 3 million people on treatment in developing countries by 2005 (WHO and UNAIDS, 2003). In order to facilitate a scale up of access to treatment it became necessary to scale up access to testing. In June 2004 UNAIDS/WHO issued a policy statement on HIV testing recommending four types of HIV testing that would be acceptable and endorsing VCT as a critical intervention for the prevention of HIV. The policy recommended both client-initiated and provider-initiated C&T approaches. These approaches have been discussed in sections 1.5 and 1.6: VCT, diagnostic HIV testing, routine offer of testing by health care providers and mandatory HIV screening (UNAIDS and WHO, 2004).

Although the policy did state the preventive role that VCT was expected to play, in practice emphasis was placed on the role of VCT as a diagnostic tool (Denison et al., 2008). However, the 2006 UN General Assembly did reaffirm
its 2001 commitment to prevention as the mainstay of the response to the pandemic and recognised VCT as a prevention strategy (UN, 2006).

With an ever increasing need to increase the numbers of people who know their HIV status, so those positive can be offered treatment and reduce transmission, guidelines have evolved to provide for a wider reach. In 2001 the CDC revised its guidelines and broadened the target population for testing to all individuals attending a health care facility in an area with an HIV prevalence of 1% or more, and in 2006 the guidelines were revised to include routine testing of all patients aged 13-64 years presenting to any health care facility (CDC, 2006).

2.5.2 Cost
The cost-effectiveness of an intervention, i.e. “the net gain in health (compared with doing nothing) divided by the cost” (World Bank, 1993) or the value for investment that will be obtained from the intervention, plays an important role in deciding which intervention will be implemented. Cost-effectiveness is measured in terms of cost per averted infection and cost per disability adjusted life year (DALY) gained (Murray, 1994, Murray and Lopez, 1994). The 1993 World Development Report recommends a ceiling of $50 per DALY for preventive interventions in developing countries (World Bank, 1993).

In 1992, the World Bank in collaboration with WHO undertook a study to estimate the Global Burden of Disease (GBD). Among the goals of this study was the development of a framework for objectively identifying epidemiological priorities for resource allocation decisions (Murray, Lopez and Jamison, 1994). The DALY, a product of this study, is a summary
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measure of population health that combines years of life lost from premature death, YLL (<82.5 for females, <80 for males) and years of life lost to disability, YLD by age, sex and time period. By taking into account both death and disability the DALY provides a more accurate estimate of total disease burden by cause.

\[
\text{DALY} = \text{YLL} + \text{YLD}
\]

Computer models which take into account various assumptions are used to calculate the DALYs by cause. Disability is weighted to take into account the value society places on time lived in various levels of less than optimal health and time discounting at a rate of 3% is applied to future lost healthy years (to provide an estimate of current value of years of life lost) (Mathers, Lopez and Murray, 2006).

A comprehensive approach to HIV/AIDS prevention and control is necessary in order to effectively address the problem (International HIV/AIDS Alliance, UNAIDS, 2006b); consequently there are many interventions which have to be funded from the limited resources made available to the HIV/AIDS prevention programme. The DALY is a useful tool to use in the prioritisation of health problems and interventions and in policy formulation. It also has the added advantage of enhancing transparency (WHO, 2003b).

Health economics theories and techniques help to guide decisions on resource allocation in the face of scarce resources (WHO, 2003b). Cost-effectiveness analyses measures and compares costs and consequences of various interventions facilitating assessment of their relative efficiency (UNAIDS, 1998). The DALY is a useful measure of the cost-effectiveness of a programme or an intervention. The cost-effectiveness is expressed in terms of cost per DALY averted, i.e. how much it has cost to prevent a DALY.
Sweat et al. (2000) estimated the cost-effectiveness for a hypothetical cohort of 10,000 people seeking VCT in two urban sites in Kenya and Tanzania. Results from a randomised controlled trial of HIV-1 VCT were used to model the outcomes which included programme cost (costs associated with attending to a client at the site - goods and services), number of HIV-1 infections averted, cost per infection averted and cost per disability-adjusted life-year (DALY) saved. The cost of averting one HIV infection was US$249 and $346 in Kenya and Tanzania respectively. The average cost per DALY saved was $12.77 in Kenya and $17.78 in Tanzania. This is slightly less than the cost effectiveness of improved STD services at $10 per DALY saved (Gilson et al., 1997) and that of Nevirapine provision to pregnant women, $5 - $55 (Marseille et al., 1999) and health interventions in child health and maternal health, between $5-50 per DALY (Jamison and Mosley, 1991).

Another study by Hogan et al. (2005) looking at the cost-effectiveness of different strategies to combat HIV/AIDS in developing countries also found VCT to be a cost effective intervention at <$Int350 per DALY averted ($Int = international dollars. A hypothetical unit of currency that has the same purchasing power that the US$ has in the United States at a given point in time). This converts to US$77 for Kenya and US$66.50 for India. Data sources were clinical and observational studies and population surveys for the biological and behavioural parameters whereas intervention effects and resource inputs were based on published reports, expert opinion and the WHO Choosing Interventions that are Cost Effective database² (WHO-CHOICE).

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A systematic review of cost-effectiveness studies of HIV interventions in Africa by Creese et al (2002) found that VCT compared favourably to other interventions being more cost-effective than provision of formula feed, home-based care and provision of HAART and less cost-effective than a combined treatment of STDs and condom promotion, blood screening and single dose Nevirapine for prevention of mother-to-child transmission of HIV.

2.5.3 Acceptability

The acceptability of a programme will determine to what extent it will be used by the target population. Therefore, assessment of programme acceptability before implementation is important (Killewo et al., 1998). With increasing acceptability more people would use the service and this has the potential of improving cost-effectiveness through economy of scale (Sweat et al., 2000). Therefore, it is important to know how acceptable VCT is in the African context. Studies done in various countries have shown that generally the number of people expressing a desire to test (readiness to test) outnumber the number that actually go ahead and have the test done.

Generally, acceptability of VCT is quite good. Studies have shown that uptake varies with mode of delivery being higher where C&T is offered right at the doorstep (Fylkesnes and Siziya, 2004, Wolff et al., 2005, Corbett et al., 2006, Lugada et al., 2009). As alluded to in the above paragraph, it has been recognised that there is an intention-behaviour gap in VCT testing behaviour. A number of studies have found that the number of people expressing willingness to test is usually higher than the number who actually test and get their results (Corbett et al., 2006, Fylkesnes et al., 1999, Fylkesnes and Siziya, 2004, Central Statistical Office, Central Board of Health and ORC.
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Macro, 2003, Central Statistical Office, Ministry of Health and MEASURE Evaluation, 2006, Sherr et al., 2007, Killewo et al., 1998, Kalichman and Simbayi, 2003). The 2005 ZSBS reports that 73% of all men and women surveyed expressed the desire to test for HIV but only 11% and 15% of all men and women, respectively, had ever tested. This was in spite of more than 80% of men and women having reported that they knew a place where they could go for VCT and only 3.2% citing ignorance of testing site as the reason for not testing (Central Statistical Office, Ministry of Health and MEASURE Evaluation, 2006).

Fylkesnes and Siziya (2004) conducted a cluster randomised trial in Chelston, an urban residential area in Lusaka, Zambia, assessing acceptability of VCT. The authors report an earlier population-based survey in the same area, in which 29% (724/2526) had expressed interest in being tested (readiness) but only 4% (29/724) had gone on to test and receive the result (acceptability) at the local health facility. In the follow-up cluster randomised trial, one group was allocated to VCT at the local health facility and the other group was allocated to VCT at an alternative site (participants’ choice). Acceptability overall increased to 33% (279/849) but was much higher in the alternative site (home in >80%) than in the health facility testing group, 56% (227/407) and 12% (52/442) respectively. In the first survey there was a gap of 2-3 weeks between testing and receiving results whereas in the second survey the results were offered on the same day. The authors report that home-based C&T and rapid tests contributed to the increased acceptance levels in the second survey (Fylkesnes and Siziya, 2004).

Corbett et al (2006) conducted a similar cluster randomised trial in Harare, Zimbabwe, focussing on the workplace as the alternative site. The twenty
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four businesses finally included in this study were stratified by absenteeism rates and randomly allocated to on-site rapid HIV testing or off-site rapid testing. Employees expressing the desire to test were given a voucher for a free HIV test at any one of the free-standing sites. Acceptance of VCT in the on-site testing arm was significantly more than that in the off-site testing arm, 51.1% and 4.3% respectively.

A study to determine the acceptability levels of VCT in a rural village in Kagera, Tanzania by Killewo et al (1998) found that 54% (245/450) of the population that had been informed about the programme responded to the invitation to be tested and 55.9% of these agreed to be tested. Kipp, Kabagambe and Konde-Lule (2002) in Kigoyera, Uganda found an acceptance level of 74% among people above the age of 15 years.


2.5.4 Effectiveness
The effectiveness of VCT in reducing risky sexual behaviour has always been a contentious issue particularly its usefulness as a primary prevention strategy (Arthur et al., 2007, Holtgrave and McGuire, 2007). The gold standard for determining efficacy would be randomised controlled trials with objectively measurable end points such as HIV incidence. Part of the difficulty in proving conclusively that VCT is an effective preventive strategy
is the inherent difficulties and cost of conducting such trials (Watts et al., Unpublished, Catania et al., 1990a). Such a trial would require a prohibitively large sample size (Glick, 2005). In addition, since project RESPECT established C&T as the standard of care any randomised trial that would be testing for HIV would be ethically bound to provision of C&T as the minimum (Holtgrave and McGuire, 2007). However, numerous studies have been conducted using proxy measures of HIV transmission and they provide some insight into the probable effectiveness of VCT. Most of the studies that have been done are before and after studies using self-reported measures of sexual behaviour change (Glick, 2005, Solomon et al., 2004).

A review of the available literature shows inconsistency in the effectiveness of VCT in producing the anticipated change in sexual behaviour. While the literature is quite consistent in showing that VCT is effective in achieving sexual behaviour change in those testing positive and discordant couples there is inconsistency in showing a positive impact in those testing negative with some studies showing an increase in risky behaviour in this group. This has been the picture from very early on in the epidemic when the availability of the HIV test made it possible to conduct studies evaluating the effect of status on behaviour. In a review of studies investigating “the behavioural and psychological response to HIV antibody testing” Jacobsen, Perry and Hirsch (1990) concluded that “results do suggest that notification of negative results has weaker effects on risk behaviour change than notification of positive results”. They suggested that an HIV negative result may either reduce or reinforce the perceived threat of HIV.

A number of systematic reviews have been conducted in an attempt to generate conclusive evidence of the impact of VCT on HIV risk behaviour.
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Higgins et al (1991) conducted a systematic review of journal articles, abstracts and oral presentations from the second through to the sixth International Conferences on AIDS and other reports from January 1986 to July 1990. The 50 studies they reviewed included 17 on homosexual and/or bisexual men, 12 on intravenous (IV) drug users, 11 on pregnant women and 10 on other high risk heterosexuals. They found that some studies showed that behaviour change among homosexuals was independent of C&T testing while others showed a positive impact of C&T on risk behaviour in those testing positive. Eleven of the 12 studies on IV drug users recruited some or all their participants from methadone treatment programs, therefore, it was difficult to separate the effects of the treatment programme from the effects of C&T. Nevertheless, there were no significant differences in high risk behaviour among sero-positive, sero-negative and untested persons. The findings in pregnant women were similar with no significant differences in pregnancy decisions by sero-negative and sero-positive women. Studies of discordant couples had found significant reductions in unprotected sex and so had two studies among prostitutes and women drawn from areas of known prostitution and drug use. Due to variations in study location, intervention type, outcome measures and risk factors the authors found it difficult to generalise findings from the heterosexual group. In their conclusion the authors gave various reasons why it may have been difficult to draw any firm conclusions from the studies reviewed. To begin with, in the majority of these studies data were not collected with the aim of evaluating the impact of C&T on risk behaviour, therefore, research design, outcome measures and analyses did not provide them with the appropriate information to answer their research question. In addition, deficiencies in methodological design and study description, and variations in type of C&T...
interventions combined to make comparisons and interpretation of findings difficult. Another problem was that of possible confounding. All the studies relied on voluntary testing, therefore, the association between C&T and risk reduction may have been due to factors associated with the decision to test and to return for results rather than with the C&T. The authors concluded that there was insufficient evidence to determine the impact of C&T on behaviour.

In a follow-up review by Wolistki et al (1997) covering studies done from 1990 to 1996 the findings were not that different. The findings of the 35 identified studies were divided into four sections according to study population: (i) men who have sex with men (7), (ii) injecting drug users and other drug users (9), (iii) women and heterosexual couples (12), and (iv) mixed populations (7). The studies utilised various formats of C&T. The findings from this review were similar to the Higgins et al review in that the studies reviewed provided mixed results. The review found no evidence of positive impact of HIV C&T on risk behaviours in MSM and drug users but found some evidence for beneficial effects for heterosexual discordant couples and people testing positive. A number of the studies included in the review had substantial methodological limitations and as in the earlier review most of the studies were not designed specifically to assess the impact of HIV C&T on risk behaviours making interpretation of the results difficult. The authors acknowledged that the varying formats of HIV C&T used in these studies may have influenced the findings. Most of these studies were conducted before the CDC published guidelines on client-centred counselling (CDC, 1993) and so were probably employing the information-oriented counselling approach.
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Weinhardt et al (1999) conducted a rigorous meta-analysis on studies on the effects of HIV C&T on sexual risk behaviour between 1985 and 1997. Because their aim was to do a meta-analysis they employed a more stringent inclusion criteria including, among other criteria, only those studies that provided information on the time interval between C&T and behaviour assessment; were longitudinal, assessing the same participant on two or more occasions; and had summary or inferential statistics that would allow for the calculation of within-group effect sizes. This is in contrast to the Higgins et al (1991) and the Wolitski et al (1997) reviews which included studies that did not provide information on the interval between C&T and behaviour assessment, and cross-sectional studies. In addition, the latter were purely narrative reviews and did not conduct a meta-analysis.

Weinhardt et al’s review (1999) included 27 studies: nineteen (70%) of the studies were conducted in North America, 6 (22%) in Africa and 2 (8%) in Europe. Overall, this meta-analytic review found that VCT appeared to be effective in HIV-positive participants and HIV-sero-discordant couples who increased their use of condoms and reduced frequency of unprotected sex, relative to HIV-negative and untested participants. The authors concluded that HIV-Counselling and testing does not appear to be an effective primary prevention strategy. This meta-analysis was not specifically evaluating the “CDC’s client-centred HIV prevention counselling model” (Weinhardt et al., 2000) and most of the studies that were reviewed had little or no details on the counselling procedures followed.

Denison et al (2008) conducted a meta-analysis of studies addressing the effectiveness of HIV VCT in reducing HIV risk behaviours focussing on developing countries. Since VCT provision in resource-constrained countries
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differs from that in developed countries and because earlier systematic reviews included only a few studies from developing countries—either because none were available or they did not meet the inclusion criteria—it was felt that conducting a review specifically focussing on the effectiveness of VCT in reducing HIV risk behaviour in developing countries was justified.

Inclusion criteria included evaluation of a VCT intervention that conformed to the CDC/UNAIDS guidelines, pre- and post-VCT assessment of, or comparison of persons who received VCT to those who did not and measurement of HIV related outcomes. The review included studies published between January 1990 and April 2005. Seven studies met the inclusion criteria, three in Africa, three in Asia and one with study sites in both Africa and the Caribbean. Most of the studies assessed VCT effectiveness on clients presenting to free-standing VCT centres or offered VCT through community-based approaches. The rest of the studies evaluated VCT effectiveness in women attending antenatal care, paediatric, obstetric or family planning clinics. The study rigor scores ranged from 1 to 6 out of a possible 8 points, with points increasing with increasing rigor. Four had a score of 2, with 1 each scoring 1, 3, 5 and 6. Only one study randomly assigned participants to the intervention, only one selected participants for assessment randomly, in only one were the comparison groups equivalent at baseline on outcome measures, two had a follow-up rate of 80% or more and two had comparison groups that were equivalent on socio-demographics. Like the other reviews this one also found that VCT appeared to be more effective in those testing positive and in sero-discordant couples. In two studies that had stratified measures of unprotected sex, the authors averaged the effect sizes across the various measures resulting in loss of noted positive effects of VCT on the risk behaviour in a particular stratum. This, the authors
admit, had the disadvantage of hiding important differences in effects among sub-groups. Another limitation was the lack of rigor in the studies reviewed and the short follow-up duration; none of the studies assessed outcome beyond 1 year after baseline.


Some studies have found an increase in risky behaviour in individuals testing HIV-negative, more so in those who repeatedly re-test (Fernyak et al., 2002, Solomon et al., 1996, Sherr et al., 2007, Matovu et al., 2007, Minga et al., 2005).

Project Respect (Kamb et al., 1998), a study commissioned by the US Centers for Disease Control and Prevention (CDC) to specifically assess the effects of interactive client-centred counselling compared to didactic prevention messages, found that a brief two-session interactive counselling intervention was effective in increasing condom use and preventing new STDs among HIV-negative individuals. However, this study also found that the relative effectiveness of counselling in preventing STDs was less among those reporting a previous HIV test i.e. repeat testers.

The strongest evidence in support of VCT as a prevention strategy comes from the Kamb et al study (1998) and a multi-centre randomised trial conducted in three developing countries; Kenya, Tanzania and Trinidad (The Voluntary HIV-1 Counselling and Testing Efficacy Study Group, 2000).
Participants were actively recruited to the multi-centre study. Before randomisation, a standard questionnaire was administered to collect baseline information on HIV risk behaviour in the preceding two months. Randomisation was by allocation of sealed envelopes to either VCT or health information. The health information group watched a short video then had a discussion about HIV transmission and condoms facilitated by a health-information officer. The VCT arm received the CDC recommended C&T and a condom demonstration. All participants were provided with condoms and a brochure about correct condom use. Tested participants were asked to return for their results two weeks later. Follow-up interviews were conducted at six months and twelve months post intervention. Both interviews were similar in format to the baseline interview. At the first follow-up interview cervical swab, vaginal fluid and urine specimens were collected for STD screening. Participants in the control arm were offered VCT at the first follow-up interview. This study recorded sustained reduction in risk behaviour in those testing positive as well as in those testing negative although men testing positive were more likely to report less unprotected sex than men testing negative.

Most of the studies discussed in this review need to be interpreted with caution due to the single-group pre- and post-test study designs that most employed. This design increases the threat to the study’s internal validity as changes in behaviour may be due to events external to the intervention or change due to passage of time (Glick, 2005). The exceptions are the multi-site Voluntary HIV-1 Counselling and Testing Efficacy Group Study (2000) and the CDC study (Kamb et al., 1998) which evaluated VCT effectiveness using randomized controlled trials.
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In contrast to the studies showing minimal benefit from VCT for those testing negative, Solomon et al. (2006), Gresenguet et al. (2002), Bentley et al. (1998) and Muller et al. (1992), found that behaviour changed in HIV-negative individuals post-testing. However, methodological limitations such as high attrition rates, non-comparable groups and modified VCT interventions may once again be responsible for a proportion of these findings.

Solomon et al (2006) used an enhanced risk reduction counselling format and deliberately targeted a high-risk population. Heterosexual participants were recruited from a STD clinic and a VCT centre in Chennai; an urban area in India. An individual was considered high risk and therefore eligible if they satisfied any one of the following criteria during the six months prior to enrolment: (1) had five or more different sexual partners; (2) diagnosed or treated for a sexually transmitted infection (STI); or (3) having had sexual intercourse once a week with an HIV-infected partner. Participants were seen at six and twelve months post enrolment. Individualised peer counselling and repeat testing were provided at the two follow-up visits. Greater reductions in risk were observed among participants in the highest risk categories.

The Gresenguet et al (2002) study, conducted in Bangui, Central African Republic, found a significant reduction in unprotected sex in both men and women, 40% and 47% reduction respectively. However, the attrition rate in this study was high: 79% (3249/4134) at second follow up, and 91% (802/881) at third follow up visit.
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In a study recruiting heterosexual men at two STD clinics in Pune, India, Bentley et al (1998) evaluated the effectiveness of an initial VCT session followed by HIV prevention counselling sessions every three months over a twenty-four month period. There was a significant increase in condom use with commercial sex workers (CSWs). An interesting finding from this study was a concomitant increase in visits to CSWs over the course of the study. The men exhibiting this behaviour were less educated, single or living away from home, had a history of STD and were less knowledgeable about HIV/AIDS. The authors speculated that some of these men may have developed a false sense of security after repeatedly testing negative. This study suffered from a low recruitment rate of 30% (1628) and the participants differed from non-participants in that they were younger, more knowledgeable about HIV/AIDS, were more likely to have used a condom in the preceding three months and less likely to have a genital ulcer disease.

Muller et al (1992), in Uganda, assessed HIV risk behaviour in clients returning for HIV C&T six months after their initial negative test. They found “a remarkably low level of risk behaviour” in this group of individuals. They compared this group to a group interviewed before testing although they do not provide information on the comparability of the two groups in terms of socio-demographic characteristics and risk profile.

Generally, the literature appears to suggest that VCT in its present format (CDC, 2001) is more effective in reducing risk behaviours in HIV positive individuals than in those testing negative (Glick, 2005, Merson, Dayton and O'Reilly, 2000, Weinhardt et al., 1999, Wolitski et al., 1997). This is an indication that there may be some shortcomings in the delivery of VCT services for the HIV negative person (Corbett et al., 2007, Fernyak et al., 2002,
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Leaity et al., 2000). In order to identify and address these shortcomings, it is essential to understand how counselling and the negative result influence behaviour in people presenting for VCT (Corbett et al., 2007, Sherr et al., 2007).

Inconsistency in research findings on the effectiveness of VCT in achieving behaviour change for people testing negative may also be due to the comparison of studies evaluating different types of VCT — most studies do not provide a full description of the VCT under evaluation (see Denison et al., 2008, Glick, 2005, Solomon et al., 2004, Weinhardt et al., 1999). Weinhardt et al have suggested that VCT may be effective in particular circumstances and for certain types of people (1999).

By conducting investigations to understand how an intervention works the causal mechanism becomes clearer aiding the development of more effective interventions (Medical Research Council, 2008).

2.6 Conclusion

Behavioural change interventions premised on theory have been found to achieve better results than those that are not theory driven. Therefore, there is need to first understand the determinants of a targeted behaviour and the underlying process or processes of change in order to apply the appropriate theoretical framework in the design of an intervention. The theoretical processes underlying HIV risk behaviour change are not well understood. Although currently available behaviour change theories provide useful insight for the development of behaviour change interventions, they do not adequately explicate the underlying theoretical processes.
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Health education has been used extensively to raise public awareness about HIV transmission and prevention and thereby influence behaviour. Although this strategy has been largely effective in raising awareness, the effect on behaviour has been disappointing in most countries with the notable exception of Uganda. In Zambia, health education has been credited with achieving some measure of behaviour change but this has not been of sufficient magnitude to impact notably on the national HIV prevalence.

Counselling or information giving before testing for HIV was necessitated by the terminal nature of the disease and its potential for adverse psychological reactions. Counselling and testing efforts have concentrated on detection of infected people so as to limit transmission of the virus. In an attempt to detect as many infected people as possible, counselling and testing has been extended to all within the sexually active age group attending a health care facility (in the USA and in countries with generalised epidemics). This shift from specific high risk groups increased the possibility of contact with an increasing number of HIV-negative people and the necessity of providing counselling that would encourage them to adopt safer behaviours. The current client-centred counselling model, which includes the negotiation of a personalised risk-reduction plan with each client, was introduced in 1994.

Studies assessing the effectiveness of VCT in reducing unsafe sexual behaviour have produced conflicting results especially for those testing negative. This has been attributed to the poor research designs utilised by these studies and the fact that these studies have evaluated different models of VCT making it difficult to draw any definitive conclusions from their findings.
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The finding that VCT appears to be effective in changing behaviour in some groups such as those testing positive and sero-discordant couples and not in those testing negative suggests shortcomings in the delivery of VCT for those testing negative.
## 3 Systematic literature review

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Chapter 3 – Systematic literature review

3.1 Introduction
Section 2.5.4, outlines the controversy surrounding the effectiveness of HIV voluntary counselling and testing (VCT) particularly in people testing HIV-negative and concluded that the mechanism by which VCT exerts its influence in HIV-negative people is not well understood. A systematic search of the literature was therefore conducted with the aim of identifying studies that have assessed the process by which an HIV-negative result—given in the context of VCT—influences sexual behaviour. Such studies would provide illumination on the nature of the relationship between VCT, an HIV negative test result and behaviour change.

3.2 Search Strategy
A search strategy was drawn up to answer the question:

How does the process of VCT, and receipt of an HIV negative result influence behaviour change in heterosexual individuals?

The following electronic databases were searched: Medline; PsycINFO; CINAHL; Embase; Global Health; Web of Science (WoS), including Conference proceedings; International Bibliography of Social Science (IBSS); Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects (DARE) and Cochrane Central Register of Controlled Trials; and the World Health Organisation Library and Information Networks for Knowledge Database (WHOLIS).

Effort was made to seek out relevant grey literature through relevant websites such as UNAIDS, Centers for Disease Control, Family Health International (FHI), AIDS Alliance, UNZA bibliography and digital
dissertations database. Authors of possibly relevant papers presented at conferences were contacted for the full paper and requested for any information on any other similar studies that they might be aware of. Contact was also made with AIDSAlliance, a charitable organisation active in HIV/AIDS prevention and research in developing countries.

Search terms used included “HIV counselling and testing”, “HIV voluntary counselling and testing”, “Behaviour change”, “safe sex”, “sexual behaviour” and “risk behaviour”. “HIV seronegative” or “HIV negative” was initially included in the search but was dropped in order to widen the search so as to be able to capture as many papers as possible. Search terms were used in various combinations to search the databases (see appendix 1 for search strategies).

The literature search originally spanned from 1996—the year when HAART became available—to June 2009. The rationale behind this was that from 1996 to date VCT has been provided in the context of availability of ARVs. This may confound the interaction between VCT, receipt of a negative HIV test result and behaviour. Therefore, studies conducted in this period would provide a more pertinent explanation of how VCT is influencing current sexual behaviour. However, due to the small number of papers that were retrieved it was decided that an extension of the period to 1994 might provide more studies that would still be able to shed light on the mechanism through which HIV VCT influences behaviour in the presence of a negative test result. Studies done from 1994 would still provide relevant information because that is the year in which the current client-centred VCT format was introduced.
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Papers retrieved using the above search terms and databases were exported or imported into the bibliographic management software EndNote 9. Relevant papers were selected using the following pre-defined inclusion and exclusion criteria:

**Inclusion Criteria**
- Longitudinal studies with pre- and post-test measurement of outcome variables
- Studies involving individuals above 15 years of age
- Studies assessing how VCT influences behaviour in those testing HIV negative
- Studies done between January 1994 and June 2009

**Exclusion Criteria:**
- Studies that focussed on men who have sex with men (MSM) and drug users
- Studies focusing on discordant couples only
- Studies focussed on pregnant women
- Studies focussed on adolescents less than 15 years of age

In the interest of clarity and focus it was felt that studies focussing on the specific groups detailed in the exclusion criteria may not be so useful for the current study because “patterns and determinants of behaviour vary considerably” in different groups (UNAIDS, 2001b).

Ogden (2007: p186), attributes the inconsistency in results of studies investigating the utility of different behaviour change models in predicting condom use behaviour, to the fact that the studies used different study populations, “homosexual, heterosexual, adolescents, adults”. She goes on to
suggest that group-specific models of condom use should be developed for the different populations taking into account the different cognitions of individuals within each group.

Initial screening of the retrieved literature was by title and abstract, studies not related to the subject under study were excluded. Full texts of potentially relevant papers were retrieved and the reference lists and citing articles of these were scrutinised for any relevant papers whose reference lists were also examined.

The retrieved papers were then read to ensure they fulfilled the inclusion and exclusion criteria. Selected papers were assessed for quality using a pre-designed quality assessment form (appendix 2). The systematic review paper was critically appraised using the Critical Appraisal Skills Programme (CASP) appraisal tool for systematic reviews (CASP, 2006). Issues relating to study design, internal and external validity, analysis and usefulness were assessed. Data were extracted using a pre-designed data extraction form (appendix 3). Data extracted included identifying features of the study, study design and characteristics such as study and target populations, intervention characteristics and outcome measures and analysis. The extracted data were analysed descriptively and compared across studies and are presented in a narrative summary.

### 3.2.1 Results

A total of 1,525 abstracts and one full text unpublished paper were retrieved by the searches. Initial screening resulted in thirty-one possibly useful papers. The full texts of these papers were retrieved and read. The references of these papers, both cited and citing, yielded a further three papers resulting
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in a total of thirty-five full text papers. Thirty-one of these thirty-five papers did not satisfy one or more inclusion criteria and were excluded, resulting in a final sample of four papers.

Four additional papers that did not satisfy the inclusion criteria but had information that was relevant to the question and therefore considered useful in answering it were also retained.

The primary reason for exclusion of most studies was non-identification of VCT factors that may be responsible for mediating behaviour change. Details of the excluded studies and reasons for exclusion are provided in appendix 4.
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Fig 3.1 provides a diagrammatic representation of the review process.

Figure 3.1: Flow diagram of review process

Source: Adapted from Moher et al, 1999

The four studies retained for detailed analysis were conducted between 1996 and 2007; two were quantitative, before and after studies from the USA (Amaro et al., 2005, Wilson et al., 1996), one was a qualitative serial interview.
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study from the UK (Coyle, Knapp and O'Dea, 1996) and one, a systematic review covering studies from various countries (Earl and Albarracin, 2007). The systematic review included studies from 1985 to 2005 which meant that it contained studies that were not included in this review. Being a systematic review it was not possible to separate out the results from the studies that were outside the scope of the current review. This review did not include the studies by Amaro et al, Wilson et al and Coyle, Knapp and O'Dea. This may have been due to the fact that the Amaro et al and Wilson et al studies did not conduct more than one post intervention follow-up assessment which was one of their inclusion criteria and the Coyle, Knapp and O'Dea study did not focus on the counselling process which was the review’s area of interest.

An additional four studies that did not meet the inclusion criteria but nevertheless could provide some information on how voluntary counselling and testing may be exerting its influence on sexual behaviour were retained. These were not part of the narrative analysis but provided additional information.

Study participants and inclusion criteria

The table below summarises participation rates, participant characteristics, and inclusion/exclusion criteria per study:
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Table 3.1: Systematic review study characteristics

<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>No. of participants</td>
<td>73% 939</td>
<td>72% 1 036</td>
<td>Not available</td>
<td>76 papers (184 statistically independent groups)</td>
</tr>
<tr>
<td>Dropout rate</td>
<td>28% 22%</td>
<td>22% 29%</td>
<td>Not available</td>
<td>I.G.* C.G* &gt;104 054 &gt;34 751 Exact figures for this review not available</td>
</tr>
<tr>
<td>Age range (years)</td>
<td>≥18 18 – 45</td>
<td>18 – 56</td>
<td>Not available</td>
<td>Not available</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td>46% White 24% Black 23% Hispanic 7% Other</td>
<td>89% Black</td>
<td>Not available</td>
<td>Not available</td>
</tr>
<tr>
<td>Sex</td>
<td>Male &amp; Female</td>
<td>Female</td>
<td>Male &amp; Female</td>
<td>Male &amp; Female</td>
</tr>
<tr>
<td>Sexual orientation</td>
<td>Mostly heterosexual Small number of MSM* excluded</td>
<td>Heterosexual</td>
<td>Heterosexual MSM Bisexual</td>
<td>Heterosexual MSM Lesbian</td>
</tr>
<tr>
<td>Inclusion criteria</td>
<td>English or Spanish speaking Able to give informed consent ≥ 18 years of age</td>
<td>Sexually active Heterosexual Living in the New York City area Between 18 and 45 years of age</td>
<td>Not available</td>
<td>Description of outcomes of a standard intervention to promote condom use Pre-test assessments More than one post-test assessment Appropriate statistics to calculate standardised effect sizes</td>
</tr>
<tr>
<td>Exclusion criteria</td>
<td>Not available</td>
<td>Pregnancy</td>
<td>Not available</td>
<td>Interventions not including a condom use component Outcomes reported for a single post-test Inappropriate statistics</td>
</tr>
</tbody>
</table>

*MSM = men who have sex with men, I.G. = Intervention Groups, C.G. = Control Groups
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Interventions and study outcome measures

The Counselling and Testing (C&T) format used in all the studies was the standard CDC/UNAIDS client-centred recommended format (CDC, 2001, UNAIDS, 2000b).

Amaro et al (2005) claimed that previous studies may not have found any significant impact of counselling and testing on sexual behaviour because they may have been measuring expected final outcomes and not intermediate changes. Amaro et al therefore set out to “capture more subtle change” following C&T by examining stages of change for safer sexual behaviour. They enrolled 939 consenting women and men presenting for HIV C&T at randomly selected publicly funded C&T sites in Massachusetts, U.S.A. Participants completed either a self-administered or administered questionnaire at baseline, before C&T, and three months post testing. Of the 672 that completed the post-test questionnaire 560 reported heterosexual behaviour. Due to the small number reporting homosexual behaviour, the study focussed on heterosexual behaviour. Stage of change for condom use was assessed according to an algorithm applying the Transtheoretical Model. Socio-demographic, behavioural and C&T service-related factors thought to be associated with changes in stage of behaviour were also collected. The collected data were then statistically analysed.

Wilson et al (1996) — working from the premise that the level of self-perceived susceptibility to HIV infection determines the interaction between HIV counselling and testing, and behaviour — conducted a study assessing “the influence of perceived susceptibility on the relationship between testing and behaviour change”. Clients seeking services at three gynaecology and family planning clinics in Brooklyn, New York, were approached and invited
to take part in the study. Prior to being tested for STDs and before being offered C&T, participants completed a self-administered questionnaire, assessing their beliefs related to HIV and STD susceptibility and self-administered measures relating to condom use and sexual partners. Participants completed a similar self-administered questionnaire at the second session, four months after receiving their STD and/or HIV test results and counselling.

Coyle, Knapp and O’Dea (1996) set out to investigate the complexities of HIV test decision making at various points in the testing trajectory. They also investigated the role of counselling in decision making around post-test risk reduction. They recruited 55 people who had tested for HIV in a UK National Health Service Trust area. Two semi-structured in-depth interviews were conducted; the first immediately following receipt of test result and post-test counselling, and the second a month later. Participants were asked about their reasons for seeking HIV testing and factors that influenced the decision, the role of pre-test counselling in their decision to test and factors that had influenced their decisions about post-test risk behaviour change. Behaviour change was assessed by asking participants about the number of times they had engaged in unprotected penetrative sex in the one month prior to testing and their intentions. The same question was asked in the follow-up interview and participants were also asked about what they thought were the reasons for their failure or success in implementing their desired changes in behaviour.

The aim of the Earl & Albarracin (2007) review was to evaluate the immediate and long term effects of fear-inducing arguments and HIV counselling and testing in improving knowledge on HIV transmission and
prevention, condom use, and self-perceived risk of contracting HIV. The magnitude of effects were calculated to represent change from the pre-test to the first post-test. This was done to assess immediate effects and from the pre-test to the second post-test for long term effects. ‘Long term’ in this review was simply defined as more than one post-test assessment.

Methodological Quality

All four studies had clear articulated aim(s), intervention, method and outcome measures, although the Coyle, Knapp and O’Dea study did not provide details about participant recruitment. Confounding variables were taken into account and appropriate statistical tests were applied in the analysis.

As mentioned earlier the before and after designs used in the Amaro et al (2005) and Wilson et al (1996) studies are prone to threats to internal validity such as maturation of the study participants and effects of other events in the participant’s environment (Glick, 2005). The use of self-reported past sexual behaviour in the Amaro et al, Wilson et al and Coyle, Knapp and O’Dea studies poses an additional threat to internal validity. Apart from recall bias the sensitive nature of the topic predisposes to the provision of socially desirable responses (Catania et al., 1990a, Catania et al., 1990b, Meston et al., 1998). The absence of a control group in the Amaro et al study makes it difficult to ascribe observed changes to the intervention. These three studies do not describe how the participants were selected as they attended the health facilities; they do not say whether all attendees were approached or not. This is a potential source of selection bias. The Wilson et al study does not give characteristics of the testers vs. the non-testers making it difficult to compare findings in the two groups. Likewise the Amaro et al study does not
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describe the individuals that refused to participate compromising any inferences to a population beyond those in the study. This is also the case in the Coyle, Knapp and O’Dea study. In addition, this study does not provide information on how many people refused to participate. The Wilson et al study also has limited external validity because it included only women of a lower socio-economic status and a particular racial group. The Amaro et al study has a similar limitation due to the difference in gender, ethnicity and education of the drop-out group when compared to the group that remained in the study.

The systematic review by Earl & Albarracin was quite robust and covered studies done between 1985 and January 2005. The authors conducted an electronic search of relevant databases, hand searched relevant journals and actively sought unpublished studies. Coding and rating were each done by two independent coders and raters and disagreements were resolved by discussion. Tests of homogeneity were conducted. A drawback with this paper is that the authors did not provide information on the characteristics of all the included studies. The review was based on studies retrieved for a previous systematic review conducted to answer a different question. The authors refer the reader to this earlier study for a detailed description but do not provide information on the additional studies included in the current review which was expanded to include an additional 16 months.

Findings

Amaro et al (2005) found that transition between the stages of change varied depending on stage of change before C&T and whether sex was with a main partner or a non-main partner. There was no significant progression or regression in the stage of change for condom use with main partners. The
authors noted a significant progression in stage of change for condom use with non-main partner but admitted that this was largely due to more people abstaining from sex with non-main partners post-test. They concluded that C&T had very little effect on intention to adopt safer behaviour. They stated that even though information given during counselling helped participants maintain intentions to change, C&T was not effective in moving people on to adoption and maintenance of safer behaviour. They suggested that C&T is just one among a complex mix of interacting factors such as, personal characteristics, HIV status, HIV risk history and stage of change influencing risk behaviour and change. The authors questioned whether HIV C&T might be more effectively utilised for the identification and onward referral of clients to programmes specifically designed for the various needs of different groups of HIV-negative people (according to stage of change at pre-test).

Wilson et al (1996) found that behaviour change appeared to be linked to perceptions of susceptibility to STDs rather than to HIV. The higher the perceived susceptibility to STDs the more likely that safer sex practices would be adopted. The authors considered this may be explained by the fact that there is more clarity around the modes of transmission of STDs and risk groups whereas there were more misconceptions around HIV transmission and risk groups. They also found that in women with low levels of susceptibility to STDs, receipt of a negative HIV test result coupled with a negative STD result served to reinforce current sex practices. They suggested that HIV counselling and testing might be more effective if it focussed more on increasing self-perception of risk in individuals.

The Coyle, Knapp and O’Dea (1996) study found that in the majority of participants (51/55) pre-test counselling had no influence on the decision to
test. The decision was made before attending for counselling and testing. Pre-test counselling served to confirm and support the decision. Counselling and testing had supported change in risk behaviour by increasing knowledge around HIV transmission and increasing awareness about personal risk. Behaviour change was also encouraged by the desire not to endure the anxiety of testing again.

The meta-analysis by Earl & Albarracín (2007) found that counselling and testing resulted in reduced self perception of risk but increased condom use over time. Interventions utilising fear-inducing arguments were found to result in initial increased perception of risk and modest increases in knowledge and condom use. However, both perception of risk and condom use declined over time. The authors argue that the receipt of a negative result without the use of fear-inducing arguments leads to reduced anxiety facilitating learning, retention and behaviour change.

**Studies retained for additional information**

St Lawrence et al (1998) conducted a cross-sectional study in the south-eastern United States comparing women who had undergone HIV counselling and testing to those who had not. They recruited their sample of 460 women from health clinics and community-based settings. Their aim, among others, was to determine whether counselling and testing had had any influence on attitudes relevant to HIV risk reduction and self reported sexual behaviour. Individuals who had been counselled and tested rated HIV disease as more serious, had greater intentions of using condoms, were more positively inclined towards AIDS prevention and showed “greater commitment to self-protective behaviour change”. However, even with these positive differences in attitude and intention, there was no corresponding
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difference noted in risky sexual behaviour between tested and untested women. The cross-sectional nature of the study makes it difficult to draw any conclusions about temporal relationships between findings and the experience of counselling and testing. As noted by the authors, it was not possible to assess the behaviour of the tested women before testing; they may have had higher levels of risk prior to testing which they had since reduced. In addition it was not possible to determine if the positive attitudes were present prior to the counselling and testing or they were a result of the counselling and testing.

Ickovics et al conducted two studies assessing behavioural and psychological consequences of HIV C&T at two different time periods (Ickovics et al., 1998, Ickovics et al., 1994). These studies were conducted between 1991 and 1992 (Turner, 1994) when counselling and testing centres were still using the didactic counselling format. Recruitment took place at four urban community-based health clinics in Connecticut. The tested group comprised women voluntarily seeking HIV C&T and women using other clinic services and had never been tested, provided the comparison group. Each participant completed an administered questionnaire after the clinic appointment, two weeks later (after post-test counselling for tested participants) and at three, twelve and eighteen months post-HIV C&T. The first study reported findings at the three month assessment and the second reported findings over the eighteen month period. Women who tested HIV-positive were excluded from the longitudinal analysis because of expected differences in “psychological and behavioural consequences” of learning that one is HIV-positive compared to learning that one is HIV-negative. The study found that at baseline and post-test counselling, tested women had more unwanted thoughts about HIV than untested women and they also had
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higher self-perceived susceptibility of contracting HIV. There was no difference in sexual risk behaviour between the tested and untested group. A significant decrease in sexual risk behaviour was observed between the baseline and second interview in both groups. However, this was followed by a significant increase from the second to the third interview and by the final interview both groups had returned to their baseline levels of sexual risk. By the second interview both tested and untested women reported significant reduction in the levels of self-perceived risk. By the third month tested women were experiencing less unwanted thoughts about AIDS. The authors ascribe this to reduced “AIDS-specific” anxiety due to receipt of a negative result. In the earlier study, using a composite measure of sexual risks which included intercourse, condom use and partner risk factors, it was determined that tested women were safer throughout the study than untested women. This led the authors to suspect that women presenting for counselling and testing may have already reduced their sexual risks prior to testing. They concluded that HIV C&T as it was currently practised then was not an effective primary prevention strategy and suggested that its effectiveness might be improved by changing the counselling strategy e.g. multiple sessions with a sexual partner and group counselling.

The Ryder et al study (2005) was nested within a larger cohort study of documented seroconvertors and HIV-negative controls in the Province of Ontario. The aim of the study was to try and understand how repeat negative testing is perceived by recipients. A purposive sample of 64 individuals, recruited mainly through a provincial database, took part in a face-to-face semi-structured interview. The narrative analysis approach was used to identify the participants’ thoughts and actions in relation to their experiences of repeat HIV negative testing and how they socially constructed
and behaviourally managed these experiences. The timing of the interviews may have had an impact on the findings considering that the interviews were at variable times after the first and subsequent HIV negative tests. Therefore, the responses may have been influenced by factors that were not related to the test. Repeated negative testing led to perceptions of safety in monogamy and immunity to HIV. For others a negative test reaffirmed the “low risk” nature of their current sexual activities, whether or not they practiced safer sex.

3.2.2 Discussion

This systematic review has limitations. Firstly, some studies may have been missed because hand searching of relevant journals was not done due to time constraints. Secondly, this being a review toward a PhD, the selection and review processes were of necessity conducted by the same person. However, it is felt that the probability of missing a relevant study is low as there is continued reference to a lack of knowledge on the question addressed by this review in a number of recent studies on VCT and behaviour change (Corbett et al, 2007, Sherr et al 2007, Matovu et al., 2007, Metcalf et al., 2005, Weinhardt et al., 1999, Wolitski et al., 1997).

There appears to be a paucity of studies investigating the relationship between VCT, receipt of a negative test result and sexual behaviour change in heterosexual individuals (as defined in this review) with the aim of delineating the active ingredients. The number of relevant studies retrieved from the systematic literature search is inadequate. Therefore, no definitive conclusions can be made in response to the study question. However, keeping in mind the caveats outlined for each study, the findings seem to suggest that counselling and a negative test result appear to reduce an
individual’s anxiety about HIV and increase knowledge about HIV. Findings on the influence of counselling and testing on perceived susceptibility to HIV infection and its influence on subsequent behaviour change appear to be inconsistent.

3.3 Conclusion

An important tentative conclusion that can be drawn, with caution, from this literature review is that one of the contributions of VCT is its capacity to reduce anxiety levels about HIV infection and hence self-perceived susceptibility.

Determining the influence of VCT in combination with an HIV-negative test result on behaviour change is a difficult task as evidenced by the variety of approaches and foci taken by the studies in this review.

The ambiguity in the literature as to the effectiveness of VCT is an indication that this interaction is not a linear one but a complex one that may vary in different cultures, social circumstances, gender and age groups (Beardsell and Coyle, 1996).

Further studies are needed to elucidate the factors influencing behaviour change in the counselled HIV-negative person (Wilson et al., 1996, Corbett et al., 2007, Sherr et al., 2007).

A purely quantitative approach to understanding the influence of VCT and a negative HIV test result on an individual’s behaviour precludes the discovery of factors not already identified by the investigators. These unidentified factors may actually be at play either on their own or interacting with the known factors, as suggested by Amaro et al (2005). Only one,
(Coyle, Knapp and O’Dea, 1996), of the eight studies discussed in the current review collected data on individuals’ perceptions of how C&T may have impacted their behaviour. Such studies can potentially provide additional insight into the interaction between VCT, receipt of a negative result and subsequent sexual behaviour (Pope and Mays, 1995, Power, 1998). Without asking the people themselves we can only infer from the pre-determined responses.

In addition, no study was found that has been conducted in the region most affected by the HIV epidemic and would therefore benefit the most from improved effectiveness of the prevention programmes that are being implemented. Therefore, further research, both qualitative and quantitative is required, especially in Africa, to shed further light on the interaction between voluntary counselling, a HIV negative test result and sexual behaviour (Pope and Mays, 1996, Mack et al., 2005). This would aid the development of a voluntary counselling and testing service that will impact more positively on the sexual behaviour of HIV negative individuals (O’Reilly, 1995).

The PhD Contribution
This PhD will attempt to: provide some depth to the understanding of how VCT mediates behaviour change in the context of a negative HIV test result; provide suggestions as to how the provision of VCT can be enhanced for the substantial group of those who will test negative; and contribute to knowledge on the subject in sub-Saharan Africa and the discussion on the utility of current behaviour change models (see section 2.2.2,) for HIV prevention and the VCT intervention conceptual framework presented in section 1.5, p18.
Chapter 4 - Study setting

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Chapter 4 - Study setting

4.1 Introduction
In this chapter a brief description and historical background of the country in general and HIV/AIDS activities in particular are provided. This will enable the reader to appreciate the findings and discussion in the broader context.

4.2 Country profile
4.2.1 Geography

Zambia is a landlocked country in central southern Africa (Map 4.1). It has an area of 752,618 sq km, about three times the size of the United Kingdom and shares borders with eight other countries.

Map 4.1: Location of Zambia

Source: http://kcm.co.kr/bethany/c_maps/zambia-1.gif. (07/05/2009)

Administratively Zambia is divided into nine Provinces (Map 4.2) and each province is divided into Districts. There are 72 Districts in total (Central Statistical Office et al., 2009).
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Map 4.2: Provinces of Zambia

![Map of Zambia showing provinces](http://www.zambiamining.co.zm/introductiontozambia.htm. (06/05/2009)

The capital city Lusaka is the largest city. The other major towns are Kitwe and Ndola in the Copperbelt province and the tourism capital, Livingstone, in Southern province. The Victoria Falls, a world heritage site discovered by Scottish explorer David Livingstone, is located in Livingstone.

4.2.2 History

Zambia was part of the British Empire from 1924 to 1964 when it gained its independence. The country adopted a multiparty system of government until 1972 when it became a one-party state. It returned to a multi-party democracy in 1991 (Central Statistical Office et al., 2009). The legal voting age is 18 and English is the official language (CIA, 2009).

4.2.3 Population

Zambia has a population of 12.5 million (projected from 2000 census) (Central Statistical Office) with an annual population growth rate of 2.4% and life expectancy of 48 and 52 years for males and females respectively (Central Statistical Office et al., 2009). The population is mostly young with
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45.1% aged 0 – 14 years and 52.6% 15 – 64 years. The literacy rate is 80.6% (CIA, 2009).

Mining and industrialisation, post-independence, led to the movement of people from rural areas to urban areas in search of employment. This has led to Zambia being among the most urbanised countries in Africa (ZNTB, 2009) with 35% of the total population living in urban areas and an urbanization rate of 2.3% per annum (CIA, 2009). The Copperbelt province is home to about one-fifth of the population. The largest concentration of people however is to be found in the capital city, Lusaka, which has more than two million people (ZNTB, 2009).

4.2.4 Economy

The country has a mixed economy with an urban modern sector and a rural agricultural sector (Central Statistical Office et al., 2009). However, mining is and always has been the backbone of the economy with copper being the main export accounting for 95% of export earnings (Central Statistical Office et al., 2009).

At independence Zambia had a vibrant economy. In the 1980s and 1990s the economy deteriorated due to the fall in copper prices. The country is now rated among the poorest in the world (The World Bank, 2009) with an unemployment rate of 14% (Central Statistical Office).

Zambia has a fairly extensive road network with roads in various states of repair. The major highways are generally tarred and in good condition. Because of its central location in Southern Africa, Zambia is at the crossroads of major transit corridors (The World Bank, 2009). Major highways cross the country running from Livingstone, on the border with Botswana to the
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south-west, to Kasumbalasa in the north, on the border with the Democratic Republic of the Congo, from Kapiri Mposhi in Central Province to Nakonde in the north-east, on the border with Tanzania and from Chirundu in the south, on the border with Zimbabwe, joining the highway from Livingstone in Kafue, just to the south of Lusaka.

This has contributed to high population mobility putting people at risk of HIV infection. Refugees, long distance truck drivers, migrant workers and cross-border traders are among the highly mobile populations. In addition the growth of the mining sector following privatisation of the mines in 2000 is expected to further increase population mobility (NAC/MOH, 2008).

4.2.5 Culture

There are more than 70 ethnic groups in Zambia each with their own language. However, most are small groupings with six major ones. The country is predominantly Christian with 50 – 75% professing to be Christians, Moslem/Hindu 24 – 49% and the remaining 1% practice indigenous religions (CIA, 2009).

The Zambian society is a male dominated one and the majority of the 70 ethnic groups are patriarchal, where the male is considered the head of the family. In the matriarchal groups it is the mother’s brother who yields the greatest authority over the children (Encarta).

Culturally women are taught and expected to be subservient to their husbands (NAC, 2006a, Family Health International, 1999) and a husband’s infidelity is tolerated as an accepted characteristic of men whereas a wife’s infidelity is totally unacceptable (Central Statistical Office, 2006, NAC, 2006a, van Amerongen, 2000). Likewise, it is acceptable for young men to “sow
their wild oats” (Ndubani and Hojer, 2001) but for a young woman sexual relationships outside marriage are frowned upon.

Most married women are housewives, do not have an independent source of income and do not own any land or property. They rely on their husbands to provide for them and the household. Like in most other Southern African countries, women are also taught, during initiation ceremonies and just before marriage, not to initiate sex or refuse their husbands sex, even if he refuses to use condoms. It is considered uncultured for a woman to do so (NAC, 2006a, UNAIDS, 1999a, Groenewold, Horstman and de Bruijn, 2004, Gupta, 2000).

4.2.6 Health services
Following independence, preventive and curative public health services were provided free to all residents. However, the decline of the economy in the 1980s meant this was unsustainable and 1992 saw the ushering in of health service reforms. These reforms included decentralisation of health care management to the district level and the introduction of cost sharing. The Zambian health policy states that ‘every able-bodied Zambian with an income should contribute to the cost of his or her health’. Vulnerable population groups such as children under five and adults over 65 are exempt and so is treatment for chronic health conditions, such as, tuberculosis, diabetes, HIV/AIDS and hypertension, and for diseases such as STDs, cholera and dysentery. Preventive health services such as safe motherhood and immunization are also exempt from the ‘user fees’ (Ministry of Health, Central Statistical Office and ORC Macro, 2006).
Chapter 4 - Study setting

Apart from the Government, Health services in Zambia are provided by churches (Mission) and the private sector, mainly mining and other industrial companies.

Organisation of health service delivery is based on the Zambia Basic Health Care Package and is delivered through a system comprising five levels of health care:

- **Third level hospital** (specialist or tertiary) are the highest referral hospitals offering services in internal medicine, surgery, paediatrics, obstetrics, gynaecology, intensive care, psychiatry, and also provide training and conduct research.
- **Second level hospital** (Provincial or General Hospital) - provide services in internal medicine, general surgery, paediatrics, obstetrics and gynaecology, dental, psychiatry and intensive care services. Also act as referral centres for the first level institutions and provide them with technical back up and training.
- **First level hospitals** (District Hospitals) - provide medical, surgical, obstetric and diagnostic services. Serve as referral centres for health centres.
- **Health centres** offer curative and preventive health services with diagnostic services being available in some of these facilities.
- **Health posts** are the lowest level of health care offering basic first aid rather than curative services.

Patients are first seen in health posts or health centres then referred on to the next level of care if necessary (Ministry of Health, 2008).
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In 2006, 95% (93% urban, 54.5% rural) of households had access to a health facility with 75.5% of these being within 5km radius of the facility (Central Statistical Office).

There are a total of 1,563 health facilities in Zambia broken down as shown in table 4.1.

Table 4.1: Health institutions in Zambia

<table>
<thead>
<tr>
<th>Facility Type</th>
<th>Number of Beds</th>
<th>Number of Cots</th>
<th>Number of Health Facilities by Ownership</th>
<th>Total no. of Facilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 3 Hosp</td>
<td>2,532</td>
<td>417</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Level 2 Hosp.</td>
<td>4,204</td>
<td>827</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>Level 1 Hosp.</td>
<td>6,016</td>
<td>859</td>
<td>39</td>
<td>4</td>
</tr>
<tr>
<td>Health Centres Rural HC</td>
<td>9,224</td>
<td>559</td>
<td>930</td>
<td>22</td>
</tr>
<tr>
<td>Urban HC</td>
<td>1,814</td>
<td>300</td>
<td>206</td>
<td>53</td>
</tr>
<tr>
<td>Heath Posts</td>
<td>198</td>
<td>11</td>
<td>161</td>
<td>8</td>
</tr>
<tr>
<td>Total (All)</td>
<td>23,988</td>
<td>2,973</td>
<td>1,354</td>
<td>92</td>
</tr>
</tbody>
</table>

Source: Ministry of Health, Health Institutions in Zambia, 2008

This translates to 12.9 facilities per 100,000 population.

However, a critical shortage of health workers in the country is impacting negatively on the HIV/AIDS programme and health service provision in general. Overall the Government has half of the workforce required with less than a third of the doctor-patient ratio recommended by WHO. This shortage is due to an exodus of health workers to greener pastures within the region and abroad. The shortage has also been exacerbated by an internal brain drain to better paying positions with non-governmental organisations (NGOs) and foreign aid agencies which have emerged following the injection of massive amounts of foreign aid for HIV/AIDS programmes by the international donor community (Schatz, 2008).
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Health services are also provided in the informal sector through Traditional Healers especially in rural areas. The Traditional Health Practitioner’s Association of Zambia, THAPAZ, with a membership of 50,000 is working with the MOH following a John Snow Inc. initiative (in collaboration with USAID Zambia), to provide appropriate preventive and referral services to the communities they serve (John Snow Inc., 2009).

4.3 Status of the HIV/AIDS epidemic

As stated in the introductory chapter, Zambia is at the epicentre of the HIV/AIDS epidemic. The country has not been spared from the ravages of the disease. Since the first case was identified in 1984 at the University Teaching Hospital in Lusaka (Bayley, 1984), AIDS has claimed the lives of thousands of productive adults leaving many youths and children orphaned, eroding gains in health, education and the economy, and completely changing the way of life (NAC, 2006a).

Findings from the 2007 Zambia Demographic and Health Survey (ZDHS) (Central Statistical Office et al., 2009) show a decrease in HIV prevalence from 15.6% in 2001 to 14.3%. Prevalence is twice as high in urban areas (20%) compared to rural areas (10%) and higher in women (16.1%) than men (12.3%). The prevalence of HIV increases with age from 5% at ages 15-19 to a peak of 24% at ages 35-39 years then falls in those aged above 39 years. Prevalence is higher in women at every age group except age 40 years and above. Prevalence peaks at a later age for men than women. Prevalence also varies by province with Lusaka having the highest prevalence as shown in table 4.2.
### Table 4.2: HIV prevalence rates per Province - 2007

<table>
<thead>
<tr>
<th>No</th>
<th>Province</th>
<th>Prevalence %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Lusaka</td>
<td>21</td>
</tr>
<tr>
<td>2.</td>
<td>Central</td>
<td>18</td>
</tr>
<tr>
<td>3.</td>
<td>Copperbelt</td>
<td>17</td>
</tr>
<tr>
<td>4.</td>
<td>Western</td>
<td>15</td>
</tr>
<tr>
<td>5.</td>
<td>Southern</td>
<td>14.5</td>
</tr>
<tr>
<td>6.</td>
<td>Luapula</td>
<td>13.2</td>
</tr>
<tr>
<td>7.</td>
<td>Eastern</td>
<td>10.3</td>
</tr>
<tr>
<td>8.</td>
<td>North Western</td>
<td>6.9</td>
</tr>
<tr>
<td>9.</td>
<td>Northern</td>
<td>6.8</td>
</tr>
</tbody>
</table>

However, prevalence varies even within provinces with several smaller epidemics in different geographical, sectoral and population groups (NAC/MOH, 2008).

Prevalence is highest among Protestants (15 percent), followed by Catholics (13 percent), other religions (12 percent) and is lowest in Moslems (4 percent) (Central Statistical Office et al., 2009).

It also increases with increasing level of education:
- Tertiary education – 19%
- Secondary education – 15%
- Primary education – 14%
- No education – 10%

Prevalence is also higher among the employed than the unemployed and increases with increasing wealth (Central Statistical Office et al., 2009).

This appears to be the case in other African countries. Using data from the nationally representative (adult population) Demographic and Health Surveys, de Walque (2009) analysed the socioeconomic determinants of health in five African countries — Burkina Faso, Cameroon, Ghana, Kenya and Tanzania. The unadjusted means suggested an association between HIV
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infection and level of education and wealth. Logistic regression showed a non-significant association between education and HIV status overall but showed a negative association in urban areas. Education was predictive of “protective behaviours such as condom use” and counselling and testing but was also predictive of “higher levels of infidelity and low level of abstinence”. The author suggests that these associations ‘cancel each other’ and that “the negative association between education and HIV status takes time to develop” and occurs “earlier in cities where information spreads faster and HIV prevalence is generally higher.”

It is estimated that 1.1 million people in Zambia were living with HIV in 2007, 600,000 youths and children (0-17yrs) had been orphaned due to AIDS and 330,000 were estimated to need ARVs (UNAIDS and WHO, 2008).

With a prevalence of 19.3% among pregnant women (NAC/MOH, 2008), Zambia’s epidemic is classified as generalised according to the WHO/UNAIDS categorization of HIV epidemic levels. A generalised epidemic is defined as one in which:

HIV is firmly established in the general population. Although sub-populations at high risk may contribute disproportionately to the spread of HIV, sexual networking in the general population is sufficient to sustain an epidemic independent of sub-populations at higher risk of infection. Numerical proxy: HIV prevalence is consistently over 1% in pregnant women (WHO and UNAIDS, 2007).
4.4 National response to the epidemic

In 1986, two years after the first AIDS case was reported, the government established the National AIDS Surveillance Committee, and National AIDS Prevention and Control Programme (Noble, 2007, NAC, 2003). A year later an emergency short-term plan to ensure supply of safe blood and blood products was developed (Central Statistical Office et al., 2009).

Between 1988 and 1992 response to the epidemic was coordinated by the First Medium Term Plan which had eight priority areas: TB and leprosy; information, education and communication; counselling; laboratory support; epidemiology and research; STD and clinical care; programme management; and home based care (NAC, 2003).

The Second Medium Term Plan covering the years 1994 – 1998 provided for “inter-sectoral coordination and collaboration” (NAC, 2003).

To facilitate a national coordinated response to the epidemic, the National AIDS Council (NAC) was created in 2000. It was subsequently established as a legal entity by an Act of Parliament in 2002. The council has been mandated to coordinate and support the national response to the epidemic (The National HIV/AIDS/STI/TB Council Act, 2002). To date three national plans have been developed by the NAC to guide national programmes and foster inter-sectoral cooperation and a coordinated response to the HIV/AIDS epidemic: the 2001-2003 National Strategic Framework; the 2002-2005 Intervention Strategic Plan; and the 2006-2010 Strategic Framework. The 2006-2010 National HIV and AIDS Strategic Framework (NASF) has been incorporated into the Fifth National Development Plan 2006-2010. This
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shows government support for the programme and ensures availability of funding for the planned programmes and activities (NAC, 2007).

To provide policy direction and guidance Government developed the National HIV/AIDS/STI/TB Policy in 2005. The policy adopts the “Three Ones” approach advocated by UNAIDS (Ministry of Health, 2005). This approach provides for a coordinated national response to the epidemic through one national coordinating body (the National AIDS Council), the development of one national strategic plan (the 2006-2010 NASF)(NAC, 2006a) and one monitoring and evaluation plan (the 2006-2010 National HIV/AIDS/STI/TB Monitoring & Evaluation Plan) (NAC, 2006b).

Government has further shown its political commitment to the national response by establishing a Cabinet Committee on HIV and AIDS which provides policy direction and guidance to the National AIDS Council (NAC, 2006a).

The 2006-2010 NASF identifies the following six priority areas for intervention:

I. Intensifying prevention of HIV
II. Expanding treatment, care and support for people living with and affected by HIV and AIDS
III. Mitigating the socio-economic impact of HIV and AIDS
IV. Strengthening the decentralised response by mainstreaming HIV and AIDS
V. Improving the capacity for monitoring by all partners
VI. Integrating advocacy and coordination of the multi-sectoral response (NAC, 2006a).
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To facilitate implementation of its mandate the NAC decentralised its activities by creating Provincial, District and Community AIDS Task Forces (NAC, 2007).

The Government began providing anti-retroviral drugs (ARVs) at two pilot sites in 2002, declared HIV a national emergency in 2004 and removed all costs on the provision of ARVs in 2005. By 2006 free ARVs were available in 71 of the 72 districts (NAC, 2007).

4.4.1 Information, education and communication campaign

The HIV prevention programme in Zambia launched an HIV/AIDS awareness campaign quite early on in the epidemic, but like other Southern Africa country Governments that were in denial in the early years of the epidemic, the Zambian Government were slow in acknowledging the seriousness of the epidemic and in providing the necessary political and economical support to launch a really effective response (Noble, 2007, Lewis, 2005, The Post, 1999, The Post, 2001).

From the ZDHS, general knowledge about HIV/AIDS has reached almost 100% in the 15-49 year age group. In contrast the level of comprehensive HIV/AIDS knowledge, in the same age group, is 36% for females and 39% for males. Comprehensive HIV/AIDS knowledge is defined as:

- knowing that consistent use of condoms during sexual intercourse and having just one uninfected faithful partner can reduce the chances of contracting HIV, knowing that a healthy-looking person can have HIV, and rejecting the two most common local misconceptions about HIV transmission and prevention (HIV can be transmitted by: 1.
mosquito bites and 2. supernatural means) (Central Statistical Office et al., 2009).

Results from the 2007 ZDHS showed that accepting attitudes towards people living with HIV/AIDS appear to be improving. 47% of women and 55% of men were prepared to have a family member publicly disclose their status (Central Statistical Office et al., 2009).

The use of condoms in Zambia has been hampered by the stance taken particularly by some churches and political leaders that condoms are acceptable for use in marriage but abstinence is the best option for those who are not married (Predrag, 2001, Shimo, 2000). The private sector and civil society are actively involved in the response to the epidemic in Zambia with various non-governmental, faith based and private organisations working in the field of prevention, treatment, care and support (NAC, 2007).

4.4.2 Voluntary counselling and testing
The VCT Programme in Zambia was set up in 1999 with financial assistance from the Norwegian Development Agency (NORAD) (NAC, 2006c). The required human resources were provided by the government through the establishment of the Zambia Voluntary Counselling and Testing Service (NAC, 2006d). The programme began as a pilot project with 22 sites in various locations in the country (NAC, 2006c).

The Zambia Voluntary Counselling and Testing programme has since expanded to 500 VCT sites (NAC, 2007). Services for the prevention of mother-to-child transmission of HIV (PMTCT) are commonly provided at the same sites as VCT services. Ninety-five percent of these sites are integrated within the government health delivery system. The remaining 5%
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are managed by the private sector and are either integrated within the private sector health delivery system or are stand alone sites. Twenty-two of the centres are quality control centres (diagnostic) (NAC, 2006c). The Copperbelt province has the most VCT sites (162) (NAC, 2007).

VCT services are free in all sites, whether public or private and to all individuals regardless of area of residence. Services are promoted through the mass media—radio, television, print—and also through occasional community mobilisation campaigns which usually provide mobile VCT as well. Some facilities advertise the availability of VCT services with banners or notices on perimeter walls or fences. HIV/AIDS educational and promotional posters are usually displayed on health centre walls. Most messages stress the importance of knowing one’s HIV status so that treatment can be accessed, one can have a free mind and to be able to plan for the future.

Counsellors are trained by one of nine National HIV/AIDS Council (NAC) approved training institutions. Training includes HIV test counselling and counselling for general psychological or social problems, hence the counsellors are referred to as “psychosocial counsellor” rather than “HIV or VCT counsellor”. The syllabus covers a range of subject areas including basic facts of HIV/AIDS, VCT, human development and self awareness, introduction to counselling and counselling skills, and problem solving. The course also has a practical field attachment component. Trainee counsellors are attached to qualified and experienced counsellors at VCT centres from whom they learn the skills of counselling by observation and practice. Candidates have to show competence in theory and practice before they can
Chapter 4 - Study setting

be certified as a trained psychosocial counsellor. Registration with the Zambia Counselling Council is required for one to practice.

The number of people testing for HIV and receiving a result has steadily increased from 4.6% in 2000, 5.1% in 2003 to 7.8% in 2005 (NAC, 2006c). Following the introduction of free ARVs in 2005 there has been a large increase in the number of people testing as shown in table 4.3. (Central Statistical Office et al., 2009, Central Statistical Office, Central Board of Health and ORC Macro, 2003, Central Statistical Office, Ministry of Health and MEASURE Evaluation, 2006).

<table>
<thead>
<tr>
<th></th>
<th>2002</th>
<th>2005</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>9.4%</td>
<td>15%</td>
<td>39.4%</td>
</tr>
<tr>
<td>Male</td>
<td>13.8%</td>
<td>11%</td>
<td>22.3%</td>
</tr>
</tbody>
</table>

There has also been a reduction in the number of VCT clients declining a test after counselling, the drop out rate is less than 10%. A total of 142 842 clients were counselled in 2005 and 130 884 were tested. 90% of these were new clients. 44% of the total clients tested were positive, 61% being female and 39% male (NAC, 2006a).

VCT is provided according to the voluntary counselling and testing guidelines provided by the NAC. These guidelines recommend an interactive model of HIV prevention counselling focussing on a personalised HIV risk-reduction plan, standardised counselling and testing procedures and the need for confidentiality. Informed consent is a prerequisite for HIV testing and may be written or verbal (NAC, 2006d). These guidelines are based on the UNAIDS guidelines discussed in section 1.5.
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According to the guidelines:

- Testing for HIV must be confidential and verbal or written consent is required
- Counselling consists of pre-test, post-test and follow-up counselling/support
- Counselling must be provided by counsellors trained at one of the nine recognised institutions
- Testing sites can only use test kits that have been evaluated by the national virology laboratory and approved by the Ministry of Health
- Testing must follow the national testing algorithm (Fig 4.1). The guidelines advocate for the use of rapid tests using finger-prick testing methodology

The test is done using the Abbott Determine rapid HIV test. If it is positive, a confirmatory test is done using the second line test, Uni-Gold™. If this gives a negative result the sample is tested using a third rapid test, Bioline, which functions as a tie breaker. Instead of doing the third test the counsellor can choose to request the client to return after six weeks for a repeat test. These rapid tests work on different principles, hence their use in the same algorithm (NAC, 2006d).
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The VCT counselling process in the study sites is described in detail in section 5.7.2.

**Voluntary counselling and testing models**

The counselling models that have been used in Zambia are: stand-alone, integrated into existing health services and mobile/outreach. Recognising the fact that they each have their own strengths and weaknesses, the guidelines advise implementation of the most appropriate approach for a particular population and region (NAC, 2006d).

In line with UNAIDS guidelines discussed in section 1.6 the guidelines also endorse provider initiated HIV testing, i.e.

1. opt-out testing
2. Diagnostic Counselling and Testing (DCT)
Chapter 4 - Study setting

3. mandatory HIV screening (NAC, 2006d)

4.5 Conclusion

Zambia is experiencing an HIV epidemic with a prevalence of 14.3%. Prevalence is twice as high in urban areas (20%) compared to rural areas (10%) and higher in women (16.1%) than men (12.3%). The following factors have contributed to this scenario:

- Zambia is one of the most urbanised countries in Africa. Mining and industrialisation has led to the migration of people from rural to urban areas. Its central position in Southern Africa has led to Zambia being at the crossroads of major transit corridors connecting the countries to the South to those to the North. The country is among the poorest in the world with an unemployment rate of 14%. These factors have resulted in high population mobility and poverty levels putting people at risk of HIV infection.

- Traditional Zambian society is male dominated with women expected to be subservient to their husbands or the male head of the household. Most married women are dependent on their spouses for their shelter and livelihood, and are taught not to refuse their husbands sex even if they suspect them of infidelity.

- Fifty to seventy-five percent of the Zambian population are Christian. These Christian religions preach abstinence before marriage and faithfulness. They are, therefore, generally opposed to teaching youths about condoms, and adults about the use of condoms when engaging in pre-marital or extra-marital sex.

- In common with other Southern African Governments, the Zambian Government was slow in acknowledging the seriousness of the epidemic and in facilitating an effective response. Early efforts concentrated on
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raising public awareness about HIV and its transmission and prevention. Political will and commitment only truly kicked in 18 years after the first AIDS case was reported with the establishment of the NAC, in 2002, to coordinate and support the national response and a Cabinet Committee on HIV and AIDS to provide policy direction and guidance.

The VCT programme, set up in 1999, was providing free services at 500 sites by 2007. VCT is provided by the public and private sectors and by not-for-profit missionary institutions. Most are integrated within the health delivery system. Counselling and testing services are primarily concerned with capturing those who are HIV-positive so they can be offered treatment.

There appears to be a reduction in levels of HIV/AIDS stigma in Zambian society probably aided by the visible positive effects of anti-retroviral therapy. The availability of free ARVs has also led to increased VCT uptake.
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5 Methods

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The purpose of research is to discover answers to questions through the application of systematic procedures. (Berg, 1995: p7)

5.1 Introduction

Chapter one detailed the historical context and research aims and questions that this thesis addresses. Chapters two, three and four provided the scientific, physical, social, economic and political context of the study. These foregoing chapters have outlined the problems encountered in the control of the human immunodeficiency virus (HIV) which have been complicated by the very personal and intimate nature of its transmission. The effectiveness of voluntary counselling and testing (VCT), particularly for those testing negative, has been a point of contention. It has been posited that this may be due to an incomplete understanding of the interaction between VCT, and subsequent sexual behaviour. Research in this area has largely been within the positivist paradigm; the perspective of people experiencing VCT on the influence of counselling and HIV testing on their behaviour has rarely been sought. In this chapter the process of answering the questions and meeting the objectives set out in chapter one is discussed. The chapter begins with a discussion of the approach taken to answer the research questions, the philosophical stance taken in this study, and the choice of research method, sites and participants. The process of data generation and analysis is presented and the chapter is concluded by highlighting the ethical considerations that were pertinent to this study.

Writing up this chapter was challenging. Undertaking qualitative research is so iterative that it is difficult to then write it up in a way that will at the same time provide clarity of process and reflect the interrelatedness of all aspects of the study. Issues of rigour and ethics are an integral part of the entire
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process (Cho and Trent, 2006, Barbour, 2001). These have been addressed in the present account where they were a pertinent part of the process. They have also been included in separate sections to provide the reader with an appreciation of their development in general, and in qualitative research in particular, and their application in this study.

5.2 Qualitative research

5.2.1 Definition

What is qualitative research? There is no single agreed definition of qualitative research with some writers resorting to a description of what it is not and basically qualifying it in terms of what it sets out to do in comparison to quantitative research (Snape and Spencer, 2003). Qualitative research has its background in various disciplines such as anthropology, sociology, education, communications, medical science, history, psychology and others. This has resulted in a variety of terms, concepts and assumptions. In addition, qualitative research lends itself quite easily to innovative methods due to its versatile nature. According to Denzin and Lincoln (1998) these characteristics may be what hinders the development of one fixed definition. This has led to the development of rather long-winded definitions in an attempt to encompass all that qualitative research is. For the purposes of this study the definition by Creswell is preferred as it encapsulates more closely the nature and process of this study:

Qualitative research begins with assumptions, a worldview, the possible use of a theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem. To study this problem, qualitative researchers use an emerging qualitative approach to
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inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is inductive and establishes patterns or themes. The final written report or presentation includes the voices of participants, the reflexivity of the researcher, and a complex description and interpretation of the problem, and it extends the literature or signals a call for action. (Creswell, 2007: p37)

It is generally agreed that qualitative research:

- is naturalistic
- is interpretive
- aims to understand phenomena from the perspective of the person experiencing the phenomena
- uses purposively selected small samples
- collects very detailed “information rich” data
- uses analysis which is not controlled by hypothesis testing but is open to concepts and ideas that are represented in the data
- produces reports that provide a detailed description and interpretation of the phenomenon including supporting quotes from the participants

(Snape and Spencer, 2003: p3-5)

5.2.2 History

Qualitative research evolved in response to dissatisfaction with natural science approaches to the study of the social world (Flick, 2006, Snape and Spencer, 2003). Positivism was very influential in social research throughout the twentieth century. Positivism is the school of thought that asserts that the natural science methods are appropriate to the social sciences; in this paradigm only those phenomena which are observable and objectively
measurable count as knowledge (Snape and Spencer, 2003). Early ideas about interpretive qualitative research can be linked to Immanuel Kant’s 1781 *Critique of pure reason*. In his writings, Kant argues that direct observation is not the only way we can know about the world; there are other ways which people use all the time. He proposed that our perception of the world does not only depend on what our senses tell us but on our interpretation of what our senses are telling us and that our knowledge of the world is based on understanding acquired through thinking about our experiences rather than from just having a particular experience. Qualitative research is generally associated with these beliefs, placing more emphasis and value on the subjective interpretation of phenomena by the researched and the researcher (Snape and Spencer, 2003: p6-7).

Qualitative research has been unfavourably compared by some to quantitative research. In general, the qualitative approach assumes that knowledge is co-constructed or subjectively created whereas the quantitative approach assumes that knowledge exists as facts (see section 5.4.1). Qualitative research is criticised as being non-scientific; it is subjective as it relies on natural settings—that cannot be experimentally controlled to produce objective, valid, and reproducible results (reliability)—and analysis is not by statistical objective methods but relies on the interpretation of the researcher (Flick, 2006, Mays and Pope, 1995, Denzin and Lincoln, 2000, Snape and Spencer, 2003). However, qualitative research has been gaining popularity in recent years and has come to be accepted as an equally valid scientific approach (Creswell, 2007, Denzin and Lincoln, 1998). It has gained popularity in several fields (Lincoln and Guba, 2000) including public health (O’Reilly, 1995) and health services research (Barbour, 2001). Pope and Mays (1996: p2) state that qualitative approaches “should be an essential
component of health services research” because of their ability to reach areas that cannot be reached by quantitative methods, and also the fact that they can provide the description that is required for good quantitative research especially in areas that are not well understood. In this way qualitative research can provide insight into why evidence-based findings are not implemented or are not achieving anticipated outcomes (Jones, 1995, Pope and Mays, 1996); as is the case with VCT.

5.2.3 Evolution
Early (late 1800s-1900s) qualitative research in sociology and anthropology, in both America and Britain, was mostly ethnographic concentrating on studying the life and culture of “native” populations in other lands and of groups, in Chicago, about which little was known (Snape and Spencer, 2003). Positivism was the dominant paradigm in social research during this time. However, there were individuals like Kant who voiced their disagreement with this paradigm.

During the 1860s to the 70s Wilhelm Dilthey called attention to the importance of “understanding” and hence the study of people’s “lived experience” within their particular social, cultural and historical contexts (Snape and Spencer, 2003).

Max Weber (1864-1920) took up Dilthey’s argument but he emphasised the importance of both an objectivist and an interpretive approach for a complete understanding of people’s behaviour. According to Weber the purpose of the objectivist approach is to produce cause and effect propositions whereas the interpretive approach aims to understand phenomena from the perspective of the person experiencing the phenomena.
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Within the interpretive worldview the holistic context of people’s lives is seen as having an important influence on their understanding of the world (Snape and Spencer, 2003). Accordingly, this study takes this approach; counselling and testing do not take place in a vacuum but are influenced by factors within the individual’s environment which influence the decision to attend counselling, and the influence of the counselling session and the negative result on subsequent HIV risk behaviour.

Throughout the history of qualitative research dissatisfaction with, and challenges to the prevailing approaches to the study of human behaviour have instigated the development of new approaches to address the perceived shortcomings and challenges (Snape and Spencer, 2003). From about the mid 1900s to the 1970s pressure from positivists and challenges from postpositivism, which maintains that a completely objective view of the world cannot be attained, prompted qualitative researchers to try and formalise their methods leading to the development of new theories and approaches such as:

- **Ethnomethodology** which seeks to describe the methods people use to construct social order and make sense of their social life (Silverman, 2005, Garfinkel, 1967)
- **Symbolic interactionism** which studies the way people assign meanings to things (Flick, 2006, Mead, 1934)
- **Oral history** which uses people’s “life stories” to understand experiences and social constructions (Thompson, 2000)

Grounded theory—the inductive development of theory from data—(Glaser and Strauss, 1967) was developed during this time in response to the
criticism that qualitative research was not rigorous enough (Charmaz, 2000, Snape and Spencer, 2003).

By the 1970s the validity of social research based on ‘scientific methods’, was being questioned (Snape and Spencer, 2003: p8). Qualitative research began to be seen as a more valid approach. New theories, approaches and methods were developed. Some of these new theories such as poststructuralism and deconstructionism—which maintain that there is no fixed meaning and reality since these will vary depending on time and place—challenged the qualitative research claim of uncovering the meaning people ascribe to phenomena (Snape and Spencer, 2003).

The absence of political and emancipatory outcomes from qualitative research invited further challenges from critical theory (Neo Marxism, feminism and race research) which claims that material conditions, social, political, gender and cultural factors play a major role in people’s lives and should be the major focus in research. This led to a redefining of researchers’ and participants’ roles in qualitative research leading to participatory and action research and a move towards encouraging a more reflexive approach to findings (Snape and Spencer, 2003).

5.2.4 Rigour in qualitative research
Challenges about the validity, generalisability and reliability of qualitative research have come up time and again in its history (Denzin and Lincoln, 2000, Mays and Pope, 1995, Snape and Spencer, 2003). As argued by Mays and Pope (1995), the problem has been the application of quantitative definitions of rigour to qualitative research—echoed by Willig (2004), Malterud (2001), Rice and Ezzy (1999)—while overlooking the fact that even
in quantitative research the application of these criteria does not guarantee a rigorous study since the findings depend on the “judgement and skill of the researcher” and how appropriate the answers are for the question asked (Mays and Pope, 1995: p11).

Rigorous qualitative research, just like quantitative research, has to be systematic and reflexive (both personal and epistemological (Willig, 2004)) in its design, collection and interpretation of data and communication of findings. Criteria for assessing the quality of qualitative research have been suggested and include a transparent presentation of the whole process of the research: theoretical assumptions should be made clear; there should be a fit between question, method, approach and theoretical perspective; provision of a clear description of the context within which data were collected; and data collection and analysis methods and techniques should be clearly described.

Other measures to ensure rigour include: strategies that ensure the conceptual generalisability of qualitative research findings such as a diverse range of individuals and settings; efforts at ensuring reliability of analysis through group approaches to analysis; triangulating data collection; participant validation, that is, providing participants the opportunity to agree or disagree with the findings as a fair representation of their perspectives; and the deliberate seeking out of deviant cases to further refine the theory. Finally the research should provide a comprehensible explanation for the phenomena under study with sufficient original evidence (quotations) to support it and relate it to what is already known in the area. (Mays and Pope, 1995, Willig, 2004, Charmaz, 2000, Cho and Trent, 2006, Malterud, 2001, Rice and Ezzy, 1999).
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Checklists, such as the ones provided by Mays and Pope (1995), Malterud (2001) and Kuper, Lingard and Levinson (2008), have been developed for assessing the rigour of qualitative research and have contributed to the increased popularity of these methods (Barbour, 2001). However, Barbour (2001) warns against the prescriptive use of these criteria: “None of these ‘technical fixes’ in itself confers rigour; they can strengthen the rigour of qualitative research only if embedded in a broader understanding of qualitative research design and data analysis”.

5.3 Why use qualitative research?

The transmission of HIV is dependant upon behaviours that people engage in, therefore, the development of effective interventions must be informed by an understanding and description of these behaviours in their various contexts (O’Reilly, 1995, Fishbein, 2000).

Whereas traditional quantitative data collection methods can provide much useful information about risk behaviours around HIV/AIDS, such as what risk behaviours people engage in, which are the most prevalent and in which groups, how many people access VCT services and the behavioural outcomes, they are not particularly suited to uncovering the reasons why people engage in these behaviours and why interventions such as VCT do not consistently produce the expected effect on risk behaviour (O’Reilly, 1995, Power, 1998). Qualitative methods are better suited to exploring people’s behaviour (Fishbein, 2000, Silverman, 2005) and “can reach aspects of complex behaviours, attitudes and interactions which quantitative methods cannot” (Pope and Mays, 1995). Using Willig’s (2004) analogy of qualitative research to an adventure, exploring these areas from within the
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qualitative research paradigm is akin to sailing through uncharted waters and discovering hitherto unknown lands and peoples.

In order to develop interventions that work, we need to understand the underlying causes, processes and customs influencing behaviour and their context. Qualitative approaches illuminate these thereby assisting in the development of interventions that are specific to cultures and context and are therefore more likely to succeed (O’Reilly, 1995).

Power (1998) conducted a systematic review on the role of qualitative research in HIV/AIDS. He came to the conclusion that qualitative research has made a significant contribution to the understanding of HIV/AIDS and interventions to HIV/AIDS in diverse groups and settings.

5.3.1 VCT – a complex intervention

Voluntary counselling and testing is a complex intervention. It is composed of more than one interrelated component (Medical Research Council, 2008), some of which are also complex in their own right. There are many different models of VCT with varying levels of complexity. Some models will provide ongoing supportive counselling while others will not, still others may provide additional interventions to support behaviour change (UNAIDS, 2000b, UNAIDS, 2001b, International HIV/AIDS Alliance Asia and Eastern Europe team, 2004). The model adopted by the Zambia National AIDS Council (NAC) is the CDC client-centred model (see section 1.5).

Understanding the components of an intervention and how they are interrelated is essential for the successful implementation of any intervention (Medical Research Council, 2008) and even more so for one as complex as
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VCT. Qualitative methods are particularly well suited to exploring complex issues (Snape and Spencer, 2003: p5, Willig, 2004).

5.4 Philosophical issues

Finding one’s way through the maze of qualitative research approaches is no easy task especially for a novice researcher. The evolution of qualitative research theories, approaches and methods in response to various challenges and perceived shortcomings has resulted in such a plethora of choices that it is difficult for one to know which one(s) to choose (Creswell, 2007, Crotty, 1998, Denzin and Lincoln, 2005). In my case this was amplified by a background in medicine with its bias towards positivism and antipathy to interpretive approaches (Pope and Mays, 1993). My progress through this thesis can be compared to the iterative nature of qualitative research itself. Knowledge acquired or clarified during the process of the PhD meant that there was a perennial looping back and forth between the different phases of the PhD. This facilitated the learning process that should be characteristic of a PhD. Through an iterative process involving a review of the literature, discussions and reading around the subject the research question was honed down to a focussed answerable question that could be investigated within the available resources—including time—and a research approach was selected.

5.4.1 Choosing an approach

There is no one single correct approach to qualitative research. The approach is primarily determined by the research question, the purpose of the research and the type of knowledge that one wishes to generate. The latter depends on one’s philosophical stance or way of looking at the world. What one believes to be reality, what actually exists, (ontology) will influence what one
believes can be known about the world and how one can go about knowing this reality or what can be known and how (epistemology). The ontological and epistemological beliefs determine the theoretical perspective that guides the design (methodology) of the research (Punch, 1998, Denzin and Lincoln, 2005, Richards and Morse, 2007, Crotty, 1998, Willig, 2004, Snape and Spencer, 2003).

The theoretical perspective or worldview is the framework used to understand the world and to explain it (Crotty, 1998, Denzin and Lincoln, 2005). This worldview in turn influences the method used to generate the data and to analyse it. In this way “purpose, data and analytic technique fit together” thereby providing for consistency which is considered to be a mark of sound qualitative research (Richards and Morse, 2007, Crotty, 1998, Mays and Pope, 1995, Punch, 1998). However, not everyone agrees with this position. Pragmatists propose that all research methods, qualitative and quantitative, should be considered as part of a tool box of available methods that can be used in any suitable combination to answer a particular research question rather than being overly concerned about the underlying philosophical assumptions (Crotty, 1998).

**Ontology (What is the nature of reality?)**

Ontology is defined as the study of being. It is concerned about the nature of reality. Snape and Spencer (2003) identify three positions on the nature of reality: realism, materialism and idealism. Realism asserts that there is a reality out there that exists independent of human cognisance and is distinct from the human perception of the same reality. Materialism holds to the belief that physical matter are the only real things in the world. In contrast,
idealists believe that there is not one single reality but multiple realities since reality is constructed by the human mind (Snape and Spencer, 2003).

**Epistemology (What can be known and how?)**

Epistemology is defined as the theory of knowledge. Epistemology is concerned with the study of the nature and validity of knowledge and is a way of explaining how we know what we know. There are a number of epistemological positions; I will describe the three that, according to Crotty (1998), come close to encompassing the concepts underlying the various positions. An objectivist epistemology claims that things (facts) exist as meaningful entities independent of human perception and research conducted in an appropriate way can find this objective truth. A constructivist epistemology states that knowledge is co-constructed, through human interaction with the world. The object and the subject interact in the construction of reality or meaning; the same object may mean two different things to two different people depending on what has influenced their construction of the object’s meaning. In subjectivism meaning is given to an object by the subject, there is no interaction between the two (Crotty, 1998). Most qualitative research is conducted within a constructivist epistemology (Crotty, 1998, Flick, 2006, Kuper, Lingard and Levinson, 2008).

**Theoretical perspective (How do I view the world?)**

The ontological and epistemological beliefs influence the theoretical perspective through which a researcher views the world. There are many theoretical perspectives: positivism; feminism; critical theory; and interpretivism which includes symbolic interactionism, phenomenology (interested in understanding the fundamental meaning of phenomena from the perspective of the person experiencing the phenomena (Husserl, 1931))
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and hermeneutics (focuses on meanings and interpretation of text, actions, and art taking into account influence from the historical, cultural and social context (Dilthey, 1922)) (Crotty, 1998, Denzin and Lincoln, 2000, Rice and Ezzy, 1999).

The approach (How do I go about knowing the world?)

The research approach or design then flows from the theoretical perspective. Again there are numerous approaches, such as experimental research, ethnography, phenomenological research and grounded theory (which aims to understand and explain phenomena using theory derived from the data). These approaches can utilise any number of methods of data collection and data analysis from an even larger pool of methods. Available methods include: observation, interview, focus group, case study, life history, theme identification, content analysis and narrative analysis (Crotty, 1998).

Both quantitative and qualitative research may be conducted from within the positivist, post-positivist, interpretivist, feminist, critical inquiry, or any of the other theoretical perspectives (with their underlying ontological and epistemological assumptions). The divide between quantitative and qualitative research occurs at the level of methods of data generation and analysis (Crotty 1998).

5.4.2 Philosophy underpinning this study

The purpose of this study was to propose an explanation of how VCT and a negative HIV test result impact on behaviour; by drawing on the insights provided by people who have experienced voluntary HIV counselling and testing and receipt of a negative result. By understanding the experience of voluntary HIV counselling and testing from the perspective of the person testing negative, we can begin to understand what influence it may be
exerting and how, in the particular environmental context. Understanding the felt needs of these people, emanating from their experiences, and the perceptions of the VCT counsellors of the service they are providing facilitated the articulation of viable suggestions for the enhancement of the VCT service.

Socio-cognitive models of behaviour change (see section 2.2.2) recognise that human behaviour does not occur in a vacuum. People are not islands; they live within a particular social, historical, political, economic and cultural context. Events and interactions within their environment influence how people perceive and experience events and objects and therefore, how they behave (Ajzen, 1988, Bandura, 1977b, Crotty, 1998).

To achieve the aim of providing a plausible explanation or theory of how voluntary counselling and a negative result influence sexual behaviour, an approach was needed that would facilitate the explication of this process through the development of a theory derived from the perspectives of the people experiencing voluntary counselling and testing negative.

**Grounded theory**

Grounded theory was developed by Glaser and Strauss (1967). Creswell defines grounded theory as “a qualitative research design in which the inquirer generates a general explanation (a theory) of a process, action, or interaction shaped by the views of a large number of participants” (with reference to Strauss and Corbin, 1998, Creswell, 2007: p63).

Grounded theory provides a rigorous, systematic approach to the inductive generation and analysis of data, using constant comparative analysis and
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theoretical sampling, leading to the development of theory that is grounded in the data (Charmaz, 2000, Glaser and Strauss, 1967).

Constant comparative analysis is the systematic comparison—intrapersonal and interpersonal—of people’s views, experiences, situations and actions; of data with emerging categories; and of categories. This method facilitates the development of a robust theory (Charmaz, 2000, Glaser and Strauss, 1967).

The principal of theoretical sampling is that subsequent data generation is guided by the desire to refine emerging concepts and theory; initial generation of data is from a purposively selected sample (Creswell, 2007). Recruitment ceases when further sampling does not yield new insight on the theory.

Conclusion

This study was approached from within an interpretive worldview informed by a broadly constructivist epistemology and a largely idealist ontology, although I do have some ambivalence as to my ontological position. This approach acknowledges that reality is constructed, dependent on individual perspective and is therefore multiple taking into account the values, perceptions and interpretations that the researcher brings to the generation and analysis of the data. This is in contrast to the positivist worldview which does not take into account individual interpretations of situations since these cannot be measured objectively (Bowling, 1997).

For the generation of data I made pragmatic use of the techniques of grounded theory; the constant comparative method and theoretical sampling. Thematic analysis, following guidelines proposed by Virginia Braun and Victoria Clarke (2006), was used for the analysis of the data. Braun
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and Clarke define thematic analysis as “a method for identifying, analysing and reporting patterns (themes) within the data.” Thematic analysis is presented as a process with six phases:

1. Familiarizing oneself with the data – involves transcribing, reading and re-reading the data and taking note of initial ideas
2. Generating initial codes – systematic coding of relevant/interesting features of entire data set
3. Searching for themes – grouping related codes
4. Reviewing themes to see if they are applicable for the coded extracts and the entire data and generating a thematic ‘map’ of the analysis
5. Defining and naming themes – further analysis of themes to refine the story told by each and the overall story
6. Producing the report – final analysis with selection of extracts that illustrate the themes, and relating these to the research question and literature.

5.5 The place of behaviour change theory in this thesis

Theories of behaviour change influenced this study at various levels where they were deemed to provide insight and guidance useful to the purpose of the study (Flick, 2006). Concepts from the models, in particular the health belief model (Rosenstock, Strecher and Becker, 1994) and the stages of change model (DiClemente and Prochaska, 1982) informed some of the questions on the interview schedule. Concepts from the theories were again utilised in the naming of inductively derived codes and themes when they provided an apt description of the code or theme, for example ‘cues’ and ‘susceptibility’ from the health belief model (Rosenstock, Strecher and Becker, 1994). Finally, in
the discussion chapter, the findings are related to the currently available theories.

5.6 Method

There are numerous methods within the qualitative research paradigm that can be used to generate data; the main ones being interview, (structured, semi-structured, unstructured), observations (participant and non-participant), documents and audiovisual materials (Punch, 1998, Creswell, 2007). Interviewing and observing are the most commonly used (Creswell, 2007).

The purpose of this study was to understand the influence of VCT, and receipt of a negative HIV test result on sexual behaviour from the perspective of people who have experienced voluntary counselling and tested for HIV. This purpose suggested the use of a method that would facilitate the generation of data representing the perceptions of individuals. Interviewing was identified as the most appropriate method to use as it allows for the individual to express their values, beliefs, attitudes, feelings and needs (Willig, 2004, Punch, 1998). The interview is “one of the most powerful ways we have of understanding others” (Punch, 1998: p175). It is an interactive process with both parties collaborating to produce knowledge (Holstein and Gubrium, 1995). This method of data collection therefore, fits well within an idealist ontology and a constructivist epistemology.

Behaviour change occurs over time, perceptions and attitudes change over time, therefore, to study the influence on behaviour of any intervention designed to influence behaviour would ideally require a design that allows for the collection of data at more than one point in time (Saldana, 2003, Flick, 2006). A brief discussion on longitudinal qualitative research was presented
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in section 1.9. This study is longitudinal since two interviews were conducted, six months apart, and change through time was examined by comparing perceptions and behaviour at the two points in time (Saldana, 2003). “It is impossible to conceive of time without reference to some change. And, vice versa, the idea of change apart from time is simply inconceivable” (Sztompka, quoted in Saldana, 2003: p3). Bowling (1997) defines ‘longitudinal’ simply as “at more than one point in time”.

The study also aimed to identify the felt needs of people attending VCT and testing negative and suggest appropriate improvements to the service. The multiperspective approach has been found to be useful when the aim is to improve services (Kendall et al., 2009). Therefore, the perspective of the counsellors on the service and client needs was sought through focus group discussions. This approach also serves to provide validation of study findings through the process of triangulation of data.

5.6.1 Interviews

Interview has been defined as “a conversation with a purpose” (Berg, 1995: p29); the researcher guides the interview in such a way that it generates data that can be used to achieve the intended purpose (Lofland and Lofland, 1995, Willig, 2004). This guidance can be more or less structured depending on the question and study approach. Studies using a life history approach, where one is interested in describing the experience of a particular phenomenon by an individual will tend to use unstructured interviews – the interview schedule for these interviews usually consists of one question and the rest of the interview is decided by the direction the interviewee decides to take
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(Punch, 1998). Focus group interviews\(^3\) can be used in place of semi-structured interviews (Bowling, 1997, Willig, 2004). Some authors suggest that they may be better for studying sensitive topics because people may feel more comfortable discussing such issues in a group than in a one-to-one interview (Barbour, 2008, Kitzinger, 1995, Rice and Ezzy, 1999), although Barbour (2008) acknowledges that it really depends on the individual. Focus group interviews may produce data that are of higher validity than that produced in a one-to-one interview because the interactions between the participants encourages the generation of data with much more depth (Willig, 2004, Kitzinger, 1995, Rice and Ezzy, 1999). Focus groups are well suited to exploring group decision-making and problem-solving processes (Barbour, 2008).

**The choice of one-to-one interviews**

In this study it was decided that one-to-one semi-structured interviews would be the most suitable since personal perspectives and experience were the primary area of interest. Focus group discussions could have been used but might not have allowed for the generation of data at the desired personal depth (Barbour, 2008, Berg, 1995). In addition the phenomena of interest in this study is one that has a certain level of stigma attached to it which would preclude the open sharing of behaviour that might cause embarrassment (Flowers, Duncan and Knussen, 2003, Lofland and Lofland, 1995, Willig, 2004). These concerns aside, it would not have been feasible to conduct focus

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\(^3\) Some authors use the terms focus group interview (FGI), focus group discussion (FGD) and group interview (see Berg, 1995, Blaike, 2000, Lofland and Lofland, 1995, Punch, 1998, Willig, 2004) interchangeably whereas others distinguish between them (see Barbour, 2008, Flick, 2006, Kitzinger, 1995, Payne, 2007, Rice and Ezzy, 1999). In this thesis FGD is used as defined by the latter group; to emphasise the point that responses were not expected from each participant on every question, it was the perceptions and opinions of the group that were of interest.
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group discussions within the time constraints of this study considering the difficulties inherent in organising focus group discussions especially with no readily available sampling frame (Barbour, 2008: p133).

5.6.2 Focus group discussions

Focus groups have been used since the 1920s when social scientists used the method mostly for the development of survey instruments. Between the Second World War and the 1970s they were used mainly by market researchers to get feedback on products and during the 1980s the technique gained recognition and popularity as a qualitative method by social scientists and others. Merton and Lazarsfield are credited with introducing focus groups into the social sciences in the 1940s with their use of the technique to evaluate response to wartime radio programmes during the Second World War (Madriz, 2000). Focus group discussions evolved from these focus group interviews (Merton, 1987).

Rice and Ezzy (1999: p76) define a focus group discussion as “a group of people gathered together to discuss a ‘focused issue of concern’.” Focus group discussions differ from focus group interviews in making specific use of group interactions to generate data (Kitzinger, 1995). The ability of focus group discussions to facilitate “the expression of criticism and the exploration of different types of solutions is invaluable if the aim of research is to improve services” (Kitzinger, 1995). Focus group discussions are therefore useful for the planning, design and evaluation of programmes (Kreuger, 1994).

Focus group discussions were the method of choice to determine the counsellors’ perspective of the service they were providing. In the focus
group setting the participants were able to challenge each other and develop ideas further facilitating a more complete and critical evaluation of the service. An additional aim subsumed in this overall aim was to get feedback from the counsellors on the authenticity and feasibility of the perceived needs expressed by the people who participated in the study. The focus group discussions were therefore conducted after almost all the follow-up interviews had taken place (29/31). The discussions also served as a source of corroboration for the data generated in the one-to-one interviews (Berg, 1995). Findings from these discussions were generally in agreement with the findings from the one-to-one interviews suggesting that the data generated from both was quite close to what is actually pertaining. Triangulation is a technique that was originally used to assess the validity of findings by using different methods—usually three—of data collection (Willig, 2004, Berg, 1995) but is increasingly being used to enrich depth of knowledge about the phenomenon under study by, for example, approaching the data from different perspectives (using different theories) and the use of different data sources (using the same method) studying the same phenomena at different times and places and from different people (Denzin, 1989 in Flick, 2006: p389).

### 5.7 Study sites
The study was conducted in two districts in the Copperbelt Province. The Copperbelt Province is in the north of Zambia and as the name implies is home to the copper mines that are the backbone of Zambia’s economy (Central Statistical Office, Central Board of Health and ORC Macro, 2003). These two districts were selected because they are located in an area with the third highest HIV prevalence in the country (17%) and the second highest
total number of people living with HIV — 322,688. Lusaka which has the highest HIV prevalence at 20.8% has a total of 345,280 people living with the virus and the Central province with the second highest prevalence (17.5%) has 220,586 people living with HIV (Central Statistical Office et al, 2009). In addition the researcher was familiar with the culture and health services in the two districts and opted to take advantage of this familiarity for the reasons discussed in section 5.8.1.

Chililabombwe and Chingola, the two districts in which the study was conducted are located in the north-western part of the province; Chililabombwe lies on the border with the Democratic Republic of Congo (formerly Zaire) and Chingola lies about 20km south of Chililabombwe (see map 5.1, p158). The two towns are connected by a good all-weather road which facilitates movement of residents between the two towns for commercial and social purposes. Chililabombwe being a border town serves as a stop for transit long distance trucks carrying goods to and from the Congo DR, Tanzania, South Africa, Zimbabwe, Malawi and Botswana. The border post, Kasumbalesa, is one of the five major border posts in the country (Family Health International, 1999, Family Health International/IMPACT, Tropical Diseases Research Centre and National AIDS Council, 2000).

The 2000 census put the population of Chililabombwe and Chingola at 67 500 and 170 000 respectively (Central Statistical Office, 2000), but a head count by the district-wide Konkola Copper Mines (KCM) Malaria Control Programme estimated the true population to be closer to 120 000 for Chililabombwe and 250 000 for Chingola (Konkola Copper Mines Plc, 2000). The population is a mixture of tribes and cultures from within and from outside Zambia due to
the influx of people in search of a job in the mines (Encyclopædia Britannica, 2009, Zambia Virtual, 2005).

Map 5.1: Study site

Chililabombwe and Chingola are both mining towns with the largest employer being Konkola Copper Mines Plc (KCM). Chingola has the largest open cast mine in Africa (Zambia National Tourism Board) whereas Chililabombwe has the world's wettest underground mine (Matandiko, 2007). KCM employs close to 15,000 people (Konkola Copper Mines Plc, 2006).

The rest of the population in these two areas are either in formal employment as civil servants or in private companies and small scale businesses or in informal employment. Most of the unemployed people in this area are small scale subsistence farmers (Chililabombwe District Health Office, 2008).
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Health services in the two towns are provided by both the public and the private sector. KCM provides comprehensive free medical care for its employees and their registered dependants (spouse and offspring) through two hospitals, one in each town and seven health centres located within the townships. The health centres provide preventive and curative primary health care. There are four health centres in Chililabombwe and three in Chingola. The furthest health centre in each town (one in each) is approximately 20-30 minutes drive from the town centre, the rest are within 5-15 minutes drive.

The government runs a district hospital in Chingola which serves as a second level referral hospital for the government-run health centres in Chililabombwe and Chingola. Chingola has nine public health centres (six urban and three rural), one rural mission health centre, and one public and one private health post. Chililabombwe has three public urban health centres and one public rural health centre (see Table 5.1) (Ministry of Health, 2008).

Table 5.1: Number and type of health facilities

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<th>Hospitals</th>
<th>Health Centres</th>
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<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Grand total</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

5.7.1 VCT services

KCM runs the largest private sector HIV/AIDS programme in Chingola and Chililabombwe. The programme was implemented in 2001. It is a comprehensive programme providing health education in the workplace and the community, VCT services, prophylaxis and treatment for opportunistic
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infections, antiretroviral treatment, prevention of mother to child transmission of HIV, syndromic management of sexually transmitted infections (STIs) and home-based care. Antiretroviral drugs are provided free through partnerships with Government and non-Governmental organisations. KCM also runs the only HIV resource centre in Chingola (Konkola Copper Mines Plc, 2008).

VCT services are provided in nine of the thirteen government health facilities and in the nine KCM health facilities and the KCM HIV resource centre. Three of the KCM testing sites and two of the government sites are manned by a trained full-time psychosocial counsellor. The rest are basically run as part of the health centre and are manned by part-time trained psychosocial counsellors. The majority of counsellors in the country are qualified health workers and conduct counselling when required to do so (Zambia VCT Partnership, 2003). As in the rest of the country the shortage of nurses and other health care workers is affecting the provision of health care in both towns and in both private and public health facilities. Counsellors are trained by one of nine National HIV/AIDS Council (NAC) approved training institutions.

VCT is provided either in a designated room(s) or if space is a problem in whatever appropriate room happens to be available at the time required. In most facilities there is no waiting area specifically for VCT clients, they wait in the same place as clients for other services. No prior appointments are necessary and people can access VCT services any time between the hours of 8am and 5pm weekdays, and 8am to 12pm on Saturdays.
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Clients are either self-referred or are referred by a health worker either because they have been diagnosed with tuberculosis, or with a sexually transmitted disease or have clinical symptoms, signs or an infection suggestive of HIV infection. If the facility has a designated VCT testing room or area the client will go directly into the room. If there is another client in the VCT room they will wait at the designated waiting area. When counselling is in progress, a notice is put on the door to avoid interruptions. In facilities where there is no fixed VCT room the client presents to one of the members of staff with their request for VCT. They are then directed to the counsellor who will find a suitable place for the counselling and testing session. If there is no counsellor or room available the client is turned back and asked to return at another time or day. In sites with a designated waiting area, HIV related health education and promotion brochures, pamphlets and posters may be available in these areas.

5.7.2 The counselling and testing process

I sat in on eight voluntary counselling and testing sessions (six different counsellors and both first-time and repeat testers) to facilitate adequate description of the sessions and provide context for the interviews. The counsellor sought the client’s consent for my presence during the VCT session.

The client is welcomed into the counselling and testing (C&T) room by the counsellor. If possible the seating arrangement is such that the counsellor and client(s) face each other with no object between them and at the same level. This is so as to enhance rapport and create an ambience that plays down any power dynamics, making it easier for the counsellor to engage with the client, and encouraging the client to speak more freely. This is a
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concept central to client-centred counselling. The client is the expert on their own past experiences and capable of achieving change if provided with an enabling supportive environment (Mulhauser, 2009, Sommers-Flanagan and Sommers-Flanagan, 2003). In some facilities this is not always possible and counsellors have to make do with whatever the space available to them has to offer. Counsellors usually insist on at least a minimum of a room that will ensure some privacy and seating. Although the NAC VCT guidelines specify minimum requirements for a C&T room (NAC, 2006d), these are difficult to ensure due to the lack of permanent rooms in a number of facilities.

Pre-test counselling

The counsellor begins by establishing rapport with the client so as to facilitate as interactive a session as possible. The counsellor introduces themself to the client and provides information about the services offered at the testing centre. This is usually followed by an enquiry into the client’s wellbeing and some general talk. The client is asked for a name or pseudo-name by which they prefer to be addressed and the counsellor will then ask what they can do for them or what has brought them in. Counselling will then proceed according to the reason for attending. Counselling for an HIV test begins with pre-test counselling; the counsellor assesses the client’s knowledge and understanding of basic HIV/AIDS issues and fills in any gaps and corrects any misconceptions. Questions about sexual history and risks of exposure to HIV were asked in a few of the observed sessions. The client is then asked if they would like to go ahead and have the test done, moving into the second part of the VCT session. Time taken to conduct the pre-test

4 A pilot quality assurance assessment that was in progress at the time of the second interviews made a similar observation (G. Mwale, personal communication, 29 May 2009).
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counselling session ranged from 10-55 minutes depending on how knowledgeable and ready the client was and if the counsellor decided to demonstrate condom use (this was observed in less than half the sessions).

HIV testing

If the client is ready to go ahead with the test, the test procedure and the meaning of the result is explained. Readiness to accept test results is assessed by asking the client what they would do if they were to test negative or positive and the consent form is signed before blood is drawn for testing.

This concludes the second part of the VCT session. The client is either asked to go and wait in the waiting area for the results or is kept in the room while the test runs. Testing is done using the Abbott Determine rapid HIV test as per testing guidelines from the National HIV/AIDS Council (see section 4.4.2).

The Determine™ HIV-1/2 is a visually read, immunochromatographic, qualitative assay for the detection of HIV-1 and HIV-2 antibodies in the patient’s sera, plasma or whole blood (from finger prick or venipuncture). The test strip is about 7-8cm long and about a centimetre wide (see Fig 5.1). At one end is the sample pad (indicated by the three white arrows) to which the client’s blood is added and in the middle are two bars; a patient bar and a control bar.

Figure 5.1: Determine™ HIV-1/2 test strip.

Source: (Inverness Medical Innovations, 2009)
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The sample pad contains a colloid of HIV-1 and -2 antigens combined with selenium. As the sample migrates through the pad it mixes with the antigen-selenium colloid and reconstitutes. This reconstituted mixture moves down the test strip to the patient bar which has antigens as well. If the sample has HIV-1 or -2 antibodies they will bind to the antigen-selenium colloid and will also bind to the antigen in the patient bar producing a red line (due to the selenium) across the bar, width wise. The control bar is provided to ensure validity and a red line appears whether or not there are HIV antibodies in the sample.

The manufacturer recommends that the test should be given ten to fifteen minutes to run. The counsellor usually takes this opportunity to fill in the register and any other forms that may need to be filled in. The VCT register is the same in all facilities and is provided by the Ministry of Health (MOH) for the collection of statistics on VCT. KCM facilities have an additional form that must be filled in for each client; this provides information required by the KCM HIV/AIDS programme and partners (appendix 5). If a test is positive the counsellor then proceeds according to the national testing algorithm outlined in section 4.4.2. Time taken for the testing stage ranged from 6-10 minutes.

Post test counselling

As soon as the results are ready the client is invited back into the room (if they had left) for the post-test counselling session. Before disclosing the result, the counsellor confirms that the client is ready to receive the result, whatever it maybe. Additional counselling is provided; this basically consists of further emphasis on prevention of transmission or acquisition of HIV usually done by asking the client what their plans are after knowing their
result. Clients testing positive are further advised about nutrition and a healthy lifestyle and referred to the ‘pre-ART’ (antiretroviral therapy) clinic for medical assessment, advice and follow up. Those testing negative are routinely advised to return after three months (window period) for a repeat test to confirm their result, whether or not there was a history of behaviour that may have put them at risk in the previous three months. Time taken on the post-test counselling session ranged from 5-10 minutes.

**Confirmatory test (after three months)**

At the three months repeat test the same procedure is followed, though most counsellors do not spend much time on the pre-test counselling on the second visit. If the test remains negative the client is then free to go and is not obliged to return unless he or she feels the need to do so. Some counsellors will ask the client to come back again after six months to make sure. This seems to be due to some misunderstanding of the guidelines by these counsellors.

If available, information, education and communication (IEC) materials, (pamphlets and brochures) are provided to all clients attending VCT. Fig 5.2 provides a diagrammatic representation of the process described above.
5.8 Recruitment of study participants

In order to answer the question posed by this study, participants had to have experienced VCT and tested negative. The only place that I could access people who have been for VCT and tested is a VCT centre. Testing is meant to be confidential so it was apparent that counsellors would have to play a major role in the recruitment of participants. Since practically all the VCT centres are health centre affiliated and the counsellors are mostly nurses.
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working at these health centres, these counsellors and VCT centres fall under the care of the health centre sister- or nurse-in-charge. The government health centres are administered by District Health Management Teams (DHMT) which report to the Provincial Health Office (PHO) which is in turn answerable to the MOH. The KCM health centres are also run by a nurse- or sister-in-charge who reports to a senior nursing officer at the hospital. The senior nursing officer reports to the hospital medical superintendent who in turn reports to the manager medical services. In addition, all research conducted in Zambia, like in most other countries, has to be approved by one of two research and ethics committees (REC). The University of Zambia (UNZA) — the oldest and largest university in the country — REC is based at the medical school in Lusaka, and the Tropical Diseases Research Centre (TDRC) REC is based at their offices at Ndola Central Hospital in the Copperbelt Province. The TDRC REC is supposed to be responsible for all research conducted in the northern part of the country while the UNZA REC takes care of the southern part (TDRC). However, these demarcations appear not to be mutually agreed and so are not observed (Karashani, 2007). For this study consent was sought from the UNZA REC.

5.8.1 Gaining access to the “field”

The above paragraph details the various levels that I needed to approach for approval to access the study sites and participants. In order for anyone at a lower level to do anything that is outside the remit of the facility, permission to proceed must be obtained from the higher level. Therefore, for me to be able to access the people that I needed to recruit it was necessary to get permission to proceed firstly from the MOH and the KCM manager medical services. The REC required proof of study site permission to conduct the
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study but were fortunately agreeable to granting approval based on MOH permission rather than individual permission from each of the facilities.

Ethical approval

Since the study was to be conducted under the auspices of the University of Edinburgh (UoE), university approval for the study was sought through the College of Humanities and Social Science REC. Conducting the study in another country meant that time and financial constraints would be more pressing necessitating even more thoughtful forward planning. The applications for ethical clearance were submitted three months before the planned date for starting fieldwork. I planned to start the first phase of the study by September 2007 and complete it by December of the same year. No problems were encountered in obtaining consent from the UoE college committee; consent was obtained at the beginning of June (appendix 6). The UNZA REC secretary had informed me that the committee meets once every month so I was hopeful that with a three month lead time I could get their consent in time for me to start my research at the planned time. However, consent was not obtained from the UNZA REC until mid-October (appendix 7). This was mainly due to delay in communication of the committee’s recommendations. The main concerns raised were around issues of supervision and authorisation from the study sites.

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5 I had already made contact with all the institutions that I was going to work with and they had all given me their verbal assurances that permission to proceed would not be a problem with the necessary REC and MOH approvals.
6 The REC forms did not come with any instructions for the inclusion of proof of study sites’ permission, therefore, this had not been included in the application and had to be sought after the recommendations were received. This caused further delay in obtaining ethical committee approval. The recommendation to appoint a local supervisor was something the study team had already considered and were actively pursuing.
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Site approvals

Once authorisation was obtained from the MOH (appendix 8) and the REC, authorisation from all the other levels was problem free. Gaining approval was facilitated by two factors:

1. The study was addressing an area identified as a national priority health area and would contribute to informing HIV/AIDS programme management as evidenced by the approval letter from the permanent secretary of the MOH, which reads in part:

   The aim of this study ... is indeed important and in line with the current Ministry of Health strategy to provide quality health services on HIV/AIDS prevention and control. In this regard it is important that findings ... are effectively communicated ... so that they inform policy and action.

2. At the time of the study I was (and still am) an employee of KCM. Before my current job I had worked for the MOH at various levels including both clinical and administrative positions in Chililabombwe, Chingola and Lusaka. This meant that at one time or other I had worked with almost all of the people I was dealing with and fortunately I had a good relationship with them. This was obviously to my advantage in gaining approval and buy-in from the various levels but had its downside when it came to the level of the participant. I discuss this aspect further in section 5.9.7. Lofland and Lofland (1995) encourage making use of such “connections” to expedite access to a site or to participants.

5.8.2 Recruitment

The plan had been to arrive in Zambia early August 2007 and begin recruitment in the first week of September. Due to the delay in obtaining
ethical approval, recruitment only started in late October; two months later than originally planned. This had repercussions on recruitment since it meant that I was beginning the study in the rainy season whereas I had hoped to have at least two months of the dry season to recruit participants. When it rains in Zambia it is usually a heavy downpour that discourages people from going out. In addition this is also the beginning of the farming season and most people maintain seasonal gardens at a distance from their homes in which they grow mostly maize (corn). The distance to the fields usually necessitates that people temporarily move to the gardens to till the land and plant. This meant that some people who may have wanted to attend for VCT might have been discouraged by the weather or needed to tend their fields first. A few of the participants did actually say that they had delayed coming because they had gone to the fields.

While awaiting ethical approval preparations for recruitment and data generation were finalised: translation of information sheets, consent forms and the interview guide; recording the information sheets; practice interviews (provided the opportunity to develop a more comfortable question flow and refine clarity of questions especially the ones in the local language) (Barbour, 2008, Lofland and Lofland, 1995); discussions with all relevant stakeholders — provincial health director, district directors of health, KCM manager medical services, medical superintendents, nursing officers, sisters-in-charge, counsellors — to appraise them about the study, get their buy-in and approval and agree on working arrangements including the identification of rooms that could be used for the interviews.

7 An economically important activity since maize is the raw material for the staple food, a stiff porridge made from maize meal.
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Counsellors to help with the recruitment were identified with the help of their respective supervisor. I met with the identified counsellors as a group when possible\(^8\) or individually, to discuss the study rationale and purpose, our respective expectations and agree on a “modus operandi” for the recruitment. All the counsellors that were approached agreed to help even though the only recompense I could offer was a little extra phone credit for their mobile phones. A total of twelve counsellors were recruited. The counsellors were each provided with a study information sheet and the inclusion and exclusion criteria conveniently printed on a small sheet of paper, about a third the size of an A4 sheet for easy reference. Eligibility criteria for recruitment included; clients self-presenting as individuals for counselling and testing, attending VCT for the first time, were 18 years\(^9\) of age or older and testing negative.

One-to-one interviews: recruitment and follow-up

Participants were recruited by the counsellor following VCT. Individuals interested in participating were referred to me and were seen either on the same day or as soon as possible after the counselling and testing session (within two weeks at the most). Initially recruitment at any particular centre only took place on days and times when I was physically present at the site and able to conduct the interview immediately or soon after the VCT session. However, it became evident early on that recruiting in this manner was too slow and the recruitment strategy was changed to an appointments based one whereby a client willing to participate was given an appointment to come back on a date and time when I would be at the facility.

\(^8\) Most of them being nurses with other general nursing duties at the health centre meant that they were working in shifts and were not always in the same shift.

\(^9\) Consent is required from the guardian before young people under the age of 18 can be tested, except for pregnant girls and young mothers (UNAIDS, 2000b).
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Three months into the study it was decided that in order to gain more insight, primarily into the support needs of people living with a negative result, recruitment should preferentially target individuals with a higher profile of risk behaviour than those already interviewed and to include people presenting for a repeat test a year or more after their last test. However, this proved to be difficult criteria to fulfil since recruitment had to rely upon people self-presenting for VCT within a limited time frame and therefore, was basically out of the researcher’s control. Barbour gives an example of a similar experience (see Barbour, 2008: p58).

For the follow-up interviews twenty-eight participants were contacted by mobile ‘phone, seven by home address, three turned up spontaneously and four could not be traced. All participants had been given a thank you card after the first interview with a date for the follow-up interview. Initial contact was made within two to four weeks of the agreed meeting date to either confirm the same date or agree on a new date if the original date was no longer convenient for the participant. The option of a telephone interview was available for participants with distance or time constraints.

At the end of the second interview participants were offered the opportunity to review the first transcript. This was to provide them with an opportunity to verify that their perceptions, views and opinions had been accurately transcribed. The first couple of participants appeared reluctant to read the transcripts immediately after the interview so I resorted to giving them the transcript to read in their own time and return it within an agreed time frame with their comments. Transcripts were provided in the language preferred by the participant. Participants were informed that if the transcript was not returned then it would be assumed that it was an accurate representation of
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what they remember to have said. Two participants provided feedback; one to say he was happy with the transcription and the other one to ask for the removal of a comment he had made about a housemate’s state of health.

Apart from getting participant validation I felt that providing participants with this opportunity would serve to make them feel a part of the process and provide some assurance that they were not going to be misrepresented. Even though not getting feedback does not necessarily mean that the person is in agreement with what has been transcribed, it still provides some level of assurance because they have been provided with the opportunity and if there was anything that they strongly disagreed with, I believe they would have responded.

Thirty-one follow-up interviews were conducted. The reasons for failure to conduct second interviews are shown in table 5.2.

Table 5.2: Reasons for not conducting follow-up interviews

<table>
<thead>
<tr>
<th>No.</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Could not be traced</td>
</tr>
<tr>
<td>4</td>
<td>Appointment confirmed but did not show up for the interview</td>
</tr>
<tr>
<td>1</td>
<td>Too busy</td>
</tr>
<tr>
<td>1</td>
<td>Moved to another town</td>
</tr>
<tr>
<td>1</td>
<td>Changed phone number after initial contact</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
</tr>
</tbody>
</table>

Of the four that did not show up for their interviews, three were rescheduled but they did not show up again and one could not be contacted after the initial telephone call. If a meeting was rescheduled twice and the participant did not turn up both times then it was assumed that they were not interested in participating again but seemed unable to say no. Telephone interviewing was considered as an alternative way of getting some information from those that could not make it for a face-to-face interview. Only one participant could
be contacted and offered this option. The rest could no longer be contacted on the numbers they had earlier provided – this appeared to confirm the assertion that they did not wish to participate any further.

**Focus group discussions: recruitment**

Participants for the focus group discussions were recruited through the respective medical superintendents and district directors of health. Letters were written requesting the nomination of between six to eight counsellors to take part in the pilot focus group discussion and for permission for between five to seven named counsellors from each participating centre to take part in focus group discussions. Permission was granted and I was provided with lists of nominated counsellors and referred to a senior person within the hospital and the district health office to help me get in touch with the nominated people. A pack consisting of an invitation letter, information sheet, consent form, basic demographic data pro-forma and consent for photographs was sent to each person with the request to return the signed consent forms by a particular date if they were willing to participate. Contact details were provided for any questions and clarifications. To secure participation, participants were also contacted by phone and seen personally to ensure they understood what was being asked of them and their rights (see Morgan, 1995). The majority had never participated in a focus group discussion so the most common question was “what is a focus group discussion and what am I expected to say and do?”

5.8.3  **Sampling: one-to-one interviews and focus group discussions**

The question posed by this study is complex; it involved delving into individual and not only personal but also sensitive and complex behaviour and a complex intervention. Therefore, the question demanded an approach
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that would permit the discovery of new insights allowing for a deeper depth of understanding, hence the choice of a qualitative approach (Willig, 2004). Since qualitative research makes no claims to statistical generalisation to the wider population (Bowling, 1997, Barbour, 2008, Rice and Ezzy, 1999), but is instead interested in understanding phenomena, it relies on non-random rather than random sampling methods and does not concern itself with sample size calculations. Purposive sampling suits qualitative research well because it allows for the deliberate selection of people or units who will provide the most useful information – sampling with a purpose in mind (Blaike, 2000, Punch, 1998, Creswell, 2007, Denzin and Lincoln, 2000).

Sampling for this study was purposive both at the level of settings and participants (see Creswell, 2007: p126). A deliberate effort was made to reflect the full diversity of facilities and people testing negative and providing counselling services, so as to maximise diversity of perceptions (Flowers, Duncan and Knussen, 2003, Mays and Pope, 1995). This is referred to as maximum variation sampling and is considered to be the ideal approach to sampling in qualitative research (Creswell, 2007, Punch, 1998). Two centres were selected in each town, one public and one private.

One-to-one interviews

Selection of interview participants was based on VCT centre workload in terms of number of HIV negative clients attended to over an identical twelve month period in each site. The number sampled from each centre was proportionate to the number of negative clients that each centre attended to in 2006. Participating VCT centre attendance for 2006 provided a sampling grid (table 5.3) for the study population according to age group and gender (see Barbour, 2008: p57-59). Participants were recruited from clients self-
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presenting for VCT. It was decided to over-recruit for the initial interviews in an effort to cushion any attrition that would occur during the follow-up interviews. The grid worked quite well with the only major deviation from the planned combination being a smaller number of female participants.

Table 5.3: Sampling grid

<table>
<thead>
<tr>
<th></th>
<th>Chingola Gov. (Kabundi)</th>
<th>Chingola Private (Nchanga Health Centre)</th>
<th>Chililabombwe Gov (Kakoso)</th>
<th>Chililabombwe Private (Konkola Mine Hospital)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
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<td></td>
<td>14</td>
<td>6</td>
<td>7</td>
<td>13</td>
<td>40</td>
</tr>
<tr>
<td>Age (yrs):</td>
<td>Number of participants</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50+</td>
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</tr>
<tr>
<td>45-49</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>35-39</td>
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<td></td>
</tr>
<tr>
<td>25-34</td>
<td>13</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>20-24</td>
<td>13</td>
<td></td>
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<td></td>
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<tr>
<td>18-19</td>
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<td>Female</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>21</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Focus group discussions

Participants for the pilot focus group discussion were recruited from among counsellors working in VCT centres, in Chingola, that did not participate in the study. Chingola was selected because it is a larger town with more VCT centres than Chililabombwe therefore it was easier to mobilise focus group participants from centres that were not part of the study.

Participants for the focus group discussions were recruited from among counsellors providing services at the four study sites. Effort was made to
ensure inclusion, in all groups, of the range of experience, gender, age and
counsellor background available in the VCT centres.

5.8.4 Sample size

One-to-one interviews

It is usually not possible to provide a fixed sample size for a qualitative study
because of the iterative nature of qualitative research which makes it difficult
to calculate or provide a sample size before the research begins. Usually
recruitment will go on until further interviews or observations do not add
any further new insights on the phenomenon under study (Rice and Ezzy,
1999, Thompson, 1999, Bowling, 1997). However, using evidence from the
literature and advice from experienced qualitative researchers it was possible
to provide an estimate of the number of people that would probably need to
be recruited to provide theoretical saturation, that is, the point after which
interviews do not provide additional insight into the categories that have
been developed (Creswell, 2007). It was estimated that a sample size of up to
40 would be adequate (Creswell, 2007, Guest, Bunce and Johnson, 2006)

Focus group discussions

The number of focus groups depends on the:

● Purpose and design of the study

● The number of subgroups required which may be determined by the
  comparisons one wishes to make or a topic that requires separate groups
  based on, for example, gender, age, hierarchy in organisations

● The resources available

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Recommendations on group size vary. Most authors recommend a minimum of six (Kitzinger (1995) recommends four) and the maximum did not go beyond twelve (Barbour, 2008, Berg, 1995, Payne, 2007, Rice and Ezzy, 1999, Krueger, 1995). The group is supposed to be large enough to enable a meaningful discussion (full participation producing varying views) and small enough to be managed by one moderator and to make sense of the resultant transcription (Payne, 2007). It is argued that if there are less than six participants and the topic is not one that they are familiar with, it may be difficult to get a discussion going and very few people may contribute, and that it may be difficult to manage a group of more than eight (Rice and Ezzy, 1999). Kreuger (1995) advises the use of smaller groups when the topic to be discussed is complex or if the participants are all well versed in the topic of discussion.

The plan was to include as many as possible of the counsellors working at the participating VCT centres. Since the number would then be too large to accommodate in one focus group and the VCT centres were in two different towns, two focus group discussions were held, one in each town, in addition to the pilot focus group discussion. Following Barbour’s (2008) and Morgan’s (1995) advice I deliberately over recruited to compensate for no-shows.

5.9 Data generation

The data generated in this study are regarded as co-constructed by the interviewer and the interviewee/focus group participants. The characteristics of either have an influence on the other and the way the questions are asked and answered has a bearing on what kind of data are produced (Holstein and Gubrium, 1995).
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A pro forma\textsuperscript{10} (appendix 9) (Barbour, 2008) was used to collect participant demographic details for both the one-to-one interviews and the focus group discussions to allow for description of the study sample and comparative analysis within the sample. The registers and KCM CT data forms were consulted to compare, where available, risk behaviours and reasons for testing given by the client in the counselling session. The initial interviews were conducted from 29 October 2007 to 6 February 2008, the follow-up interviews from 30 April to 28 August 2008. The pilot focus group discussion was conducted towards the end of the second round of interviews on 31 July 2008. One focus group discussions was conducted in Chililabombwe on 6 August 2008 and the other in Chingola on 15 August 2008. All interviews and focus group discussions were digitally recorded.

5.9.1 Interview schedule

The interview schedule was developed based on the research questions as detailed in chapter 1. The questions on the schedule were narrower; focussing in on the detail subsumed in the research questions so that when taken in combination the responses to these questions would provide an answer to the research question and contribute to achieving the intended aims (Creswell, 2007). The questions were open-ended and partly informed by concepts from behaviour change models and the literature (Berg, 1995), especially those pertaining to self-perception of risk. The schedule was designed to begin with rapport building and questions that would encourage the participant to open up. The more personal questions were in the middle and the closing question was an open invitation to the participant to say

\textsuperscript{10}This is similar to what Flick (2006: p288) calls a “documentation sheet” used to capture interviewee and context characteristics required for contextualizing the research and findings.
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whatever else they felt they would like to say. This follows the advised standard format of an interview schedule (Creswell, 2007, Willig, 2004, Barbour, 2008). In practice, however, the flow of questions was determined by the direction the participant took in their response to the first question. Some participants were volunteering quite personal information early on in the interview and these were then discussed. This is a desired feature of interviewing in qualitative research, letting the participant lead and probing to get more in-depth information and when seeking clarity as it provides for the generation of data that is less driven by the researcher’s preconceptions (Willig, 2004, Barbour, 2008). In a research with an agenda to fulfil this has to be skilfully balanced against unobtrusively guiding the interview so that all the questions that need to be covered are covered (Willig, 2004). Such an interviewing style allows for the generation of richer data than one that places stricter boundaries on the flow of questions. The questions on the interview schedule were carefully formulated with the aim of avoiding directive questions and encouraging expansive in-depth responses (Willig, 2004).

The first interview aimed to explore:

• The decision making process for HIV-testing behaviour
• Perceptions of and attitudes to VCT, HIV/AIDS IEC materials, antiretroviral therapy, sexual risk behaviour, and a negative test result
• Future plans and sexual behaviour intentions
• Personal impact of VCT and a negative result
• Felt needs.

The follow-up interview focussed on exploring:

• The experience of living with the knowledge of a negative HIV status
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- Facilitators of and hindrances to sexual behaviour change
- Subsequent testing behaviour and felt needs

The schedule for the follow-up interviews included all the areas covered by the first interview to allow for the assessment of the influence of time on perceptions, attitudes and behaviour. Four slightly different schedules were prepared for the follow-up interview to cater for people who (1) had not had a repeat test, (2) had a repeat test and received a negative result, (3) had a repeat test and received a positive result, and (4) those that would opt for a telephone interview. Due to cost considerations the telephone interview schedule only covered what were considered to be the most essential areas. The schedules for the initial and follow-up interviews are available in appendix 10 and 11 respectively.

It is advisable to pre-test schedules to ensure that the questions elicit the responses that will serve the purposes of the research and are easily understood (Berg, 1995). The first ten interviews served as a pilot for a number of issues (Creswell, 2007): the interview schedule; the recruitment process; and administration issues around availability of rooms to use for the interviews and of counsellors. In addition these ten interviews also provided practice in conducting semi-structured interviews following personal training in the technique. Barbour advises the use of piloting to hone research questions and to develop a progression through the interview that is comfortable for both interviewee and interviewer (Barbour, 2008). The decision-making process that preceded VCT attendance was initially explored to provide historical context to the experience of voluntary counselling and testing. However, as data analysis and generation proceeded it became clear that this could be a critical period influencing the experience
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of counselling and testing and subsequent sexual behaviour. This area was therefore elevated to a core research area within the study addressed by a specific aim and further probes were developed to cover finer details in the decision making process.

5.9.2 Focus group discussion schedule

The focus group discussion schedule was designed along the same principles as the interview guide. A schedule with five\textsuperscript{11} broad questions and subsidiary probes was developed and pre-tested in the pilot focus group discussion. The purpose was to assess the effectiveness of the ice-breaker/stimulus, assess the effectiveness of the questions in stimulating discussions relevant to the purpose of the research (see Barbour, 2008), and to address any organisational problems. The focus groups were to be run with the help of an assistant\textsuperscript{12}, therefore, the pilot group session also served as a practice run for both the facilitator and assistant.

5.9.3 Consent and process

One-to-one interviews

Counsellors were instructed to ask clients who had tested negative and fulfilled the inclusion criteria if they would be willing to talk to a doctor who was doing a research study on HIV/AIDS. If the client was willing the counsellor would either direct them to the room I was working from or personally bring them over and introduce them. If I was not at the centre they made an appointment on my behalf or they called me so I could personally talk to the client and agree on a date, time and place for the

\textsuperscript{11} The original schedule had six questions but one was removed following the pilot testing of the schedule

\textsuperscript{12} Non-researcher, male full-time psychosocial counsellor at KCM HIV/AIDS resource centre with a background in human biology and project management
discussion. The use of the word “discussion” on the information sheets and consent forms was deliberate. I wished to portray the meeting as a dialogue between two people with a common interest, playing down the anticipated power dynamics that would be at play in the interview since it was a possibility that I would be viewed as ‘learned, more knowledgeable than they, so what could I possibly learn from them?’ The information sheet (appendix 12) had also been carefully phrased to put emphasis on the participant as the expert, in the area under study, whose opinion was being sought. A few of the interviewees did actually state that I was the learned one so I should be telling them; I managed to convince some of them that I was interested in what they had to say about things not what they knew but a few adamantly stuck to their position resulting in a couple of very difficult interviews which were more of question and answer sessions than semi-structured interviews (Lofland and Lofland, 1995).

All the interviews were conducted in one of the rooms at the health facilities. Effort was made to get the quietest room available but this was not always possible and a few interviews were conducted in quite a noisy part of the facility making transcription difficult.

Rapport building and information giving

I welcomed the client into the room, made sure they were comfortable, introduced myself and asked for their name and preferred language. This was done as part of the rapport building routine since it is not possible to get an interactive discussion going without rapport between the discussants (Willig, 2004, Punch, 1998). When the client was more or less settled I proceeded to inform them about the purpose of the study, their expected involvement and rights. The purpose of the study was simply explained as
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an attempt to learn more about the VCT process and service from the users of the service so as to improve the service. I took care to impress upon them that their participation was voluntary and non-participation would in no way impact on their use and access to health care and services. If the client was still willing to participate they were provided with an information sheet in either English or Bemba according to their preference and given time to read it. The client was also offered the option of listening to a recorded version of the information sheet or they could opt to have it read out to them.

Obtaining informed consent

After ensuring that the client had understood what was on the information sheet by going over the pertinent points and asking them if they had any queries or points that they were not clear about I then proceeded to obtain signed consent. The consent form (appendix 13), which had also been translated into Bemba, listed the study expectations and participants’ rights, and required the client to acknowledge each item by accepting it or not and then to finally sign the form if they were still willing to participate in both interviews. The form included the fact that the interview would be digitally recorded and the recording stored securely for five years after which it would be completely erased.

Conducting the interview

Before beginning the interview, I reassured the participant about protecting their privacy, reminded them that I was interested in what they had to say and so they would do most of the talking, and encouraged them to feel free and share openly as that was the only way we could learn more about the service and be able to improve if necessary. The opening question was a broad general question asking them to tell me about how they had made the
decision to come for counselling and testing. Progression through the rest of
the schedule was determined by the interviewees’ responses. The flow of the
interview was therefore, generally directed by the interviewee unless in the
few cases where I had the misfortune to have a shy or recalcitrant
interviewee accepting to participate. I made a conscious effort during the
interviews to let the interviewee do most of the talking, prompting and
probing at relevant times. Tolerating silences was acutely difficult in the first
few interviews but it is an essential skill to develop to allow the interviewee
time to reflect and think thereby providing information that is of more depth

At the follow-up interview consent was again obtained to ensure that the
participant was still willing to continue with the study.

The duration of the initial interviews ranged from 17-46 minutes and the
follow-up interviews ranged from 18-80 minutes.

**Focus group discussions**

The focus group discussions were moderated by me with the help of an
assistant who helped with taking notes on the sequence of speakers (Barbour,
2008, Patton, 2002). He also provided me with helpful and useful feedback on
the sessions. My role in the discussion was to:

- Introduce the focus and purpose of the discussion
- Guide the discussion by posing questions or probing further at appropriate
  points in the discussion
- Encourage participation by drawing in individuals who were not saying
  much and reining in those who threatened to dominate the discussion
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The groups would have been very difficult to run without an assistant as it would have meant dealing with multiple tasks simultaneously which would have resulted in poorly run focus groups (Barbour, 2008).

I began the group discussions by introducing myself and my assistant. I then provided an overview of the study and the purpose of the focus group discussion, and explained what was expected of the participants. Issues of collective confidentiality and mutual respect were stressed. The set-up, tone and pace of the discussion were designed to create a relaxed informal atmosphere that would encourage an open discussion (see Kitzinger, 1995). To “break the ice” and facilitate an interactive discussion an opening question was posed to all individuals (box 1) (Flick, 2006, Barbour, 2008).

Box 5.1 Opening question for focus group discussions

| To begin with let us get to know each other. Would you kindly each introduce yourselves by telling us your name, which institution you are coming from and very briefly, how you personally conduct your VCT sessions? Evans*, do you mind taking the lead and then we’ll go round the table? |

*Name has been changed to protect identity

This introductory round also served to link each person’s name and voice on the recording making it much easier to transcribe the discussions. The brief comments on how they personally provide counselling and testing were designed to get them to focus on the subject and stimulate discussion (Barbour, 2008).

The pilot and the Chingola focus group discussions were conducted in the nurses’ tea room at Nchanga Mine Hospital. A round table was provided for the focus group discussion. The Chililabombwe discussion was conducted in
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the meeting room at Konkola Mine Hospital, participants sat around an oval table. Refreshments and snacks were provided before the discussions began and individuals were free to help themselves to these during the course of the discussions. Very few actually did though. They got so caught up in the discussion and did not want to disturb the flow.

On average the focus group discussions took about two hours.

5.9.4 Incentives for participation

No incentives were offered for participating in the study. Participants were provided with transport refunds. The majority were not aware of this until after the first interview or after the focus group discussion except for the few who were asked to return for an appointment, who had been assured of a transport expenses refund.

5.9.5 Lessons learnt from pilot interviews

Organisational:

● It became clear during the pilot that recruiting only on days when I was physically present at the site would not result in a sufficient number of participants and the strategy was changed to an appointment-based recruitment.

Interview schedule and process:

● The pilot interviews were particularly of benefit in improving my confidence and familiarity with semi-structured interviewing. Self-reflection\textsuperscript{13} and feedback on the interview process were useful in making

\textsuperscript{13} After each interview reflective notes were written and areas requiring improvement noted. Listening to the recorded interview while transcribing also provided an opportunity for reflection on the interview process
me more aware of how I was phrasing questions and using or not using probing questions.

- Getting in-depth useful responses to the question on how helpful VCT had been for the person proved to be difficult. Through a process of trial and error the question was re-phrased and supplemented by the use of relevant probes and prompts.
- Data from the pilot interviews led to the realisation that the decision making process seemed to be playing a significant role in the whole process and this led to a revision of the aims to include one that specifically addressed this area.

5.9.6 Lessons learnt from pilot focus group discussion

Organisational:

- A pro-forma to capture participant demographic characteristics and photograph consent forms was given to each participant upon arrival. This served to delay the start of the discussion as some people arrived late and also created some fluster at the beginning which did not auger well for a calm relaxed atmosphere. For the subsequent groups these were delivered to the participants with the invitation pack mentioned earlier and provided for a much smoother beginning to the discussions.
- Oversight and overlap were noted in facilitator and assistant roles which were streamlined facilitating a much more productive partnership
- Due to the large number of late-comers it was decided to ask participants to come thirty minutes earlier to allow time for refreshments and snacks.

Focus group schedule and process:

- The opening question was not specific enough as people went on to share counselling strategies in other psychosocial areas unrelated to VCT,
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otherwise it worked well in getting everyone to talk. It was made more specific for the subsequent groups.

- There was not much discussion generated on question two which asked about their perception of a “good VCT” session as all the participants seemed to hold very similar views. Therefore, this question was removed from the schedule and participant’s perception on this area was sought through asking them to make a comment on it during the closing round.

- I personally learnt that I needed to manage the group better in terms of maintaining focus and moving on to avoid running out of time before all the questions were covered.

5.9.7 Reflection on my position in the interviews

How to present oneself in a research setting is a question that every researcher faces and has to answer for themselves depending on the context of the research, ethical concerns and what their intentions and aims are (Barbour, 2008, Lofland and Lofland, 1995).

I decided to disclose my professional background even though I knew this might have its disadvantages in the status the interviewee would accord me in the interviews and predispose them to providing me with what they feel are the appropriate views since I would be perceived as part of the health system and hence the VCT service. My hope was that this would be partly offset by telling them that I was away at school and therefore, not actively part of the system at that time. Although the fact that I was in a position (from their perspective) to actually be able to do something about the service may have also encouraged some honest responses. The reason I decided to do so was two-fold; firstly the two towns in which I was conducting the study are small and I have worked in both so the chances were high that
some participants would actually know who I was anyway and would wonder why I didn’t introduce myself as such – deception even by omission does not augur well for a trusting relationship (cf Colbourne and Sque, 2004, Richards and Emslie, 2000). Secondly I felt that participants would be more likely to agree to take part if they were told it was a doctor who wanted to talk to them. As discussed earlier this resulted in some problematic interviews but on the whole I believe it did work to my advantage. Being an “insider” (Lofland and Lofland, 1995) as in being a trained, though an inexperienced and non-practising, psychosocial counsellor had more disadvantages than advantages for me though. It made me more prone to making assumptions and not following up on some answers that would have provided more in-depth information. Although, knowing this from the outset I made deliberate effort to not make assumptions by asking for clarification on points that would otherwise appear obvious (Willig, 2004, Barbour, 2008). I was not always successful though and on reflecting on my sixteenth interview which was with a twenty year old young man I realised I would have got more useful information about the influence of counselling on this young man if I had probed further to find out what exactly had been said to convince him that he could live positively with HIV and not bother about stigma. I assumed it was the usual things that counsellors say, missing the opportunity for a potentially different perspective. This limits what I can say about how counselling influenced this young man’s perceptions. A contributing factor in this particular interview was that this was one of the few interviews where the participant had a very limited amount of time to spare and was not willing to reschedule, therefore, I was acutely conscious of the time. I had decided to proceed with this interview even with the time constraints because (1) the client had agreed to participate and I didn’t want
to disappoint him and (2) I considered that some additional data would be better than none.

5.10 Data management and analysis

Data were collected in the form of digital recordings that were downloaded to a secure, password-protected personal computer (PC) as soon as possible after the interview.

Forty-two initial interviews were conducted; one recording was lost before transcription resulting in 41 interviews with a full transcript, notes were made of the lost interview. Thirty-one follow-up interviews were conducted including one telephone interview resulting in a total of 73 transcripts of which 30 were paired.

The downloaded interviews were transcribed verbatim as soon after the interview as was practically possible within the time frames between individual interviews. Transcripts in the local language were then translated into English by a team of three including the researcher. The bulk of the transcribing was done by the researcher (all the focus group discussions and 20 of the 31 interviews). Transcription was time consuming and the need to translate 37 of the transcripts added to the time demands. A total of approximately 43 hours of individual interviews and 6 hours of focus group discussion recordings had to be transcribed and this took a total of about 307 hours. However, this process allowed for greater understanding and familiarisation with interview contents and facilitated reflection on interview technique—especially in the early stages—and analysis (Lofland and

14 All were native Bemba speakers and fluent in English. The other two were male primary school English teachers.
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Lofland, 1995, Payne, 2007, Richards and Morse, 2007). Findings from the pilot group discussion were included in the analysis as they also provided useful insight into counsellors’ perception of VCT and the needs of VCT clients.

5.10.1 Translation

Translation aimed at conveying the meaning of what was said and not a literal representation. Translating literally would have resulted in mostly incomprehensible transcripts since the context in which a word is used conveys the meaning and some words or phrases are local slang. Take for example the following quote in Bemba from a 40 year old married female:

*Ba njeba ati” awe teti tu cite, first tu ku cite counsel”, so elyo ba citile, nanti oh kanshi efyo fye enda*

Translated literally this would read:

*She tells me that “no we can’t do, first we counsel you”, so when she did I said to myself “oh, so that’s how it moves”*

This is what she was saying:

*She told me that “we cannot take blood before the counselling”, so that’s what she did and I said to myself “oh, so that’s the procedure”*

Because of the difficulty of conveying the nuances of speech, translation inevitably results in loss of some of the original nuance of the original spoken word. In the above example, in translating the slang phrase “efyo fye enda” there is loss of the depth of the associated feeling of discovery conveyed by use of the phrase (see Birbili, 2000, Temple and Young, 2004, Suh, Kagan and Strumpf, 2009, Larkin, Dierckx de Casterle and Schotsmans, 2007).
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5.10.2 Descriptive statistics
To facilitate description of the study group basic demographic data were collected and information on self-reported risk behaviour obtained from the interviews was used to classify people as either “higher risk” or “low risk” using the UNAIDS definition.

Definition of risk behaviour
In high HIV prevalence settings the levels of risk in relationships are more difficult to differentiate. The difference between “high risk” sexual partners and “low risk” partners such as husbands is blurred (UNAIDS, 2000a). Acknowledging that both relationships are associated with a level of risk, the UNAIDS guide to monitoring and evaluation for national AIDS control programmes defines “higher risk” sexual behaviour as “sex with any non-cohabiting, non-marital partner” (UNAIDS, 2000a: p81). It is acknowledged, though, that unprotected sex, that is, sex without the use of a condom is more risky than sex with a condom. This definition of “higher risk” sexual behaviour was adopted in presenting the levels of sexual risk behaviour in this study. This definition may mask differences in actual level of risk due to other factors, such as concurrent partners and use of condoms, these differences have been highlighted to give a clearer picture of the actual risk pattern in the study group. A person was classified as practising safer sexual behaviour prior to testing if they had been consistently practising this behaviour for six months or more, based on Prochaska, DiClemente and Norcross’s (1992) definition of maintenance of behaviour change.

5.10.3 Computer assisted qualitative data analysis (CAQDAS)
To facilitate data management and analysis transcripts, that had been edited to ensure accuracy of transcription, were imported into Nvivo7; a qualitative
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data analysis software. As Kelle (1997) discusses in his paper ‘Theory building and qualitative research and computer programs for the management of textual data’, the use of computer packages for the analysis of qualitative data has been viewed with some misgivings by some qualitative researchers who argue that: the packages are aligned to particular theoretical frameworks thereby stifling the diversity that is characteristic and desired of qualitative research; they distance the researcher from their data and present the data out of context; and they will take over the analysis.

Kelle counters some of these arguments by showing that the packages are not tied to any one particular theoretical perspective as they use the basic approach to analysis that is common to most perspectives; it is the terms used that are characteristic of particular approaches e.g. coding in Nvivo is a term borrowed from grounded theory. Analysis of the data is one task that still has to be done by the researcher. Kelle (1997) blames the perpetuation of this myth on the use of terminology such as ‘software for qualitative data analysis’ and suggests that these programmes be addressed as “software for ‘data administration and archiving’” to clarify their purpose. Berg (1995) illustrates the incapacity of current day computer programmes to perform analysis by highlighting the point that even though programmes for quantitative data analysis are able to provide a variety of statistical results they equally need the researcher to make the analytic decision of which tests to apply and how to interpret them. He concludes his argument by stating that for computers to attain this level of sophistication requires the “perfection of artificial computer intelligence” which is not something that will be available any time soon.
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The problem of decontextualising the data has been ameliorated in recent versions of most programmes by allowing easy viewing of the context from which the data segment was drawn, for example, in Nvivo the data segment can be linked back to the source and viewed in context (Gibbs, Lewins and Silver, 2005).

In the beginning I used Nvivo basically as a data management tool – storing, organising and retrieving data. I did most of my initial coding on the printed transcripts. As I became more familiar with the programme’s capabilities I slowly moved more and more of my analysis to Nvivo but never actually completely did away with paper and pencil especially when analysing the more complex interrelationships. This is apparently common practice among qualitative researchers (Kelle, 1997, Barbour, 2008). As Barbour advises (Barbour, 2008: p195), I found that learning the principles of qualitative analysis by using manual methods made it easier to make use of only those functions that I felt were useful to me and in ways that served my purposes, thereby maintaining control of the process of analysis. Analysis and data generation were iterative with ideas and preliminary themes identified from the initial interviews informing further data collection. Development of the follow-up interview schedule was particularly influenced by the themes that were being recognised in the data. Analysis was guided by the research questions and aims; themes relevant to the research objectives were inductively derived from the data (see Bowling, 1997: p109). I began coding using what are described as free nodes in Nvivo, that is, nodes that are not related to any other node(s) as opposed to tree nodes which have subordinate nodes; reflecting a relationship (Gibbs, 2002).
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Cross-sectional analysis was conducted on all data sets to identify common underlying themes and paired transcripts were analysed longitudinally to assess change over time.

5.10.4 The process of analysis

Phase 1: Becoming familiar with the data

Authors of qualitative research textbooks advise researchers, especially novice researchers, to personally transcribe at least some of the recorded interviews themselves, and to carefully edit all transcriptions by listening back to the recording. This allows not only for an appreciation of the work involved in transcribing but also creates awareness of the level of analysis required, which determines the extent of transcription: verbatim transcription; include pauses, laughter, coughs; reflect speech volume, pitch and tone; indicate body language accompanying speech. A grounded theory analysis would require a verbatim transcription but discourse analysis, which focuses not so much on what is said but on how language is used, requires more detailed transcriptions (Payne, 2007).

Transcribing most of the interviews myself and editing them and the ones that had been transcribed by someone else, facilitated not only a more intimate familiarisation with the text of each interview but also a more accurate interpretation of the text. Listening to the interviews enabled the clarification of meaning through speech intonation, volume and stress, and the occurrence of pauses and laughter. In addition, listening back also aided recall of the interview situation and the on-going non-verbal communication (Barbour, 2008).
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Phase 2: Initial coding

The process of analysis begins during the interview as the interviewer attends to the interviewee and probes and questions. This is continued immediately following the interview in the writing up of the interview notes and later by listening to the recording, transcribing and editing (Rice and Ezzy, 1999, Barbour, 2008, Lofland and Lofland, 1995). In order to develop ideas on what the data are saying it is necessary to become very familiar with the data. This is referred to as “immersing” oneself in the data (Braun and Clarke, 2006). The familiarisation process essentially began with the initial playing back of the recording, transcribing and editing. This was followed by the reading and re-reading of the transcripts. This process facilitated the identification of initial ideas for codes relating to the research questions and the creation of summary notes on initial thoughts about what the data were saying (Lofland and Lofland, 1995, Braun and Clarke, 2006). Interviews were compared to identify similarities and differences; to facilitate comparison I designed an excel sheet listing all the participants and the emerging themes. Summarised notes were made of findings from each individual according to the themes. To maintain focus on the aims of the study these were structured to reflect the research aims.

The initial coding frame was derived from the research questions (cf Barbour, 2008: p198) and the notes from the initial readings. Boyatzis defines a code as ‘the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon’ (Boyatzis, 1998: p63, quoted in Braun and Clarke, 2006). The initial codes were used as broad categories in which to store segments of data relating to that particular question; below are some of the broad themes and notes. The full list is available in appendix 14.
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1. Contemplation/Action triggers
   - Personal contact with infected/sick relatives or friends
   - Personal or partners risky behaviour
   - Pre-occupation with preservation of self

2. Perception of /Feelings about VCT
   - Ultimate purpose is to know result
   - Allays fears about consequences of positive result

3. Perceptions of HIV/AIDS/transmission/prevention
   - Killer – no life after infection/Life continues
   - Negative status confirmation of partners negative status even if unknown
   - Condoms not trusted/Condoms work/Dislike of condoms – uncomfortable

Contradictory ideas were actively sought and coded. These were used to refine emerging explanations (Willig, 2004, Charmaz, 2000, Creswell, 2007, Glaser and Strauss, 1967).

The coding frame was modified and extended as additional transcripts were read and coded and had extended to seventeen codes by the time the last transcript from the initial interviews was coded. These codes were reviewed and I discovered that they were too broad covering a lot of data reflecting different ideas within them which were all providing a certain aspect of information related to the research question represented by the node. I therefore decided to deconstruct the nodes and create smaller nodes inductively from the coded extracts. Each node was unpicked and re-coded using additional concepts I thought the data were portraying. For example, from the material coded under the node “Perception of /Feelings about VCT”
three codes were developed: benefit of counselling; benefit of testing; and perception of VCT.

This resulted in a coding frame of forty-one codes. By this time I was doing the bulk of my coding using Nvivo. As each transcript was carefully read and re-read phrases or sections of text relating to a particular idea were identified and coded at the node representing that particular concept. If a new idea was identified a new code was created and so on until all the transcripts had been coded through once. This process resulted in a list of codes obtained from all transcripts but not necessarily capturing all the ideas related to all the codes from all the transcripts; since codes were added as additional transcripts were coded. Some individuals expressed ideas that others had also expressed but in such a way that the expression triggered a new concept; therefore, it was necessary to go back and re-code all the transcripts after the full list of codes had been identified (all transcripts from first and follow-up interviews, and focus groups were coded at least twice). Additional codes were created for newly identified ideas; by the end of this exercise the coding frame had lengthened to seventy-eight codes (appendix 15). Additional themes identified during this process include: control; taking responsibility for one’s health; and sensitising others.

**Phase 3: Organising codes into themes**

When I was relatively satisfied that all the ideas from all transcripts that could relate to a particular code had been coded the next step was to review the list of codes and work out any relationships between them. Codes that were theoretically related to each other in some way were grouped and overarching themes identified; codes were also either combined or split further during this stage. At this point it was easier to manage grouped codes
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by converting them to tree nodes, where the theme (which may be one of the codes) has various levels of subordinate codes arranged beneath it in a hierarchical manner (Gibbs, 2002). For example the node ‘benefit of counselling’ was subsumed under the tree node ‘counselling process’, a section of which is shown below:

Counselling process
- Advice_Guidance
- Empowering
  - Advocacy
  - Enhanced understanding
  - New knowledge
  - New skills - use of condom

This process was facilitated by the visual representation of the relationships between the codes and themes using paper versions of mind-maps and the modelling facility provided by Nvivo. Modelling in Nvivo allows for easier manipulation of codes and themes and the relationships between them. The relationship between the codes in a theme was then expressed in prose. This process was helpful in facilitating a more critical and in-depth analysis of how the codes within each theme related to each other and to the theme and how the different themes were related. The initial thematic map is provided in appendix 16. The final thematic maps for each aim are provided in chapters 7, 8 and 9.
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Phase 4: Reviewing the themes

The data extracts within all the codes making up a theme were then reviewed to ensure that they were logically supporting the theme. Dynamic models—updated automatically when any changes are made in the coding—facilitated the collection and viewing of all the data extracts coded at a theme. The shapes representing a project item (may be a code, interview transcript or any other item in the project) in the Nvivo models are linked to the item, therefore, data extracts within each code were viewed directly from the model. During this process some codes were removed or combined, some were moved around and others were created. For example, the codes ‘Time’ and ‘Accessibility’ were moved from the tree node ‘Restrainers’ under the theme ‘Emotional and mental work’ to a newly created tree node ‘External barriers’ which was linked to another new node ‘Attend VCT and test’.

The themes were then reviewed to ascertain their validity in relation to all the transcripts. The transcripts were re-read to ascertain that the themes were reflecting what was contained in the transcripts. Data that had been missed in the earlier coding were coded. This process resulted in further refinement of the thematic map.

Phase 5: Discovering the story

The codes in each theme were then analysed to determine the “story” that was being told by each theme and how all the themes linked together to tell the overall ‘story’ in relation to the research objectives. The conceptual framework developed from this process is presented in chapter 6.

Phase 6: Writing the story

Writing up the findings of the study involved presentation of themes as they related to each aim and to the overall research question, providing a final
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opportunity for the analysis of the data. The themes were supported by selected extracts of data which served as examples of each particular theme within the data set. To protect participant identity and ensure privacy and confidentiality quotations from interviewees have been identified by age, gender, and marital status. Quotations from focus group participants have been identified by designation, gender and marital status. Source of the quotation is identified as either from the initial or follow-up interview or from a focus group as outlined below:

Age: XXyrs
Sex: Male or Female
Marital status: Married
Single (never married)
Divorced
Widowed
Separated

Designation of focus group participants:
Nurse
Community volunteer
Data Management Officer
Laboratory technician
Social worker

Initial interview: 1st (superscript)
Follow-up interview: 2nd (superscript)
Focus group - pilot: FGpil (superscript)
Focus group 1: FG1 (superscript)
Focus group 2: FG2 (superscript)
Interviewer: Int:

For example, a quotation from the initial interview transcript of a 25 year old single, male interviewee will be identified as: 25yrs, male (single)\textsuperscript{1st}. In cases where two or more people had identical demographic characteristics, the individuals are differentiated by a superscript number, for example, 25\textsuperscript{1}yrs, male (single)\textsuperscript{1}. 
Chapter 5 – Methods

Consistent with the qualitative approach, the above process was iterative and not as straightforward as presented. It is in the interests of clarity that the process has been presented in such a sanitized manner.

5.11 Credibility check

A randomly selected sample of transcripts were independently broadly coded by three other individuals with varying levels of qualitative data analysis skills and two experienced qualitative researchers. The purpose of this exercise was to ensure that the transcripts were being mined as thoroughly as possible for all possible themes and to provide some level of verification for the codes I was identifying. This, as Mays and Pope (1995) point out, is one of the ways to provide a certain level of assurance about the reliability of the analysis, in the same vein Willig (2004) refers to this as a “credibility check”.

5.12 Ethical considerations

Ethics govern the conduct of research be it quantitative or qualitative. Historically the need for ethical consideration in the design and conduct of research was brought to the fore with the uncovering of a series of atrocities perpetuated in the name of research; beginning in the 1940s with human research in the Nazi concentration camps of World War Two (Kor, 1992), the Tuskegee syphilis study (Caplan, 1992) and others in the USA in the 1960s – 1970s, and HIV drug trials in Africa in more recent years (Angell, 1997, Lurie and Wolfe, 1997, The Petra study team, 2002). These revelations led to the development of ethical codes and guidelines for the conduct of human research—the Nuremberg code (U.S. Government, 1949), the Declaration of Helsinki (World Medical Association, 1964) and The Belmont
Chapter 5 – Methods

report (1979). The Belmont report identified the three basic principals that must underlie all research on human subjects;

1. Respect for persons – all persons must be treated as autonomous individuals whose participation in research must be with informed voluntary consent and confidentiality must be ensured to protect privacy.

2. Beneficence – the benefits to the person of taking part in the study must outweigh the harm

3. Justice – there must be a fair distribution of the benefits and risks of research, selection of research subjects must be impartial and vulnerable populations and groups must be protected.

To ensure that studies comply with these ethical guidelines institutions were set up requiring the ethical approval of research before it is conducted (Brody, 1998). The World Health Organisation Africa Region reports that there is no such institution in 35% of African countries and is working towards the establishment of research ethics committees in all countries of the African sub region (Kirigia, Wambebe and Baba-Moussa, 2005).

Qualitative research was not routinely scrutinised by ethics committees because this type of research does not involve any physically invasive interventions. However, as in the above scenario, outcries of foul play following some qualitative studies — involving covert research — led to the requirement for qualitative research studies to be subjected to ethical scrutiny (Barbour, 2008).

Ethical considerations permeate every level of qualitative research. Before embarking on a study there is need to determine the need for the study and its impact on those studied and the researcher (Lofland and Lofland, 1995,
Chapter 5 – Methods

Punch, 1998). Research that will be of no benefit to anyone or for anything is unethical as it not only wastes resources but it also wastes participant’s time and puts them at risk of potential harm for no justifiable cause. In the same vein research must be planned and conducted as rigorously as possible to produce useful results. Hence, studies of poor design may be considered unethical.

Informed consent is desirable for the recruitment of any person into a study of any kind. Consent must be given voluntarily without undue coercion, such as large amounts of monetary payments or whatever the REC defines as such (see Barbour, 2008: p80). How much information should be given to fulfil the requirements of ‘informed’ consent is a point of continued discussion; how much detail of the study objectives can be revealed to the participants without compromising the study (Christians, 2000, Lofland and Lofland, 1995) and how much of the provided information is actually understood by the participant in adequate detail to enable them make a truly informed decision (Lofland and Lofland, 1995). Obtaining consent at various points in the study may be necessary. It has been suggested that in qualitative research, where the focus may change during the course of the research, it is better to use the term “process consent”. This term highlights the need for continually assessing the participant’s continued consent to participate taking into consideration any changes to the original research and passage of time (Barbour, 2008).

Once a person has accepted to take part in a study they must be assured of confidentiality. Confidentiality in this study was ensured by anonymising transcripts, storing identifying features separately from the transcripts and storing transcripts, recordings and any other data about participants in
Chapter 5 – Methods

secure locations (locked filing cabinet, password protected personal computer). The participants were assured that only my supervisors and I would have access to the recordings and these would be permanently deleted after five years.

The main benefit of this study for the people who took part was that the interviews acted as an additional intervention. This was anticipated (Barbour, 2008, Mays and Pope, 1995). It was assumed that reflecting on what they had experienced in making the decision to test, what they had gained from the counselling session, and their future plans would have some influence on future sexual risk practices. Some individuals did actually say that they had learnt more from our discussion and the discussion had helped them resist risky behaviour. This has implications on the findings which have to be interpreted in this context.

Analysing and writing also has to be done in an ethical manner to ensure accurate and fair reporting. Being reflexive about one’s role in the generation, analysis and presentation of data acknowledges the role of the researcher in the process thereby apportioning fair responsibility for the findings (Rice and Ezzy, 1999).

During the conduct of the research the researcher will be confronted with various ethical issues which they will need to deal with in the field. “... the onus is on the researcher to deal with their participants with integrity, honesty and fairness.” (Rice and Ezzy, 1999: p41).

The ethical concerns outlined above have been addressed in various sections of this thesis. Ethical approval was obtained from both the UoE REC and the UNZA REC. Chapter one provided just cause for pursuing the study, due
diligence was exercised in planning and executing the study as discussed in this chapter and overall I believe that the benefits to the participants outweigh any anxiety and embarrassment (harm) that may have been caused by taking part in the interviews.

5.13 Conclusion
Qualitative research has been labelled subjective and therefore lacking validity, reliability and generalisability while overlooking the fact that even quantitative research, which is said to be objective, relies on the skill, knowledge and judgement of the researcher. To be rigorous, both qualitative and quantitative research have to be systematic and reflexive in the design, collection and interpretation of data and communication of findings.

Qualitative and quantitative approaches are both underpinned by ontological and epistemological assumptions. Either approach may utilise any of the available theoretical perspectives. The two approaches come to differ at the level of methods of data collection, analysis and presentation.

To achieve the aims of this study an approach was required that would allow people to share their experiences in their own words and allow for the generation of an explanatory framework from their accounts. A qualitative approach is well suited to such an aim as it allows for the generation of data that is minimally directed by the researcher and allows presentation of the voices of the participants. The study was generally conducted within an ontology that recognises a multiple reality, an epistemology that espouses the co-construction of knowledge, and a theoretical perspective that acknowledges that all data is interpreted at all levels of generation.
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Concepts from behaviour change theories were utilised in the design of questions and prompts; the study did not set out to test any particular behaviour change theory.

The setting was a predominantly Christian urban mining area, along a major transit corridor, with a high HIV prevalence, high population mobility and high unemployment. Participants were recruited from four diverse VCT sites. Interviews were conducted at health facilities immediately following counselling and testing or soon thereafter, and at six months post test. Informed written consent was sought before each interview. The follow-up interview, while seeking new information related to the experience of living with an HIV-negative result, covered the same ground as the initial interview so as to assess consistency and change over time. Following the interviews, focus group discussions were held with service providers to obtain their perception of the service and client needs.

It was anticipated that though revealing my status as a health professional might facilitate recruitment and encourage sharing of sensitive personal details, it might also predispose participants to provide responses that were deemed appropriate for a health professional to hear. The wording of the information sheet, conduct of the interviews, and analysis of the interview transcripts were deliberately tailored to address these concerns.

Data were analysed with the aid of a qualitative data analysis software, Nvivo7. The data sets were initially subjected to cross-sectional thematic analysis to identify common themes then paired transcripts were analysed longitudinally to assess consistency and change over time.
Chapter 6 – Findings: Participant characteristics and overview of findings

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6.4 Overview of chapters 7, 8 and 9 ..................................................................................... 218
6.1 Introduction
The methods employed to generate and analyse the data are discussed in the previous chapter. The actual findings generated from this process are presented in the following chapters 7, 8 and 9. This chapter presents the descriptive statistics providing a context for the findings in terms of study participants’ characteristics and provides an overview of chapters 7, 8 and 9. The descriptive statistics presented in this chapter do not in any way suggest an attempt at statistical analysis of the data: they are provided solely for the purpose of providing background information that allows the reader to better understand and interpret the findings and conclusions of this study.

6.2 Characteristics of participants – demographic and behavioural

6.2.1 Initial interviews
A grid (see table 5.3, p176) was used to guide sampling to facilitate recruitment of a wide range of age groups. The final study grid as it compares to the initial sampling grid is shown in table 6.1.

<table>
<thead>
<tr>
<th>Age (yrs):</th>
<th>Sampling grid</th>
<th>Final grid</th>
</tr>
</thead>
<tbody>
<tr>
<td>50+</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>45-49</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>40-44</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>35-39</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>25-34</td>
<td>13</td>
<td>16</td>
</tr>
<tr>
<td>20-24</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>18-19</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>40</strong></td>
<td><strong>42</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>19</td>
<td>15</td>
</tr>
<tr>
<td>Male</td>
<td>21</td>
<td>27</td>
</tr>
</tbody>
</table>
Chapter 6 – Findings: Participant characteristics and overview of findings

The only difference of note is the fewer females and more males in the final grid. It is not clear why this is so but a contributory factor may be that the busiest site, Konkola Mine Hospital in Chililabombwe, from which most of the people were recruited (see table 6.2) usually sees more males. This may be so because this VCT centre is affiliated to a hospital whereas the others are affiliated to community health centres. At the time of the study mine health care policy stipulated that mine employees’ first point of contact was the hospital out-patient department whereas all dependants including spouses were to report to a community health centre and only attend the hospital if referred or out of hours. Another possibility is that the statistics on number of females attending VCT may be combined with those attending PMTCT at some centres; a problem encountered on some VCT monthly report forms. This may have led to an erroneous estimation of the number of expected women.

Table 6.2: Participants per study site

<table>
<thead>
<tr>
<th>Site</th>
<th>Konkola Mine Hospital (KMH)</th>
<th>Kabundi Health Centre</th>
<th>Kakoso Health Centre</th>
<th>Nchanga Health Centre</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>13</td>
<td>6</td>
<td>5</td>
<td>3</td>
<td>27</td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
<td>7</td>
<td>3</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>Total</td>
<td><strong>16</strong></td>
<td><strong>13</strong></td>
<td><strong>8</strong></td>
<td><strong>5</strong></td>
<td><strong>42</strong></td>
</tr>
</tbody>
</table>

Of the 55 people approached, 42 (76%) were interviewed; 27 (64%) males and 15 (36%) females. Participants’ age ranged from 18 to 53 years, most (29/42) were between 20 and 34 years. Twenty-six (62%) were single; 20 males and six females. Thirteen were married; eight females and five males (one male and one female were on separation at the time of the first interview). Two males and one female were divorced. Most of the men had secondary or tertiary level education (certificate and diploma levels) whereas most of the females had primary or secondary levels of education. Almost all the men
Chapter 6 – Findings: Participant characteristics and overview of findings

were employed, with more than half of them being employed by the mines mostly as artisans.

All except one male professed to belong to a faith group, 33 Christian with close to half belonging to a Pentecostal church, seven Jehovah’s Witness and one Moslem.

Nine people (19%), four males and five females attended VCT because of symptoms suggestive of HIV infection, the rest were asymptomatic, that is, had no physical signs or symptoms suggestive of HIV (see table 6.3, p214).

**Characteristics of those that declined to participate**

Of the 13 that declined to take part in the study, eight were male and five female. Their ages ranged from 18 to 34 years. Nine simply did not attend for interview, three females declined due to time constraints (two had babies to look after) and one male was willing to take part in the initial interview but not the second one. The risk characteristics of this group are unfortunately not known. It is therefore not possible to say with certainty whether this group was fundamentally different from the interviewed group. A comparison of the proportion of HIV-negative people reporting a history of multiple partners (the only risk behaviour indicated on the VCT forms) attending at the study sites to the proportion included in the study, showed a higher proportion of people with a history of multiple partners in the study group. This suggests that it is unlikely that those who declined to take part were, as a group, more risky compared to the group that agreed to participate.
Chapter 6 – Findings: Participant characteristics and overview of findings

6.2.2 Follow-up interviews

Thirty-one (74%) of the 42 people interviewed returned for the follow-up interviews—12 women (80%, 12/15) and 19 males (70%, 19/27). Thirty were face-to-face and one was a telephone interview. Sixteen of the 31 (52%) people had returned for the confirmatory test three months after the initial test. Qualitative sample sizes are usually small (see section 5.8.4) and it is therefore not possible to calculate the significance or otherwise of the differences in the group that was lost to follow-up compared to those that completed the study. However, a descriptive comparison can be made to ascertain whether there was a systematic loss to follow up that may have a bearing on the scope and type of data generated and its interpretation. For example, if all the people with the highest risk behaviours did not return for the follow-up visit the data would not reflect the perceptions and needs of this group of people. The retained group and the group lost to follow-up were generally similar. The demographics and risk behaviours of the group lost to follow up were in approximately the same proportions as those of the retained group (see table 6.4 and 6.5, p214).
Chapter 6 – Findings: Participant characteristics and overview of findings

Table 6.3: Characteristics of participants in the initial interviews (n=42)

<table>
<thead>
<tr>
<th>Age group</th>
<th>Total 50+</th>
<th>45-49</th>
<th>40-44</th>
<th>35-39</th>
<th>30-34</th>
<th>25-34</th>
<th>20-24</th>
<th>18-19</th>
<th>Married</th>
<th>Single</th>
<th>Widowed</th>
<th>Divorced</th>
<th>Educational level*</th>
<th>Employed</th>
<th>Symptomatic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>16</td>
<td>13</td>
<td>4</td>
<td>42</td>
<td>13</td>
<td>26</td>
<td>0</td>
<td>3</td>
<td>6</td>
<td>17</td>
<td>13</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>16</td>
<td>13</td>
<td>4</td>
<td>42</td>
<td>13</td>
<td>26</td>
<td>0</td>
<td>3</td>
<td>6</td>
<td>17</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td>4</td>
<td>2</td>
<td>6</td>
<td>6</td>
<td>32</td>
<td>26</td>
<td>8</td>
<td>88</td>
<td>26</td>
<td>53</td>
<td>0</td>
<td>6</td>
<td>12</td>
<td>33</td>
<td></td>
</tr>
</tbody>
</table>

* not available for 6

Table 6.4: Characteristics of participants in the follow-up interviews (n=31)

<table>
<thead>
<tr>
<th>Age group</th>
<th>Total 50+</th>
<th>45-49</th>
<th>40-44</th>
<th>35-39</th>
<th>30-34</th>
<th>25-34</th>
<th>20-24</th>
<th>18-19</th>
<th>Married</th>
<th>Single</th>
<th>Widowed</th>
<th>Divorced</th>
<th>Educational level*</th>
<th>Employed</th>
<th>Symptomatic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>10</td>
<td>7</td>
<td>1</td>
<td>19</td>
<td>3</td>
<td>15</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Female</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>12</td>
<td>6</td>
<td>5</td>
<td>0</td>
<td>1</td>
<td>5</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>15</td>
<td>9</td>
<td>3</td>
<td>31</td>
<td>9</td>
<td>20</td>
<td>0</td>
<td>2</td>
<td>5</td>
<td>14</td>
<td>10</td>
</tr>
</tbody>
</table>

* not available for 2

Table 6.5: Characteristics of participants lost to follow-up (n=11)

<table>
<thead>
<tr>
<th>Age group</th>
<th>Total 50+</th>
<th>45-49</th>
<th>40-44</th>
<th>35-39</th>
<th>30-34</th>
<th>25-34</th>
<th>20-24</th>
<th>18-19</th>
<th>Married</th>
<th>Single</th>
<th>Widowed</th>
<th>Divorced</th>
<th>Educational level*</th>
<th>Employed</th>
<th>Symptomatic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>8</td>
<td>2</td>
<td>2</td>
<td>5</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>11</td>
<td>4</td>
<td>6</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>8</td>
<td>6</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

* not available for 4
6.2.3 Focus group discussions

Following the initial pilot group, two focus group discussions were conducted. A total of 25 trained and currently active psychosocial counsellors participated in the focus group discussions. The groups were composed of between six and 10 people. Most of the participants were female: the pilot group had one male participant, one of the other two had two and the other none. The age range was from 24 to 56 years. Years of experience in psychosocial counselling ranged from three months to 18 years. Fifteen had between one and five years’ experience, eight between five and 18 years, one less than a year and one did not indicate years of experience.

All except five were nurse-counsellors, the others being a laboratory technician, a data management officer, a social worker and two were community volunteers. Four of the nurses, the social worker and one of the community volunteers were working as full-time counsellors. The rest were part time counsellors. Workload per counsellor varied from one to 21 clients per week.

Twenty-two of the focus group participants identified themselves as Christian, one was a Jehovah’s Witness and two stated no religious affiliation. Most (14/25) of the focus group participants were married, six were single, two were widowed and two were divorced (one did not provide information on marital status). Twenty-four of the 25 counsellors had been tested for HIV and knew their status. Table 6.6 provides an overview of the focus group participants’ characteristics.
### Chapter 6 – Findings: Participant characteristics and overview of findings

Table 6.6: Characteristics of focus group (FG) participants.

<table>
<thead>
<tr>
<th>No.</th>
<th>Pilot group</th>
<th>FG 1</th>
<th>FG 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>9</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>9</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Age range</td>
<td>37 – 56</td>
<td>24 – 47</td>
<td>38 – 50</td>
</tr>
<tr>
<td>Counselling experience (range)</td>
<td>3 – 17 years</td>
<td>3 months – 12 years</td>
<td>2 – 18 years</td>
</tr>
<tr>
<td>Participant's professional background</td>
<td>Nursing</td>
<td>4 nurses, 1 laboratory technician, 1 data management officer, 1 social worker, 2 community volunteers</td>
<td>Nursing</td>
</tr>
<tr>
<td>- Part-time</td>
<td>10</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>- Full-time</td>
<td>0</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>- Full-time</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>No. of clients counselled per week (range)</td>
<td>4 – 15</td>
<td>1 – 21</td>
<td>1 – 11</td>
</tr>
</tbody>
</table>

### 6.2.4 Risk behaviours of interview participants

All but three people (all female) reported having been engaged in sexual intercourse at some point in their lives and were therefore considered to be potentially at risk. Thirty-five (83%) people were considered as being at “higher risk” (see section 5.10.2). Twenty-eight had engaged in sex with a non-cohabiting partner at some point in their lives and seven married females reported being at risk due to their husband’s extra-marital sexual behaviour. Among the 28 who had engaged in sex with a non-cohabiting partner, five were at lower risk relative to the others as they had used condoms and two were at much higher risk due to multiple concurrent partners. Twenty-nine (69%) people were practising safer sexual behaviour for six months or more prior to testing: eight males and five females were abstaining; six males were using condoms; the five married males, three single males, one married and one single female were practising monogamy. The 13 people that had engaged in unsafe sexual practices in the six months prior to testing were: five single males, one single female and the seven
married females with unfaithful partners. Table 6.7 shows the distribution of stated sexual behaviours in the six months prior to testing.

Table 6.7: Distribution of risk behaviours according to gender and marital status six months before initial testing

<table>
<thead>
<tr>
<th>Behaviour/risk</th>
<th>Males</th>
<th>Females</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Married</td>
<td>Single</td>
<td>Divorced</td>
</tr>
<tr>
<td>Abstinence</td>
<td>8</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Monogamy</td>
<td>5</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Condoms (consistent use)</td>
<td>4</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Unprotected sex</td>
<td>5</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Unfaithful spouse</td>
<td></td>
<td>7</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6.3 Conclusion

A sampling grid based on participating VCT sites statistics facilitated recruitment of a broad range of age groups, but more males and fewer females than planned were recruited. This may have been as a result of recruiting most participants from a site that traditionally sees more males. However, it may also be due to inconsistencies in routine data entry resulting in erroneous estimation of the anticipated proportion of females. The quality of data entry differs across facilities with noted overlap in entry of prevention of mother-to-child and VCT statistics. Women attending for antenatal clinic are routinely offered HIV testing. These statistics are supposed to be recorded under PMTCT attendance and not VCT.

The response rate of 76% (42/55) and follow-up rate of 74% (31/42) were satisfactory, and facilitated by mobile ‘phones. The characteristics of those lost to follow-up were generally similar to those of the retained group.

All except two of the 42 participants professed to be Christians. The majority were single, though most of the females were married. Males generally had a higher education status than women with more men having achieved
secondary and tertiary level education compared to women. Almost all the males were employed whereas only four of the 15 women were in employment.

Nine of the participants attended VCT because of symptoms suggestive of HIV infection. Thirty-nine had ever had sex and so were potentially at risk. Twenty-nine were practicing safer sex in the six months or more prior to testing. Being female and married or male and single appeared to be associated with unsafe sex in the six months prior to testing.

Of the 25 trained and practising counsellors that participated in the focus group discussions, most were female and the majority were trained health workers working as part-time counsellors. This reflects the scenario in most of the VCT centres. The majority of the counsellors were Christian and most were married.

6.4 Overview of chapters 7, 8 and 9

Each chapter presents findings that relate to one of the three aims of this study, as set out in section 1.8.2. They could have been presented by study phase, that is, “first interviews”, “second interviews” and “focus group discussions”, but this would have fragmented the findings relating to the same aim, since each phase produced findings relevant to all the aims. In addition, it would still have been necessary to bring the individual cross-sectional findings together for a complete discussion of the aims. This would have detracted from a coherent presentation of the findings. Presenting the findings by aim is logical and clarifies the link between study objectives and findings.
Chapter 6 – Findings: Participant characteristics and overview of findings

The aims will be presented by chronological order of events in the voluntary counselling and testing (VCT) process and not by the order in which they were developed as presented in section 1.8.2. In section 1.8.2 the aim dealing with the decision making process before presenting for VCT is presented as the third aim. A process ordered presentation facilitates the telling of a story with a beginning, middle and end. This is not to say that this story could not have been told in any other order (Wolcott, 2000) but it was my belief that it is better told in a manner that allows the reader to follow a logical sequence of the unfolding of events. Analysis of the entire data set revealed six main themes in relation to the three aims. The findings are presented in the three chapters as follows:

Chapter 7 thus presents findings relating to understanding the decision making process that precedes VCT attendance. The three main themes were: “Recognising susceptibility”, “Emotional and cognitive engagement”, and “Need to know status regardless of test result”.

Chapter 8 presents the perspectives of people who are HIV-negative on how voluntary counselling and a negative result influenced their attitudes, intentions and subsequent sexual behaviour. The main theme was “Empowerment and being in control”.

Chapter 9 presents the perspectives of people who are HIV-negative on support systems and networks that would enhance their ability to remain HIV-negative. The two main themes were “Reinforcement of behaviour change” and “Access to recreational activities”.

Fig 6.1 provides a diagrammatic representation of the themes presented in the three chapters. The main themes are in shaded boxes and the sub themes in white boxes.
Chapter 6 – Findings: Participant characteristics and overview of findings

Figure 6.1: Diagrammatic representation of relationship between main themes (in shaded boxes) and sub themes (in white boxes) by chapter for people testing negative

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7.1 Introduction
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*To gain an understanding of the decision making process that precedes voluntary counselling and testing (VCT).*

Making the decision to attend VCT and test is a complex process facilitated and frustrated by various psychological, physical, social, cultural and structural factors.

Three themes were prominent in the decision-making process preceding attendance for HIV testing:

1. Recognising susceptibility
2. Emotional and cognitive engagement
3. Need to know status regardless of test result

The discussion in this chapter relates to the first part of Fig 6.1, p220.

Fig 7.1 displays the relationship between the main themes and sub-themes.
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Figure 7.1: Thematic map of factors facilitating and inhibiting the HIV-test decision-making process showing main themes and sub-themes
7.2 Recognising susceptibility to infection with HIV

The HIV and AIDS information, education and communication (IEC) strategy adopted by the Zambian Government has led to exceedingly high levels of awareness about the existence of HIV and AIDS — 99% of all females ages 15-49 and males ages 15-69 (see section 4.4.1). This high level of awareness should facilitate the recognition of the factors that constitute risk. In addition the high visibility of AIDS in countries with a high prevalence, such as Zambia, has also contributed to this high level of awareness (Central Statistical Office, Ministry of Health and MEASURE Evaluation, 2002). The following quotations from participants appear to support this:

"My source of information is the media ... TV, radio, the print media, then back in Kitwe at church they used to organise some seminars, I attended one, then in the community where I used to live I also attended one, so I also had friends who were trained as peer educators back in Kitwe, so they used to tell me more. 27yrs, male (single)" 1st

"Because of the information you people are disseminating through the media, the pamphlets, we read the posters we find almost everywhere ... we know what we are supposed to do and what we are not supposed to do in order not to get the infection. 43yrs, male, (married)" 1st

"Having learnt from people teaching us, in schools, in televisions and radios, nearly everyone knows what is..., what to do exactly, how to prevent themselves, we know... 25yrs, male (single)" 1st

Knowledge facilitated recognition of risk as the quote below, from a young man who only came to realise that he had put himself at risk when he learnt that he could not rely on looks to tell if someone is infected or not, illustrates:
Chapter 7 – Findings: Factors facilitating and inhibiting the HIV-test decision-making process

I believed that maybe my girlfriend was not infected so that is why I had sex with her. But still more I started learning and reading these papers which they give out and I discovered that you cannot trust a person just by looking. 24yrs, male (single) 1st

People believed they had been exposed to the risk of HIV infection through sexual or non-sexual behaviour such as the sharing of razor blades.

7.2.1 Due to sexual risk behaviour

Almost all the people in this study regarded themselves as being susceptible to infection with HIV. Most interviewees believed they may have been exposed to risk through either their own sexual activities, as in the first three of these quotations, or those of their partners, as in the last three quotations:

It’s because of the sex I had with that girl that is what made me come here because maybe she was sick since I didn’t know her status. 24yrs, male (single) 1st

After we divorced I had other women but I was using condoms. But there were times when the condom would tear. 34yrs, male (divorced) 1st

I have had five sexual relationships. So that is the reason why, that’s what prompted me to like even consider of coming for a VCT test. 25yrs, male (single) 1st

I started thinking of coming for the test because I noticed that my husband’s behaviour was not good he has many women, so I am worried. 43yrs, female (married) 1st

When I was with my first wife ... I discovered that she was having an affair with this other man ... so I thought that since she has started having this affair maybe this man she is moving around with is sick. 36yrs, male (divorced) 1st

When I first realised that he was misbehaving too much I thought that I might be sick. 28yrs, female (divorced) 1st
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Justification for risky behaviour

Most people did not actually try to justify their risky behaviour and seemed to accept that they had behaved recklessly:

*I was just careless because I exposed myself to a situation where I couldn’t even resist, like they say “to be brave does not mean to look for trouble” so I went looking for trouble when I knew, just because I was brave, you see. 25\textsuperscript{yrs}, male (single)\textsuperscript{1st}*

Some attributed their engagement in risky behaviour to alcohol, peer pressure and beliefs about male sexuality and vulnerability to HIV.

Alcohol and peer pressure

Alcohol and peer pressure were the most common excuses cited for engaging in risky sexual behaviour:

*I was in a bad group, they liked a lot of girls, when there’s function or things like that, … I was involved with alcohol. 19\textsuperscript{yrs}, male (single)\textsuperscript{1st}*

*I just went with friends that side in town we bought some beers, we were drunk just there in town … So after that just there in the car, my friends brought some girls and I didn’t intend to do it but they just got them and one of my friends organised one for me … 20\textsuperscript{2yrs}, male (single)\textsuperscript{2nd}*

*Every time I went to functions at town centre somewhere there I used to get drunk and sleep with girls that’s why I wasn’t sure of my status that’s why I came to test. 20\textsuperscript{4yrs}, male (single)\textsuperscript{2nd}*

*’Coz most of the time when I drink I like following up girls … when you are drunk if you see a girl, you always think of having sex with her. 20\textsuperscript{3yrs}, male (single)\textsuperscript{1st}*

*It is all about peer pressure, the pressure from peers actually that’s where it comes from. 27\textsuperscript{yrs}, male (single)\textsuperscript{2nd}*

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It was recognised that alcohol reduced self control resulting in the performance of behaviour that would not normally be engaged in as illustrated by this quote from a young man who had engaged in unprotected sex following alcohol consumption at a party:

_This disease usually comes through sleeping around and taking alcohol. When going to the bar you were just normal but when you start drinking alcohol the person who was not attractive to you before becomes attractive and you forget and have sex with her and only remember after you have already made the mistake._ 24 yrs, male (single)

**Myths about male sexuality and vulnerability to HIV**

Two male participants cited some myths that had been circulating among their peers that encouraged early sexual debut, unsafe sex and feelings of immunity to HIV:

_When they were talking about sexual intercourse, they said “no, if you stay more than fifteen years then you will stop erecting, so at least you are doing it (sex) ... sometimes you are doing it”. I was only twelve to thirteen years that’s what I was being told “ah you, if you won’t do this, after 15 years then you’ll stop even erecting”. 23 yrs, male (single)_

_We used to hear what they used to say about HIV and the like, we used to hear that but we didn’t pay much attention because we were about seventeen years, and according to our tradition, it says when you reach eighteen years and above you can get HIV. So I was thinking that “they are saying that it’s eighteen years and above so it means that since I am seventeen I can’t have the HIV virus._ 25 yrs, male (single)

**7.2.2 Due to non-sexual behaviour**

A few thought they may have acquired HIV through non-sexual transmission. Some of the male participants felt that their exposure to non-sexual risks, such as sharing razor blades, was more threatening than their
exposure to sexual risk. When asked why they thought they were at risk they initially provided a non-sexual exposure and information on sexual risk was only obtained on further questioning:

**Int:** ... *how did you start thinking about coming for counselling and testing?*

*20yrs, male (single)*; ... *what actually made me come today was that I went to the (inaudible) just to find that a best friend of mine ok was uhh like the mum was HIV positive, she’s a nurse and now just like using razor blades and other things the guy also got the virus when we were still young so I was like also worried ’coz we were brought up together, my friend is HIV positive so I wanted to confirm ’coz we almost used the same tools even at school it’s like razor blades and all those things, so I was very worried*

**Int:** Ok. So there are no other ways you could have got the virus?

*20yrs, male (single)*; There are many ways but I thought that one was the major one, but there are still many ways that I was also, that I am also suspecting

**Int:** Mhm, like?

*20yrs, male (single)*; Like maybe, mmm, I thought my girlfriend was cheating on me because she stays very far. I’ve got another sexual partner, so they are two ...

Similarly, another dialogue with a single male:

**Int:** *What made you decide that you must go for VCT?*

*24yrs, male (single)*; *What made me to decide was mmm, I just wanted to know my status*

**Int:** *Mmm. Have you been exposed to any chances of getting the virus?*

*24yrs, male (single)*; *Chances are high because it is not always that you have sexual intercourse that you get AIDS,’ coz there are some modes of transmission like using unsterilised items and you know how it is when you are working in the mines*

**Int:** *Mhm*

*24yrs, male (single)*; *you are risked by, somebody is injured, then like me I am, I’ve done red cross so you are able to be exposed to blood when you’re handling the casualty or in case of an accident so chances also they are high that you can contract HIV*

**Int:** *What about through sexual intercourse, you haven’t been exposed?*
Chapter 7 – Findings: Factors facilitating and inhibiting the HIV-test decision-making process

24 yrs, male (single); Yah, I’ve been exposed, now..., but it’s been a long time, but when you’re not tested you might never know and they say you’re not hundred percent proven (negative) unless you’re tested.

The 20 year old male quoted above — although engaging in unprotected sex with two concurrent partners — felt he was more at risk of having acquired HIV from his friend with whom he had shared razor blades because he was proven to have HIV:

20 yrs, male (single); ... not all the time (use of condom) with the other sexual partner I talked about, ‘coz every time we could like use a condom it could like burst so I thought it was of no use sometimes, so sometimes we could just do it that way.

Int: ... you thought that the chances of getting HIV from your friend, by sharing razor blades with him, were higher than getting it from these two partners?

20 yrs, male (single); The reason why I said that, because I confirmed that one, I went to see him, he is generally weak so it gave me that feeling. He is HIV positive and I was sharing things with him.

It is not clear whether their reluctance to make a direct link between unsafe sex and risk, and their assumption that they were more at risk from non-sexual encounters was due to the wish to provide a socially desirable reason for being at risk or was due to a genuine perception of the non-sexual source as more risky than the sexual. The reference by 20 yrs, male (single)(p229) to his friend’s mother getting HIV through her work as a nurse, and his friend then getting it from her through the sharing of razor blades ‘s, and subsequently his own exposure through the same medium suggests a desire to provide a socially desirable reason. On the other hand his use of the word “confirmed” suggests that he may actually have considered sharing razor blades with his friend who definitely had HIV as
more risky than unprotected sex with two concurrent partners who were not proven to have HIV.

Sharing of razor blades was the most common non-sexual risk mentioned by those who felt they had been exposed to a non sexual source of infection either as the sole source of risk or in addition to sexual risk:

He’s my brother and we usually share instruments like razor blades or whatever, that brought doubts for me ... 20yrs, male (single)1st

I just wanted to try, to see how my health is, just in case because of the things that have happened in the past, to see if I am sick. Using my friend’s razor blades to cut my nails and having sex with that girl. 18yrs, male (single)1st

One young female, with no sexual experience, thought she had been exposed to risk at birth because her mother had died of AIDS. Another one thought she may have got it from casual contact with her HIV-positive college room-mate (the laughter that accompanied the disclosure of this fear suggests that she may have thought it irrational while still believing it):

Because when I was at college, I had my friend and then..., she is sick, so I was staying with her and then ... I didn’t really trust her, you know, because of something, I don’t know, so I thought maybe I might have been infected. I was just thinking to say maybe my friend could have done something (laughs). Maybe put something in my drink (laughs out loud). 27yrs, female (single)1st

7.2.3 Factors facilitating recognition of susceptibility (Cues)
Some people’s recognition of susceptibility was triggered by personal experience of physical signs and symptoms, seeing the effects of HIV/AIDS on family, friends and in their community, or exposure to sensitisation materials.
Chapter 7 – Findings: Factors facilitating and inhibiting the HIV-test decision-making process

**Presence of physical symptoms and signs**

For some people physical signs and symptoms suggestive of HIV infection was their cue to contemplating their risk of HIV infection. The married women, in particular, appeared to rely on the appearance of physical signs and symptoms to prod them into thinking about the possibility of HIV infection. Ascribing symptoms to infection with HIV followed either learning about the symptoms of HIV infection from HIV education programmes mostly on radio or sharing similar symptoms with another person believed to have AIDS or to have died from AIDS, and having a partner who was perceived to be unfaithful. The following two quotes are from interviews with two women who had previously been aware of their husband’s infidelity but did not feel the need to test until they developed signs and symptoms that to them were suggestive of HIV infection:

*I found a young woman here and I asked her how it is, she explained that what made her come for VCT, was that she was feeling the same as I was, she would have headaches sometimes, so she decided to come for the test and that is how she was found with the disease. So that is how I started really feeling the need to come and test so that I know my status.* 51yrs, female (married)1st

*My husband married two wives, but my friend died. She also just started feeling pain in her chest just like I am. I also started feeling the same things that my friend had complained of, so that is why I decided to just go to the clinic and get tested so that they can help me.* 48yrs, female (separated)1st

The two young men quoted below engaged in unprotected sex but did not think of testing until they too developed signs and symptoms they thought were due to infection with the virus:
Chapter 7 – Findings: Factors facilitating and inhibiting the HIV-test decision-making process

I played (had sex) with my girlfriend, so I found that the way I was feeling isn’t the way I usually feel, that is how I thought that I should go and get my blood tested so that I know the truth. **22 yrs, male (single)**

26 yrs, male (single); I developed a rash. I went to the clinic and they gave me some medicine and an injection, the rash disappeared but then it came back again ... I look after my late uncle’s child who has HIV so I thought that the rash I was having was similar to the one he had. So I started thinking that maybe I am also infected so for me to know my status it’s better I go and test.

**Int:** What if you didn’t have that rash?

26 yrs, male (single); I wouldn’t have known my status

The symptoms were of a chronic nature and included loss of weight, persistent general malaise, skin eruptions and aches and pains in various body parts. The chronic nature of the symptoms appeared to be particularly worrisome. The quote below captures the above dimensions quite well:

*This is not my body, I’ve actually lost weight. In twenty zero one that’s when I started experiencing chest pains, they checked my sputum, they checked my blood but they didn’t find anything so I remained worried why I was actually losing weight and appetite. So that is why I became suspicious. I’ve been coughing for maybe now three weeks... this issue of HIV just came lately after I’ve actually tried some ways to actually gain my weight but in vain. AIDS is the one that, which goes for a long time until somebody maybe dies, yah, that’s why I started suspecting maybe it could have been HIV, because of the time, starting from twenty zero one up to this time. 29 yrs, male (separated)*

The focus group findings echoed those of the one-to-one interviews:

... when somebody has been sick for some time, they don’t know what is eating them up and after sometime they’ll decide maybe to come for VCT and at the end they find that they are negative. **Nurse, female (married)**

Now because that time he was fat, you know, he didn’t see the importance of doing the VCT but now, I saw him the other day, ok he’s now..., the body is wasting and each time he moves around people will say “ah ba mudala (big
Chapter 7 – Findings: Factors facilitating and inhibiting the HIV-test decision-making process

... are you sick? You are wasting, you are thin ...” just like that but because of those words he just walked in the clinic and when he talked to me I thought maybe he was joking but he was serious and I did a test. So after all this long time you know, until when he starts presenting with signs and symptoms of AIDS that’s when he accepts. Nurse, female (divorced)

High disease visibility – ‘living in difficult times’

Additional cues from the environment such as the high visibility of the disease and its effects in the community—with more than a third reporting personal experience of HIV/AIDS through the illness and/or death of friends and relatives due to AIDS—served to increase feelings of susceptibility:

The friends whom I was playing, you know, the situation they are looking it’s not good and others maybe they have died, ... so I was scared, and I said no, for this reason am supposed to go for VCT ... three weeks ago I met a friend of mine and the way he was looking and the way he was explaining things, how life was, it showed that the guy is not well so that’s how I decided “oh, I’ve just seen my friend how he’s looking, its better I go for VCT’ coz it may be me or him” so I... But for the girls, for the girls, I’ve seen two of them they are not in good condition, yah, they are not in good condition. Because I even heard a rumour that they used, from that time we were friends, that they used to go for ARVs and they were not looking healthy. 19yrs male (single)

Int: Why did you want to know your status?

20yrs male (single); Its because I’m, I’m like affected very much, now than ever with the HIV and AIDS, that’s why … I just found out that three of my family members are infected with HIV and just to make sure that in the life which I’ve been leading also, I had doubts that I can also have contracted HIV

I’ve got my cousins at home then I’ve got my aunty as well, first of all my aunt was diagnosed last year that she is HIV positive, then she is also taking the drugs and she is ok. Then I also have friends who died of the same disease so I wanted to know because I just think it is important, it’s good to know, I have a right to know what’s happening in my life. All these things that were happening were prompting me to come. I see it every day, people talking about it, people dying of the same disease. 27yrs male (single)
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I had seen my uncle who had this HIV disease. He was just in a bad situation that’s why I decided that no, I have to go for VCT so that I should know my status then try by all means to keep safe because I saw with my own eyes that this AIDS disease is just so crazy. There are so many people who are sick so I looked at them, see how they are and then I decided to go for VCT. **23yrs male (single)**

One single female talked about how her irrational fear that she had contracted HIV through casual contact was initiated and encouraged by close contact with an HIV-positive relative and friend:

> I think, I did think about it (HIV) but when I saw and lived with a person who was like that and then before I even lived with my friend umm, there was this cousin of mine she came home and then she was very sick and eventually she died, so from there I had those little thoughts but when I was with my friend then it grew. **27yrs female (single)**

This idea of AIDS being everywhere was encapsulated in the concept of ‘difficult times’ referred to by some people as being an important factor in their decision to test. The following quote captures this concept quite well:

> These days the world is a difficult place it’s only a few people who don’t have the disease. **23yrs, female (married)**

**Sensitisation materials and activities**

A few people stated that the trigger to contemplating susceptibility to infection with HIV was exposure to HIV sensitisation programmes or any other IEC materials:

**Int:** Why did you think it might be HIV?

**48yrs, female (separated);** Because of what they say on the radio, that if you are feeling weak, have no appetite and you are having aches and pains everyday it might be HIV
We said look at the way our friends are doing it, the husband was there, the wife was there, they were chatting doing all such kind of things. So that South African programme (TV show) actually gave us a very good plan, “I think let’s go as well”. 35yrs, male (married)\textsuperscript{1st}

\textbf{Int:} So if I get you correctly you are saying that from zero-four, zero-five you didn’t think about testing?

29yrs, male (single)\textsuperscript{1st}; No, no because we didn’t even have that workshop (workplace HIV sensitisation workshop) during that time

\textbf{7.2.4 Factors hindering recognition of susceptibility}

\textbf{Denial and the belief that to know you are positive hastens death}

A few people refused to engage with the possibility of their own vulnerability to HIV by opting for denial as their way of coping with their fear of the disease. These people continued to engage in risky sexual behaviour after the initial recognition of susceptibility:

\textit{I just, I just forgot about it ... the next time I wanted to do it, to do the VCT again, it was the second time I engaged in casual sex. Again I didn’t, I didn’t even use a condom, it was very, it was very ahhh, I was very devastated ... I felt bad, but then again I just forgot to.} 27yrs, male (single)\textsuperscript{1st}

And from a young man who had watched his brother die from AIDS:

\textit{I never just wanted to hear about it, about AIDS, or whenever it is on the television I could switch off the TV, I just don’t want to hear on that message about AIDS. I never just wanted to be concerned about it.} 24yrs, male (single)\textsuperscript{1st}

There appears to be what also may be a common coping mechanism (see Perry, Baranowski and Parcel, 1990: p174-175) preventing people from confronting their risk and dealing with it; that it is better not to know than to know that one is HIV positive. Knowing that one is positive is inviting worry
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about death. One young man when asked why people had discouraged him saying “this testing business is not good” had this to say:

_They are afraid of being told they are positive, because if he is told that he is positive he will just be thinking that “I am dying” he will just be worrying, he will just be thinking about dying. I was thinking that maybe I have it and if they go and tell me I have it, it will be worse so its better I have it but don’t know._ 26 yrs, male (single)¹st

Similar sentiments were voiced by others:

_Because most of them they say they are so scared, they don’t want to know, that it’s better not to know._ 24 yrs, male (single)²nd

... there are some people who have other reasons why they shouldn’t do the testing ... “no I cannot taking the testing because once I know that I am positive then I will die fast”._ 29 yrs, male (married)²nd

**Inferred negativity**

Believing that one was negative delayed testing by encouraging a sense of false security. Some people inferred that they were negative because their partners had tested negative. Others thought they or their partners had been or would be tested for HIV when visiting a health facility either for antenatal care (ANC) or employment related medical examinations although HIV testing was not mandatory at ANC and was not a routine part of medical examinations:

_When I was in the mines they used to test the blood, now that I have been staying without going for tests I thought that maybe in... there was a time I was jumpy (sleeping around), maybe I may find that I have it ... even if we didn’t know what they were testing, I had an idea that they were testing a lot of things maybe even this HIV/AIDS, ... so I used to be negative. So that is why I believed that I was ok._ 53 yrs, male (married)¹st
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A married female participant felt she was safe because she had tested negative and like the 53 year old male quoted above believed her husband (a miner) was being tested when he went for his annual medical examinations ("silicosis"): 

... he was tested before, they test them at work ... they have also started testing for it when they go for “silicosis”. 40yrs, female (married)2nd

And this man believed that his wife had been tested at ANC:

I think, although I am not so sure, but I think they do that because for them to be rather treating somebody, a pregnant woman they have to be sure of her status (HIV), I mean, so that they know how to do, I mean, to handle her, whatever, what to give her, what she should do. 29yrs, male (married)2nd

While this divorced male participant thought his wife (who had left him for another man) was negative, while they were together, because their children were all healthy and he had also assumed she was being tested at ANC, which may or may not have been true:

I know (she is negative) because all the children are fine. When a woman is going to have a baby don’t they get blood (for HIV testing)? 36yrs, male (divorced)1st

One female participant tried to encourage her partner to go and test, his response was:

... “since you are ok I am also just fine”. 28yrs, female (divorced)2nd

7.3 Emotional and cognitive engagement

Recognition of susceptibility to infection with HIV should rationally lead to a desire to test leading into the second phase of the process, that of battling with the felt need to test for HIV. The decision-making process varied in
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duration and angst. For most people coming to the decision to test was a protracted process:

... nine months have elapsed; it was last year when I had sex with that person ... 24\text{yrs, male (single)}^{1\text{st}}

I was wondering the past two years but ahh now I was shunning to come for VCT. 24\text{yrs, male (single)}^{1\text{st}}

\textbf{Int:} ... how did you start thinking about coming for counselling and testing? 25\text{yrs, male (single)}^{1\text{st}}, Well, it all started a very long time ago but I was always scared to come for a VCT test...

Then it came now in my mind thinking about it (testing for HIV) then I said “no”. But I was only struggling with it all these years. 23\text{yrs, male (single)}^{1\text{st}}

However, a few people appeared to require less time to decide like the young man quoted below:

... for a long time I never thought of coming for counselling and the HIV test, but it was after I had found a reason, this reason was after involving in sexual intercourse. Because...I’d never done that before ... It happened uhh, this month, yes, in January ... Just a week ago ... just upon doing that thing (having sex) I regretted so much … the only thing that I thought of doing that could help was to visit the VCT centre and have..., and being tested, get tested that is what I thought could help. 25\text{yrs, male (single)}^{1\text{st}}

Most of these were testing because of signs and symptoms related to HIV infection and others were testing either due to recent sexual exposure to risk of infection, getting married or in response to VCT promotion messages.

For most people this period of grappling with the decision to test was characterised by great angst and uncertainty.
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I’m not free, I feel that maybe I’m sick (before testing). 20yrs, female (single)

I’ve been just worrying myself, troubling about AIDS (for one year)... it’s really difficult to come for VCT. 20yrs, male (single)

Ahh you see, when the mind is troubled, there is no peace ... 29yrs, male (separated)

I was not free, I had that in my mind that am I positive or negative I was not free even if I am walking I was “ah but I don’t know my status”. 29yrs, male (single)

For some people, however, this process entailed less angst. The seven married women in particular seemed to have accepted it as their role or fate as exemplified by the following quotes:

I was not afraid since this thing has come and there is nothing one can do. 26yrs, female (married)

Ah, I was just thinking that “God whatever comes out of this I have accepted according to the way my husband behaves”, and the women he has affairs with, when I’m shown that this is the one I even feel sorry for myself and I just think that this thing (HIV) has come let me just go and test. 30yrs, female (married)

... since it hides (referring to window period) maybe it will reveal itself, then let it be, it is God’s will, how can you refuse because it would have come. 51yrs, female (married)

The married women appeared to be more worried about not accessing available support or advice in time:

I just said I’m going to get tested because they can help me if they find I am sick. 26yrs, female (married)
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Now with this one (HIV), it is helpful if you catch it early, if you first wait for it to be firmly entrenched in your body, that is the end of you. 43yrs, female (married) 1st

I decided that before I die in the house let me go to the hospital so that I can be assisted. ... I am not worried about anything. Even if they had found me with the virus I wouldn’t have been worried, even if they had not found me with it or found me with it it’s all the same I wouldn’t be worried. All I want is help so that I feel better and prolong my life on earth so I can look after my children, that is all. 48yrs, female (separated) 1st

The others, apart from the seven married women, who appeared not to go through a particularly anxiety ridden period did not consider themselves to be at any real risk of HIV infection. Two tested because they felt pressured to do so by their relatives who thought they were infected since they had been unwell for some time:

People at home kept telling me to come, because I am usually sick so they kept telling me to come and test, so that is how I came here. 20yrs, female (single) 1st

People were telling me that... because several times I was not feeling well, almost for one month so people were telling me that “you should just go for the test” so it was upsetting me so I said “let me just go for test”. 26yrs, male (single) 1st

Others appeared to have little cause for concern believing that their chances of infection were low since they were either in a monogamous relationship, had no history of sexual risk or simply did not think their previous behaviour was a real threat. These were testing because they felt it was the right thing to do according to the health messages that they had been exposed to:
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I came because they keep saying you should go and test whether you are sick or not you should go and know your status. 23yrs, female (married)\textsuperscript{1st}

I just wanted to know how my health is, to know how my life is whether I am sick or not. 18yrs, male (single)\textsuperscript{1st}

I had just completed schooling and I thought that was the best way to do something because you never know. I decided to go for VCT so that I know my status. 25yrs, male (single)\textsuperscript{1st}

7.3.1 Factors inhibiting or facilitating testing

The decision making process, especially for those who experienced anxiety about testing, was influenced by various factors which served to either discourage or encourage testing.

Inhibitors

Three factors were identified that discouraged individuals from seeking an HIV test: fear of a positive result; fear of being asked difficult questions during VCT; and fear of stigma and discrimination.

Fear of a positive result

The initial desire to test was thwarted, in most cases, by the fear of a positive result. This fear was the single most cited reason for avoiding testing:

\begin{quote}
\textit{I was greatly troubled at heart. I pondered deeply, “now, what if they find I am sick?”} 24yrs, male (single)\textsuperscript{1st}
\end{quote}

\begin{quote}
The difficult part is you keep asking yourself what of if I’ll be positive, yah, what will I do maybe I’ll be just thinking of my status and eventually I can kill myself … 20yrs, male (single)\textsuperscript{1st}
\end{quote}

\begin{quote}
Maybe, it has taken years, but the first time I engaged in casual sex, just the following week I wanted to go for VCT, now when I, I just decided not to go, I even took the step then I felt bad, “I think I know I’m positive”. 27yrs, male (single)\textsuperscript{1st}
\end{quote}
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…it’s just something that I’ve always like something that I always wanted to do. But at times there was that kind of fear in me to say “ah what about if I find that my status is positive?” 25hrs, male (single) 2nd

... you know some people are just afraid, they are afraid maybe of the disease or whatever, maybe because of the way they have behaved in the past, I don’t know. Sometimes they are just afraid of the testing centre “ah that place, they can catch you with the disease” some have that fear. 26hrs, male (single) 2nd

This fear appeared to be fuelled by a lack of knowledge of the progression, management and treatment of HIV and AIDS:

Yah you know people they have that fear, they have that fear that “maybe if I go and I am positive, what am I going to do?” ... you know the problem is if you have the knowledge, the information, get the information clear, I don’t think you can have that fear. The problem people don’t go for VCT because they do not have enough information on how to handle these issues, that’s where the problem is ... most of the people find it difficult to go for VCT because they have that fear of how they will handle the results. 29hrs, male (single) 1st

People could not see how they could possibly live with the knowledge of a positive result:

... what discouraged me was I thought that if I know maybe that will just be the end of the world for me, there is nothing I can do. 24hrs, male (single) 1st

I was just having the fear that “mm what will..., how will I live when I test positive, how will I live?” Just that fear and the fear of knowing my results, my HIV status. 20hrs, male (single) 1st

Others had personal experience or second hand knowledge of the negative outcomes of HIV infection which had given them the perception that there is no life worth living with HIV:
I was scared. What was coming in my mind was, “suppose I am positive, what will be my next step now?” I had a brother, that brother I think he died of AIDS, so I know the pain and the suffering he undergone. I was wondering “suppose also I get positive and be like my brother” so that thing was the one which was hindering me most to come for VCT. 24 yrs, male (single)1st

I had that fear that “no if I go” ’coz I was hearing some people when she or he goes for a test they find it is positive maybe he’ll commit suicide, so that fear developed in me. 23 yrs, male (single)1st

Fear of being asked difficult questions during VCT

A few people made reference to the personal questions that may be asked in the counselling session. As previously suggested by Sheon (2004), these may have deterred some individuals from attending VCT:

I thought probably I would be asked more difficult questions or probably the counsellor would want to know much about my private life ... 43 yrs, male (married)1st

... the only thing I was thinking about was like they will ask me if I’ve maybe slept with a guy before. 27 yrs, female (single)1st

But other people can just decide not to do it because of some of the things that they don’t expect to be asked there and then in the counselling session. 27 yrs, male (single)1st

Stigma and discrimination

Only one person mentioned the fear of stigma as having deterred him from testing and made reference, in his second interview, to others who refused to test because they feared discrimination:

The difficult part is you keep asking yourself what of if I’ll be positive, yah, what will I do? ... The thinking is “how will they see me?” 20 yrs, male (single)1st
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... some of my other friends, most of them they are still refusing to go for an HIV test ... they fear the danger of being discriminated. 20 yrs, male (single)2nd

However, another two people made comments suggestive of reduced stigma to HIV and AIDS:

... because this illness is just the same as malaria and the other diseases that we suffer from. 43 yrs, female (married)1st

... it’s just the same as any other illness, no one can laugh at me to say I am sick, that used to happen in the past but now if someone is sick I can’t laugh at them because many people have it. 26 yrs, male (single)1st

Facilitators

A number of factors, mostly highlighting the benefits related to knowing one’s status and encouraging the acceptance of a positive result, encouraged testing. Some of these formed the basis of the various reasons given for testing, in particular, the need for control, peace of mind and the desire to preserve health. These are now highlighted thematically in a series of 11 paragraphs.

The desire to be in control

The uncertainty surrounding their HIV status left people feeling out of control of their own lives and unable to make decisions as to how to move forward. The desire to regain control appeared to be a compelling motivator and was the most common underlying reason for testing:

I have many plans and things to do in my life, so I cannot plan for things in future when I don’t know how I will be, so that’s why I said let me go and know my status so that my plans can be fulfilled. 24 yrs, male (single)1st
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I was just anxious to know because I have other programmes. **28yrs, female (divorced)**

I felt that I cannot continue living like this, I should know how my body is and then when I know how it is then I can know what to do next. **22yrs, male (single)**

Be it negative or positive I just wanted to know my status so that at least I can plan well for my future and know what the future holds for me and know where to touch and not to touch. **25yrs, male (single)**

I took the step for test, to come and do the test to see my status so that I know which way forward. **29yrs, male (married)**

I decided that even though my husband was saying we should divorce I will not leave until I know that I am ok. **39yrs, female (married)**

The above 39 year old female had been asked to leave by her husband before the end of the day. He had provided her with transport money that same morning. Her husband had been unfaithful and having nothing to lose and a whole lot more to gain she decided to take control of the situation and make an informed decision by ascertaining her HIV status (she decided to wait until after the confirmatory test – did not return for follow-up interview).

**Peace of mind**

The anxiety and uncertainty of not knowing whether one had HIV meant that people seemed to always have a burden on their minds. Getting the test done and knowing one way or the other was a way of freeing oneself of this burden:

I was not having a free mind. I was just thinking about the same thing then finally I just decided “I will just go and test”. **36yrs, male (divorced)**

I thought that it was wise for me to come and test and be sure and have a carefree mind than that doubting. **18yrs, female (single)**
Ahh you see, when the mind is troubled, there is no peace. So you can try to do a lot of things so that you can actually free your mind. Ehhh, my going there for that blood test, I just wanted to free my mind... 29yrs, male (separated)1st

One of the focus groups identified facilitation of peace of mind as one of the purposes of VCT:

I think the purpose of encouraging people to go for VCT, I think one of them is to make them have a free mind. Data Management Officer, male (single)FG1

The need for self-preservation

Almost everyone in this study was more concerned about their own health and protecting it rather than protecting the health of others. Knowing their status would enable them to better protect their own health as evidenced by the response from a young married female when asked what she would do if her husband refused to test (she was convinced she was positive and was hoping to access anti-retroviral drugs):

I am looking after my health, he should also look after his. 26yrs, female (married)1st.

The following quotations reflect a focus on the self suggesting a similar perspective:

I’ve never gone for VCT and maybe if I decide to get married, I might accuse my partner that she is the one who has infected me so before I do that, I have to know my status so that when I know my status I will know how to take care of myself from there. 29yrs, male (single)1st

I wanted to know so that I can know how I should live and take care of myself. 27yrs, female (single)1st
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I realised I needed to know my status “how am I, how is my health?”, “what can I do if I am sick?” 24 yrs, male (single) 1st

A few mentioned protecting others as part of the reason they had decided to test:

... the other thing that made me start thinking was that still more even if I don’t go and then I find a woman with whom I can have a relationship and if I am sick I can infect her with the disease and that would be unfair. ... I do not want to infect someone else. 34 yrs, male (divorced) 1st

I thought that as a man I must marry, then maybe in the near future have children, but like eh, before I do that I have to know my status then... I decided to go for VCT in order to save more lives. 23 yrs, male (single) 1st

Only one person appeared to be primarily motivated by concern for his wife following physical signs suggestive of a sexually transmitted disease:

I could have HIV because I have had sex before I got married, my wife never had it ... so I could bring the infection to her so I started fearing that no it’s better I become sure that my status is this and so that is what has brought me here. 29 yrs, male (married) 1st

Availability of antiretroviral drugs (ARVs)

The focus groups of counsellors suggested that the availability of ARVs appeared to encourage testing:

Nurse, female (married) FGp1, ... they (clients) are increasing in number those who are coming for VCT...

Nurse, female (married) FGp2, ... they know there are ARVs

Nurse2, female (married) FGp2, Because they know at least even if I am positive I will go and get the ARVs

... people have seen the importance of knowing their HIV status, they are having access to treatment, their lives are being prolonged. Nurse, female (married) FG2
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Close to half the interviewees either categorically stated that they would not have tested if there had been no ARVs or gave the impression that the availability of ARVs had played a significant role in their decision to test:

*I think I wouldn’t have come if I didn’t know anything about ARVs, I wouldn’t have.* 20yrs, male (single)\textsuperscript{1st}

... because there was hope that there are ARVs that’s why I had an encouragement that I’ll keep on living positively because I’ll be taking medicines. 29yrs, male (single)\textsuperscript{1st}

*I would not test, I would just wait for death. Because that is why people test, that there is medicine to help me...* 26yrs, male (single)\textsuperscript{1st}

The majority of people in this study claimed that they would have tested even if ARVs had not been available because there would have been other ways of helping them. This may be so but then again it may be because the question was asked after they were aware of their HIV status, the answer may have been different if they had been asked before testing. This view is supported by the fact that a number of those who claimed that the availability of ARVs did not influence their decision to test had earlier stated that they had decided to test so that if found with the disease they can be put on medication. The following pairs of quotes illustrate this contradictory stance. The first of the pair is the reason given for testing while the second is the response given when asked if they would have tested if ARVs had not been available:

1. ... all I want is that if I have it, I should prolong my life with those medicines that they give.
2. Yes, I would have come to be tested, yes. ... I would come so that I know. 43yrs, female (married)\textsuperscript{1st}
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1. ... maybe he will die and I will start taking these medicines which have come and I won’t die.
2. I would have come, because there is need to know your status and how to look after yourself. 40yrs, female (married)

1. I just realised that all those who go, they go and they are taught what to do, you know your health status, if you are found with the disease you start taking ARVs.
2. I would have come … Because I need to know how my health is. 24yrs, male (single)

In the follow-up interview the above 24yr old young man actually admitted the central role that ARVs played in his decision to test:

... if there was no medicine I wouldn’t go. 24yrs, male (single)

The above quotations suggest that ARV availability, implicitly or explicitly, did play what seems to be an important role in the decision making process.

General physical improvement in people living with HIV/AIDS

Having observed or learnt of positive outcomes of HIV-positive people served to confirm benefits of knowing one’s status and encouraged testing:

Like someone would come they would say “I’ve seen a friend who was sick and I’ve seen how that person has improved so I would also like to have this VCT done on me” ... the state of the friend has really encouraged them that they come for VCT. ... they’ll refer to something which they have seen happening. Nurse, female (married)

I pay more attention to one programme (on radio) ... they were saying that some of them are even going to school and completing their education ... it encouraged me. 26yrs, female (married)

Very helpful, it taught me a lot (book on HIV/AIDS) ... it even explained about the people that have HIV and they went for VCT ... there were some people, that gave stories on the experience that they had, who are HIV
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positive and they had babies so I was very encouraged. 29yrs, male (single)\textsuperscript{1st}

... those taking ARVs, some are even fatter than I am but they are infected, so it is better to at least take ARVs. 26yrs, male (single)\textsuperscript{1st}

These positive outcomes are linked to the availability of ARVs supporting the assertion that ARVs played an important role in the decision-making process.

Normalisation of HIV – It’s just like any other disease

The perception that AIDS is like any other disease — engendered by witnessing the improvement in physical well being and social lives of people treated for AIDS — as reflected in the quotes on stigma (section 7.3.1, p244), served to encourage testing. The counsellors in one of the focus groups shared a similar perception:

\textit{I think people are becoming to be highlighted about this problem to say there are other problems which are like HIV which can go on until the person dies, so I think in that relation a lot of people are opening up and they are coming forward and they are tested} ... Nurse, female (married)\textsuperscript{FG1}

\textit{... now HIV and AIDS is just like diabetes and that’s the way people want to take it} ... Community volunteer, female (single)\textsuperscript{FG1}

Significant others who have tested for HIV

Having a partner or a friend that had previously tested appeared to encourage testing, more so if they had tested HIV negative;

\textit{... my wife also was tested and she was tested negative and I got an encouragement also.} 35yrs, male (married)\textsuperscript{1st}
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... looking at life nowadays, it is difficult, that is why if your friends are doing the right thing, even me I developed interest that “let me also be a part of this thing they are talking about” ... a lot of my friends in the neighbourhood were doing or seem to be doing the same. 53yrs, male (married)\textsuperscript{1st}

... she was tested negative and then..., uh, uh, I mean I think it is also one of the reasons that prompted me to know my status because I was like ah you know if she is negative, and then what about me, I think I’ll just go for one as well so that I just know my status. 25yrs, male (single)\textsuperscript{1st}

... after I got my results, the first person I shared my results with was my spouse. ... she also got interested and she went for VCT as well. 43yrs, male (married)\textsuperscript{2nd}

Similar to the phenomenon of inferred negativity discussed earlier, a partner testing negative may have provided the interviewee or their partner with hope that they will also test negative.

\textbf{Encouragement from peers and others}

Encouragement from friends, and work, church and casual contacts was also important in getting people to decide for the test probably by normalising HIV-testing within the person’s social network:

\begin{quote}
I got encouragement from a friend ... other friends, the other one also encouraged me ... there’s a certain lady, I teach her extra lessons, she also encouraged me. 27yrs, male (single)\textsuperscript{1st}
\end{quote}

\begin{quote}
I thought I was ok, I was going to be negative but like they say you never know but I was a little bit scared ... but a certain doctor (church mate) encouraged me saying “you know it’s important to know your status”. 27yrs, female (single)\textsuperscript{1st}
\end{quote}

\begin{quote}
At first I didn’t make up my mind to come for a test until when my friends convinced me that’s when I went ahead for the test. 20yrs, male (single)\textsuperscript{2nd}
\end{quote}

... when I was in town there were some parents who were just discussing but myself I was just beside them. They were discussing about HIV and AIDS,
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about how to know your status, just to know your standard of living and other things. So now I was very interested in their discussion and they even encouraged me “if you’re not tested, if you don’t know your status, you better go to be tested then you’ll know your status so that you know how to live on this earth”. 23\textsuperscript{yrs}, male (single)

**Information, education and communication**

IEC materials and programmes not only served as cues to recognition of susceptibility as earlier mentioned but also encouraged testing:

_Especially those who just come in and you ask them “why have you come?” “I’ve come for VCT” “where did you hear this?” Then they’ll tell you that “no a lot of people are talking about this on radio, on TV and there are posters all over” ... Nurse, female (married)\textsuperscript{FG2}_

Most people cited exposure to the various media as having encouraged them to test by providing information about the benefits of testing and knowing one’s status:

... without those (IEC materials and activities) even I wouldn’t have come here ... if it wasn’t for those things they have stuck up there (posters), what they were teaching us and others who were talking about the same things, I would have been thinking that I am sick and I would have continued having sex with others. But those things they have stuck up were discouraging me that I should wait first, get tested first so that I know my health status. 24\textsuperscript{yrs}, male (single)

... they are very helpful because they, (written IEC materials and programmes on TV and radio), sometimes they can give you strength that since this one has gone through this, what can stop me? You see people who are already positive and who are negative, the life that they are leading. 20\textsuperscript{yrs}, male (single)

... that magazine which is written “Kwatu” ... especially when K said you should know about your status and that’s how you can live if you know your status. Now that’s the information which is very important to me and that’s the reason why I came here. 19\textsuperscript{yrs}, male (single)
... now there is this thing (IEC campaign) that you should go and test so that you know what your status is. So I started thinking that I should also go and test and know how my health is. 23yrs, female (married) 1st

However, some people felt that more interactive community-based IEC strategies would be much more helpful in enhancing knowledge and understanding of HIV/AIDS thereby facilitating testing:

I haven’t seen much of the community work ... So if only that can be improved where people ... in the community can be educated ... I think through the community you’d learn more unlike on TV because where you like meet ... that somebody who is like teaching you it’s very easy for you ... to ask questions there and then and be answered, ... unlike where you just like get the education minus that access of like asking back directly the same person who is teaching about that (HIV/AIDS). 25yrs, male (single) 2nd

... those messages, they do help a bit. I would say no, that is my own opinion, they help a bit. But all I can suggest is probably for people to go out there and sensitise people, you know it’s not everyone who can see something on the wall and read and understand, but you need people to go round, sensitise people, tell them what it is and what happens because even the testing I’m sure here if we were to look at the number and flow of people coming for VCT, I don’t think we can know those who are not coming and it is lack of sensitisation ......they may see on TV, they may see it on wherever it is put up but that can’t help so much, we’ve got to talk to them, they’ll open up, you know face to face uhh, kind of talk actually helps, ... 35yrs, male (married) 1st

**Availability of rapid testing**

A few were encouraged to go for the test when they learnt that they would learn their results the same day:

... that’s when I also thought of like uh anyway since they, I mean after doing the test and then you are given the results there and then, I think I’ll go for one as well so that I know my status. 25yrs, male (single) 2nd
Chapter 7 – Findings: Factors facilitating and inhibiting the HIV-test decision-making process

... there is nothing like first you wait for one week or two weeks, they give you the results there and then. 26 yrs, male (single)

Provision of incentives

The perceived benefits of testing may be increased by the provision of incentives. From the focus group discussions it emerged that attendance at VCT had improved when a small incentive (a coloured plastic bangle) was being provided:

The time when we were giving bangles, it brought a lot of people ... we had a good turnout for VCT saying “no I also want a bangle” “I decided to come for VCT so that I could be given a bangle”. Nurse, female (married)

7.4 Need to know status regardless of test result

It seems that when people had come to the realisation that it is possible to continue living with a positive result, either by seeing, reading or hearing about how infected people were able to pursue normal life styles, and were ready to accept either result, they were then at the point where they could move on to the next stage and make a decision for testing. Even though people were more or less prepared to accept either result they had quite definite expectations of either being positive, negative or were truly expectant of either result. What seems to have been important, however, was the readiness to accept an HIV positive result. This step appeared to be pivotal, for most, in the decision making process:

We don’t just go there promptly you have to sit down first you make a decision, you know, you are ready for the results whether negative or positive ... When you are prepared eh, you prepare yourself, ... Because there are only two outcomes, positive or negative, so one of these things you should expect it and you should be ready for whatever comes out. 29 yrs, male (separated)
Chapter 7 – Findings: Factors facilitating and inhibiting the HIV-test decision-making process

I was prepared now for the results whether positive or negative because I had read the information and I knew that if it is positive I will know how to handle my life, if it is negative I’ll still know how to handle my life … I was just prepared whether it is positive or negative I will take it. 25 yrs, male (single) 1st

I also realised that it’s not the end of the world to know if I’m positive, it’s not the end of the world, because there are other people who are living with the virus and they are still productive, they are still keeping their lives safe and I just had to know, that’s why I came. 27 yrs, male (single) 1st

I pondered deeply, “now what if they find I am sick? Ok still more it’s not the end of the world, what they will tell me, that is what I will be doing, so that I myself will take care of my health”. 24 yrs, male (single) 1st

What was coming in my mind was, suppose I am positive, what will be my next step now? Those things were lingering in my mind until last year that’s when I started thinking ah no, still, because I’ve been hearing that whether you are positive or negative life has to continue and being positive is not the end of the world, you can die at that time, people can still live for maybe even ten or fifteen years. So that was giving me courage, ah no I just have to take a test this year so I have even managed to come for VCT today. 24 yrs, male (single) 1st

However, a few people were only able to finally commit to testing during the counselling session. They appeared to go into the counselling having accepted the possibility of testing positive but having not made a commitment to testing because they were not sure how they could live with a positive result. Counselling appeared to provide for a better understanding of HIV/AIDS issues, especially around treatment and survival, allaying anxieties and encouraging testing. One young man had earlier refused testing post-counselling but later (the same day) went back into the counselling room and tested:

Int: Why did you refuse to have the test done at that time?
Chapter 7 – Findings: Factors facilitating and inhibiting the HIV-test decision-making process

20 yrs, male (single)\textsuperscript{1st}; I was not very clear, I didn’t think about what she said. Until such time when I had time to think about what she said

Int: What was it that you were not clear about?

20 yrs, male (single)\textsuperscript{1st}; Mmm, how I can live positively for many years

One female decided to just go for counselling and see how it would work out:

... it was the discussion that made me decide to go ahead. ... when going I was saying that “I will go and hear what they will say, maybe I will just come back”. I decided that I would live with it but another part of me was saying that it is better to die. ... But after being counselled I was encouraged that it is ok I can live with it, I would be taking the medicines which I would be given. 28 yrs, female (divorced)\textsuperscript{2nd}

It appears that when a person reached this point the benefits of testing outweighed the barriers to testing and they were able to justify why they should seek testing. The general reasoning, as suggested in section 7.3.1, appeared to be that if one knew their status the better placed they would be to control events in their own lives and take responsibility for their own health.

Counsellors in one of the focus groups acknowledged that people who have had time to go through this process of emotional and cognitive engagement seemed to have come to a point where they were ready to test by the time they attended VCT. These people were easier to counsel (for testing) compared to people who presumably had not actively engaged with the question of testing:

... there are different clients that we see. Some they come through referrals especially from the doctor, ... and there are those who are just coming from the community, who just opt to come and do the VCT ... those who are coming through referrals, uhh, it’s very difficult to counsel them because it’s
coming from somebody else, who has told them to go for VCT. So ... actually it becomes very difficult for them to reach that point where they will say “ok can I be tested” but those who are coming from home they have already made up their minds that they are going for VCT and already counselled themselves, in short, I can say. They know why they are coming for VCT unlike those who are referred. Some, yes they accept they have a test done but some really you have to give a lot of information for them to reach to a point where they will say “yes I want to be tested” Nurse, female (divorced)FGpil

7.5 Attending VCT and testing

7.5.1 Perceptions of VCT

Most of the people in this study appeared to view VCT primarily as a diagnostic tool. When asked what they understood by the term and what they had gained from the counselling, most responses focussed on the testing and the result:

VCT means to come and test. 23yrs, female (married)1st

... I thought that you just come, they get your blood and tell you, but I found that there is even counselling. 40yrs, female (married)1st

I know that it is the place where you go to know how your health is. ... How your blood is if you are alright or if you are sick. ... I thought they just take your blood and tell you that you are sick, you have the disease. 51yrs, female (married)1st

... it’s a test that should only be decided by you the person who wants to know the status ... something that you just decide on your own to say “ahhh I think I want to have the test now”. 25yrs, male (single)1st

It means you have to know your status... 30yrs, female (married)1st

... to know how you are, if you don’t have the HIV virus which causes the disease AIDS. ... counselling, ok it’s like....telling him how he is if he has the HIV virus or he doesn’t. 25yrs, male (single)1st
Chapter 7 – Findings: Factors facilitating and inhibiting the HIV-test decision-making process

Is it not the hospital where you can know your status, whether you are sick or you are not sick? 26 yrs, male (single)

... I found it helpful because I wanted to know how I am, if I am infected I would like to be given medication, if I am ok then there is nothing I can do. 51 yrs, female (married)

This was a position recognised in one of the focus group discussions:

... if a client comes through for counselling and testing for the first time, it’s not that they’ll get all the information at the same time. Sometimes they’ll just be desperate to get the testing done. Nurse, female (married)FG2

The perceptions of the counsellors in the focus group discussions appear to be similarly oriented to testing and less on the preventive role of voluntary counselling:

... first and foremost the purpose is that we establish the status of this individual. Nurse, female (married)FGpil

To add on what my colleague has said uhh the purpose of VCT in most cases we look at early diagnosis of the disease or the infection because once someone is diagnosed this will open up care and support for this individual. This is the only key, this person can access ARVs ... and not only that we need to put information across on the prevention part of this infection and what people should do and what they shouldn’t do ... Nurse, male (married)FG1

... we are doing the VCT so that they are tested and then once they know their status then they would know what next. Nurse, female (married)FG2

... once someone goes voluntarily to have..., to be tested, know their status, it opens ways to how they are going to improve their lives or which direction they have to go, who to see and most of all where to get medical support, what they should take, how they are going to just prolong their lives if they are positive or negative. Nurse, male (married)FGpil
Most people therefore attended VCT with the perception that they were going for an HIV test; deciding to attend VCT was in effect, for most people, a decision to test for HIV.

### 7.5.2 Immediate triggers for attending

For most people there was nothing remarkable or specific that prompted them to go and test on the particular day and time that they did. It appears that having made the decision to test, when to test was more of a spontaneous activity:

... *my heart told me to go, I had just knocked off from work and it said “just go”*. 24yrs, male (single)

... *this question came up three weeks later (ago), yah, yah, this question came up that yah I’m supposed to go for VCT, and then today I came kuma 06 (around 6am) so then I passed ku (at the) plant that, ahh, let me go straight home and then that no, me am passing near my hospital I have to go for VCT and I mean it, that is why I came*. 19yrs, male (single)

... *I said to myself “tomorrow if we won’t work I will go, this is my chance”... I just came myself that “I want to know now”*. 36yrs, male (divorced)

... *I was lying down then I thought “this talk about testing has gone on for two days, so tomorrow I will go whatever will happen, will happen*. 31yrs, female (single)

... *I’d been struggling some time back, now today I just made up my mind that no, whatever comes I just have to go, I’ll know how to handle my life if it is positive, I’ll get the advice on how to live positively if it is negative fine, then I have to continue living negatively*. 29yrs, male (single)

It can be appreciated from the quotes above that, from amongst those who agreed to take part, once individuals had made the decision to test they were quite determined to carry it through. This is further supported by the
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following quotes from individuals who had to make more than one visit to the VCT centre:

... there was a day I came but I found they were not in ... so I came again, I found that “no this week we are not working”... 51yrs, female (married)1st

I started some time ago but I used to find the place locked and there was no one. This was the fifth time I came. 20yrs, female (single)1st

7.5.3 Factors hindering or facilitating access to VCT services

Hindrances

Accessibility to testing services in terms of time, distance and availability of counsellors were important considerations. Accessibility includes among other parameters, time that service is available, availability of service and distance to VCT centre.

VCT service hours

Even though services may be within easy reach, they may be inaccessible in terms of the time of day and day of the week that they are available. VCT services are available during the normal working hours from Monday to Saturday. These hours are not convenient for people who are employed and therefore unable to attend at these times:

... I used to think about it often but I never used to have the time to come because of work. 28yrs, female (divorced)1st

... it’s just time, because when I go for work in the morning I knock off maybe eighteen hours (18:00), by the time I bath and walk here it would be late. 36yrs, male (divorced)2nd
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Non-availability of counsellors

Services sometimes were not available because of shortage of staff or non-availability of counsellors:

... before we could start the session I have to find out whether I’ve got enough time if I don’t have enough time I just make an appointment with them to come some other time. Nurse, female (married)\textsuperscript{FG2}

So when the client comes, normally they come to ask, and with this shortage of nurses, so maybe when they come they will just find that maybe you are the only counsellor on duty and you’re the only one in maternity side, you even have the clients (maternity clients) so normally we just give them appointments. We make appointment with them to come on a day whereby you can have ample time to talk ... Nurse, female (married)\textsuperscript{FGpil}

... there was a time I came but there was no one. 34yrs, male (divorced)\textsuperscript{1st}

(See also quotations from 51yrs, female (married)\textsuperscript{1st} and 20yrs, female (single)\textsuperscript{1st}, p261)

Distance to VCT centre

Some people had not tested earlier because the services were at a distance from their homes:

... one time I had told him that let us go and get our blood tested but transport was a problem. 43yrs, female (married)\textsuperscript{1st}

... where I stay ... the hospital is far away. 53yrs, male (married)\textsuperscript{1st}

Facilitators

VCT attendance was facilitated by the availability of services within the same location as other health services and by peers who themselves were attending VCT.
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Health facility affiliated VCT services

Ease of access facilitated by the availability of services within the health facility appeared to be conducive to testing. People decided to test on days when they were at the health facility for a different personal or relative’s health-related problem. They took the opportunity to test while they were in the health facility for this other purpose thereby ‘killing two birds with one stone’, saving time and money in the process:

...I thought that since I am going to K clinic for the abdominal pains I will also go there where they say that they test the blood. 43yrs, female (married)\textsuperscript{1st}

I have an in-law who is sick and is on the same medicine, she is the one I was looking after in that room, now since they have discharged her I said let me go and also know how I am. 51yrs, female (married)\textsuperscript{1st}

... I just came to get my sister, who was in the maternity ward ... So that is when I asked how I would go about it ... So I came here and tested. 23yrs, female (married)\textsuperscript{1st}

Peers

Peers played a central role in physically getting some individuals to the VCT centre:

... my friend came home and she told me she’s coming to the clinic and I said that I also would like to test and she encouraged me to come with her, so that is how I just came with her. 22yrs, female (single)\textsuperscript{1st}

... my friend helped me to come, he accompanied me so I think it made everything easier because he was there by my side. 27yrs, male (single)\textsuperscript{1st}

A few of these were still contemplating testing when they attended VCT with their friends:
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I’ve been just worrying myself, troubling about AIDS. Troubling myself, in my thinking and yesterday my friends they are the ones who came up with the idea of coming here for VCT ... there was one person, my friend who was very confident to have a test today ... we were just like escorting him. 20 yrs, male (single) 1st

I was just having the fear that “... how will I live when I test positive, ...”, just that fear ... but after I came here the counselling helped me to get away that fear. ... we were coming as a group, there was just someone influencing us. 20 yrs, male (single) 1st

7.5.4 Pre-test decision-making resulting in risk reduction

Fourteen (48%) of the twenty-nine people that were practicing safer sex before attending for VCT reported implementing risk reduction strategies during the decision making phase before coming to the decision to test. This appeared to be a strategy to reduce chances of acquiring HIV if they did not already have it, as illustrated by this quote from a young man who had been abstaining for more than nine months:

... even women, I just stopped thinking about women, I was thinking “even just that one I had sex with, ahhh in fact I might find that maybe I am sick”. 24 yrs, male (single) 1st

Two married women (both of whom were symptomatic) reduced their risk of HIV infection before testing by creating physical distance between themselves and their partners thereby facilitating abstinence. This may have been easier for them to do than insisting on condoms:

... (he) likes women too much so I was afraid he might infect me with this same disease which has come, HIV. Because he has become a womaniser so I thought it is better we just separate, he lives on his own and I live on my own. 48 yrs, female (separated) 1st
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*I told him that “I am going to get my blood tested so even you when you come, if you want to be with me you should go and test”. 43yrs, female (married)*

Such control and independence is not usual for married women (especially those who are unemployed as these two were) in Zambia and their emancipation may have been due to the fact they were both in a polygamous union which means they may have been more accustomed to fending for themselves since the shared resources may have been inadequate and secondly they both had adult children and others who supported their decision and were willing to assist them:

*I said that I should just leave him to marry whomever he wants they will take care of me.* 48yrs, female (separated)

*I even my relatives and children say the same “You should just stay on your own, we can’t fail to provide you with food and clothing”*. 43yrs, female (married)

7.6 Conclusion

Coming to the decision to attend for VCT was a complex process. Recognition of susceptibility to risk of HIV infection appeared to simultaneously trigger a prolonged angst-filled decision-making process and the adoption of protective sexual behaviour.

Recognition of susceptibility was aided by high levels of awareness facilitated by the national IEC campaign and the high visibility of AIDS. The majority of males felt they were susceptible due to their own risk behaviour whereas most of the females felt at risk due to their partners’ behaviour. Among the married females, irrespective of age, there was a propensity to acknowledge risk only after experiencing symptoms suggestive of HIV infection.
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Males, mostly those 25 years and below, cited alcohol, peer pressure and beliefs about male sexuality and vulnerability to HIV among the reasons for engaging in sexual risk behaviour. Females, most of whom were married, cited cultural and religious reasons.

Denial, the belief that to know that one is positive hastens death (most commonly expressed by males), and believing that one is negative because a spouse or partner had tested or was thought to have tested negative hindered self-perception of risk.

For most, contemplation of testing for HIV was a protracted process filled with much angst due to the anticipated disadvantages of testing positive, and probably exacerbated by ignorance and underlying perceptions of stigma and discrimination. Most of the females, who in most cases believed themselves to be positive, experienced less angst and seemed to accept it as their fate and were more concerned about accessing available treatment in time.

Ignorance about one’s status appeared to induce a sense of lack of control and unease with most people citing the desire for peace of mind and the ability to make life-decisions and proceed with their lives as a reason for testing. Generally, participants in this study appeared to seek testing so as to safeguard their own health rather than that of their current or future partner(s).

The availability of ARVs and their noted positive effects seemed to have played a major role in convincing people, across all age groups and both sexes, that testing was to their advantage. The majority of participants
Chapter 7 – Findings: Factors facilitating and inhibiting the HIV-test decision-making process

perceived VCT as testing for HIV. For most, the decision to test was made prior to attending for VCT. The focus groups confirmed that VCT services focussed on identifying those who were infected to consider treatment, that is, VCT = counselling + TESTING.

Hindrances to accessing VCT services included inconvenient VCT service hours especially for those in employment, shortage of counsellors and distance to VCT centres. The availability of VCT services within health facilities facilitated attendance.

Most of the males appeared to have made decisions about and implemented safer sexual behaviour before attending for VCT. However, most of the women, even though they were aware of what they needed to do to protect themselves, had been unable to practise safer sex because such decisions were not within their control.
8 Findings: Effects of counselling and testing

8.1 Introduction

8.2 The Counselling process

8.2.1 Is counselling necessary?

8.2.2 Benefits of the counselling process

8.3 Being empowered and in control

8.3.1 Effect of counselling on knowledge, attitude, skills and behaviour

8.3.2 Effect of the negative test result

8.3.3 Provided impetus and resolve to maintain status

8.3.4 Advocacy

8.4 Conclusion
8.1 Introduction
The findings related to the process people in this study went through in coming to the decision to attend voluntary counselling and testing (VCT) and test for HIV have been presented in the preceding chapter. These findings took us from the point a person recognised their susceptibility to HIV infection to the point where they overcame their fear of a positive result and proceeded to seek a test. The current chapter picks up from that point and presents findings related to the actual experience of voluntary counselling and testing, addressing the second aim:

*To gain the perspectives of people who are HIV negative on how voluntary counselling and a negative result influence their attitudes, intentions and subsequent sexual behaviour.*

One overarching theme emerged from analysis of the findings related to this aim, that of empowerment and control.

The findings in this chapter relate to the second part of Fig 6.1, p220.

In this thesis control is defined as the “power to direct or determine: “under control”” (Webster’s Online Dictionary). Katherine Shear defines the concept of “sense of control” as “confidence in one’s ability to influence and regulate the environment in such a way as to fulfil needs and desires, and to protect oneself from dangers” (Shear, 1991). Empowerment is a process that increases self-efficacy (or the sense of control) through acquisition of knowledge, skills and understanding enabling one to make informed choices and “influence and regulate the environment” (Anderson and Funnell, 2009, Feste and Anderson, 1995).

Fig 8.1 provides a diagrammatic representation of the effect of counselling and the negative result on knowledge, attitude, self-efficacy and behaviour.
Chapter 8 – Findings: Effects of counselling and testing

Figure 8.1: Effect of voluntary counselling and receipt of a negative HIV test result on behaviour

8.2 The counselling process

8.2.1 Is counselling necessary?
Although the purpose of VCT was commonly perceived to be diagnostic, most people appreciated being given the opportunity of a counselling session before testing and were of the opinion that counselling was an essential part of the testing process. This is reflected in the responses to the suggestion that counselling be done away with:

*I would prefer to have the counselling so that I can be encouraged.* 31yrs, female (single)\textsuperscript{2nd}

*... the counselling part is the most important one. It’s very important that one is told about what actually happens during the test, what the results..., how he or she should react after getting the results. So I feel and think the counselling part is very cardinal.* 43yrs, male (married)\textsuperscript{2nd}
Chapter 8 – Findings: Effects of counselling and testing

I think the counsellor is very important in the equation. He is very important. There has to be information given to a person before receiving a certain piece of, ah big information in the end. 27 yrs, male (single) 2nd

Counsellors were also of the opinion that counselling is necessary to prepare someone for the results as evidenced by their responses to the suggestion that people be given the option to test themselves at home:

... there is a reason why you talk, we talk, we go into those sessions (counselling) and the like. So whether saliva or what but the issue is whatever outcome we (person self-testing) won’t be ready to handle it.
Nurse, female (married) FG1

Self-testing, me I don’t encourage it because psychological preparation is very important. Nurse, female (married) FG2

In contrast, a few people felt that there was no real need for counselling since they already had adequate information about HIV:

... even without counselling I think it would be, testing would be helpful because I know, one, I know the media’s of transmission, getting infected. So it’s just a matter of avoiding those ways and I would live negatively.
(maintaining a negative status) 25 yrs, male (single) 2nd

The following quote is from a young man who had participated in a number of HIV and VCT sensitisation sessions at the workplace and had been exposed to other sensitisation materials. These had apparently provided him with all the information he required to make an informed decision to test:

24 yrs, male (single) 2nd; ah I was ready from home, I decided at home that I would test
Int: So if we had tested you without counselling...?
24 yrs, male (single) 2nd; There would have been no problem because I would have known that now that I am like this since I know that there are medicines I’ll just start taking the medicines, no problem, it has happened
Chapter 8 – Findings: Effects of counselling and testing

Thus, some people thought they had acquired enough information enabling them to make informed decisions on the options available to them. All they required was knowledge of their status to implement their desired course of action through an actual test. One married female, who did not believe she was at any risk, was testing because the information, education and communication (IEC) messages were advising everyone to know their status (see quote - 23yrs, female (married)\textsuperscript{1st}, section 7.3.1, p254). Another two married females were suspicious of their partner’s behaviour. One was testing specifically with a view to accessing treatment:

\begin{quote}
\textit{51yrs, female (married)\textsuperscript{2nd}; }... all I want to know is how I am ... What I wanted was to know how I am, whether I am sick or not

\textbf{Int: }And if you were sick?

\textit{51yrs, female (married)\textsuperscript{2nd}; }I would start getting the medicine
\end{quote}

While the other was testing so she could make a decision between asking her husband to leave and staying with him:

\begin{quote}
... so that even if he leaves me it is ok because if I am not ok I wouldn’t spare him ... I would just be living with him and he would have to provide me with whatever I want rather than being a burden for my younger siblings. 43yrs, female (married)\textsuperscript{2nd}
\end{quote}

8.2.2 Benefits of the counselling process

Counselling was felt to be an important part of the process because it prepared people to receive a positive result, provided them with an opportunity to reflect about their lives and make an informed decision to test and provided advice and guidance on how they should maintain the negative status.
Chapter 8 – Findings: Effects of counselling and testing

**Psychological preparation for testing**

As can be expected the few people that had attended VCT without prior commitment to testing, regarded counselling as an essential prerequisite:

*I think it’s best to counsel..., to counsel me before I go through the test.* 20yrs, male (single)\(^1\)

*Me I can’t, me I can’t be tested before counselling, unless there’s counselling. That’s when..., the first time I came, I just came for counselling I didn’t come for testing, but then after counselling then I said oh, I think I should know my status. But all that while, I wanted to know my status. Ya, when I came for counselling, then after the counselling process then I said ok this is the time ... counselling should be there before anything.* 20yrs, male (single)\(^2\)

As mentioned in section 7.4, people required affirmation of life even with a positive result before they could consent to testing. These people had acknowledged that this could only be provided through the counselling session. The young man above who says that “counselling should be there before anything” goes on to say:

... they told me that even if you are HIV positive, you wouldn’t just die there ... you’ll still lead a normal life unlike if you just come there, no counselling you just go straight for testing, you’re tested positive you wouldn’t like ahh, put much concern on the counselling afterwards you’ll just be disturbed in the mind. That’s why I needed the counselling first so that they tell me what life is when you’re HIV positive. 20yrs, male (single)\(^2\)

As presented in the previous chapter fear of a positive result appeared to be the greatest deterrent to testing (see Fig 7.1, p224 and section 7.3.1). For those people attending VCT with the intention to test, counselling served to allay the anxiety associated with testing by providing a clearer understanding and hence deeper appreciation of how one could live with a positive result:
Chapter 8 – Findings: Effects of counselling and testing

It was very helpful especially if the results were to be positive ‘coz we talked about life after being positive and so many things. We also talked about life after negative, after testing negative. We talked about what life will be after that. So it was very helpful the counselling helped me to get away that fear and just to feel at home, so it really helped me to get away that fear. 20yrs, male (single)1st

... it gave me also hope before she gave me the results ... Even if I tested positive I could still live ... positively. 25yrs, male (single)1st

... that discussion is very helpful because it makes you relax ... it helps because if you are like afraid and then you’ve got doubts about everything then you can understand. 27yrs, female (single)1st

If you start with counselling the heart is calmed first because you know that “even if I am sick I can still exist, my life can be prolonged if I follow what she told me”. You even feel your heart calm down “even if I am sick it is no problem”. 24yrs, male (single)2nd

Providing a time for reflection

The counselling process was considered a "point of reflection" (25yrs, male (single)2nd). A number of people referred to going through a process of self-reflection during the pre-test counselling session. The over-riding concern during the counselling session was the result of the HIV test. As the counsellor talked people replayed their lives, weighing their chances of being positive or negative depending on the information being provided by the counsellor:

... I was very anxious to know my status and having been told what the counsellor told me about HIV, like reminding me over things I know, like it’s incurable, it’s all that. I started imagining how I would lead my life when I am positive. It was like a point of reflection ... it was like a reflection point I so much looked into things that I already knew, now I started thinking about them deeply and it helped me to decide. 25yrs, male (single)2nd

... I started thinking that I will be negative because she has ruled out the shaving machine. 26yrs, male (single)1st
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... a person also assumes a certain position before the results, “I think I’m negative”, that’s what they think even though they are positive they still have that glimmer of hope that they may be negative but there is still that small voice whispering “ya, you can be positive” so they are still arguing so after trying to, after counselling then they are now, actually they can know themselves there and then, that “maybe the chances of me being negative are slim” or “the chances of me being positive are slim” after receiving the information. 27yrs, male (single)2nd

This time of reflection appeared to convince people “that what he (sic) is about to do is the right thing” (29yrs, male (married)1st):

... the way we were talking and the answers she was giving me would make me think..., when she says something I would think “ah maybe I’m positive” as we talked some things would touch me, so I was thinking “I don’t know what’s coming” on further discussion something else would be in my favour and I would think “it will be ok” so until the end of the discussion then I said “I will accept whatever comes”. 19yrs, male (single)2nd

Even after accepting that they can live with a positive result and anxiety levels being reduced by the counselling, some people described having what can be described as an irrational anxiety attack just before testing or while waiting for the results, when they wondered if they might have actually contracted the virus from any of the possible mentioned sources and how they would cope with that. The imminence of the moment of truth with ‘that small voice whispering “ya, you can be positive”’ (27yrs, male (single)2nd) appeared to be associated with its own angst and doubt about their ability to cope with a positive result:

... after going through everything the knowledge about HIV and AIDS, I just started imagining if in any way, because I’ve been to hospitals, I’ve been injected before, so if I happened to contract it through all those ways ‘coz I thought I had not exposed myself to anything that could endanger me (partner tested negative) but if I had contracted how would I accept this. That is what came into my mind so that’s what brought fear. 25yrs, male (single)1st
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My heart was thumping especially when she drew my blood and put it there and she was telling me that when the blood comes this side and it remains clear then you are ok. 24 yrs, male (single) 2nd

... when she was doing the test you know being human there is always that “ah so..” when she put the blood on the strip “ah, so she will tell me that it is like this, but if they find it is ok still more..” that feeling also comes that “I will feel good” but again the doubt also comes in, that’s how I was feeling. 26 yrs, male (single) 2nd

It appears that people found it helpful being asked, by the counsellor, to reflect on what their response to either result would be. This seems to have provided an opportunity for a more concrete and realistic consideration and acceptance of the possibility of a positive result and how it would be dealt with:

... where you just do like a test minus being counselled you may end up maybe killing yourself after finding out that you are positive, something like that ... Because at least before you do a test you’ll be asked to what you would do with your life if you were to find out that you are positive or negative because there at least you’d like.., I mean you would come to a decision to say this is what I would do and then that will keep you moving. 25 yrs, male (single) 2nd

‘Coz that’s the only part of it I think the most crucial one, ‘coz there she really asked me, “suppose if your results are now negative or positive what will be your reaction?” so I think that one is the most crucial part of it. 24 yrs, male (single) 1st

Counselling is important, you should be tested after counselling because they give some advice ... they explain to you, they ask “you want me to test you?” “then if we find you don’t have or you have the virus what will you do?” 26 yrs, male (single) 2nd

She explained to me, “if we find you to be HIV positive, what are you going to do?” I said “there is nothing I can do because it has happened”. “What if we find you are ok, what would you do?” I said “I will accept it because I am just ok”. 23 yrs, female (married) 1st
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... I was first of all asked if I was like willing to take the test and what were my plans, I mean, if I, if I tested negative or positive. 25yrs, male (single)1st

In the same vein, being given the opportunity to make the choice to either proceed with the test or not also appeared to be of some significance; giving them a second, seemingly unexpected (for most), opportunity to accept or reject testing seemed to emphasise that they were in control and may have further reduced anxiety:

... first of all he asked me if I, if I really wanted to take the test, then he let me decide, so it was up to me to decide. 27yrs, male (single)1st

... counselling is required because during that counselling they ask you and you only agree to the test if you feel you are ready. 24yrs, male (single)2nd

Providing advice and guidance

Advice and guidance from the counsellor was anticipated and appreciated for providing instructions on how to live post testing; even though this information was something that most people were already aware of and some were already practising:

... she told me that now that your result is negative it doesn’t mean that you should now start having affairs just because you think you are perfect now, you should just maintain your current situation until the time you get married ... I appreciate because they give me a lot of advice. 25yrs, male (single)1st

... the last one (post-test counselling session) was as well helpful because I knew my status and ... I was like told how I should live. 27yrs, female (single)1st

... there’s one thing that I really found helpful, in fact there are so many things especially that after testing you are told how to stay after you test negative. 20yrs, male (single)1st
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... you are like educated on how to like maintain your negative living or positive living according from the information that I received there I think it would really help me. 25yrs, male (single) 1st

... when I sit at home no one explains anything about these things to me now when I come here they advise me on how one should live these days. 43yrs, female (married) 1st

8.3 Being empowered and in control

Counselling and testing empowered people with various types of knowledge and understanding facilitating personal control and encouraging not only responsibility for safeguarding one’s own HIV status but also a felt responsibility to help others acquire the knowledge they themselves had acquired.

Fig 8.2 shows the relationships between the main theme and sub themes relating to the second aim, as this chapter proceeds to detail.
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Fig 8.2: Relationship between main and sub-themes of effects of counselling and testing
8.3.1 Effect of counselling on knowledge, attitude, skills and behaviour

The counselling process facilitated empowerment through the provision of knowledge and enhanced understanding of HIV transmission, prevention and treatment influencing attitudes to risk and condoms, acquisition of skills in condom use, and reinforcement of previous behaviour.

Knowledge

Most people claimed to be knowledgeable about HIV and AIDS before attending VCT. Counselling served not only to reinforce this knowledge that had been obtained from various sources but also provided new knowledge about HIV and AIDS. In the words of one young man “it’s an issue of just topping up” (29yrs, male (separated)2nd)

... it is like the same things I was hearing on the radio are the same things I heard here. 51yrs, female (married)1st

How to look after oneself? They talk about it even on the radio and the counsellor also talked about it. 23yrs, female (married)1st

... most of the things that he told me there I already knew ... but he also told me many other things that I didn’t know. 27yrs, male (single)1st

There were some things she was explaining which I have never heard before ... I appreciated because I didn’t know those things. 30yrs, female (married)1st

Ok some of the things she told me I just heard them today, other things I knew. 18yrs, male (single)1st

... counselling is a good thing ‘coz you learn a lot more. 20yrs, male (single)2nd

Apart from providing new knowledge, counselling improved understanding of HIV/AIDS issues around transmission, prevention and treatment:
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... she explained to me about the virus and how it gets multiplied and she also explained the role the ARVs play in someone who is HIV positive, that is making the virus sort of sleep or stop multiplying so that at least the immune system improves ... they give you information on how this HIV can be infected from one person to another and examples of people that have been infected and how they have been infected. 29yrs, male (single)1st

I learnt more when I had my counselling yesterday ... I learnt about ... ways in which you can get the virus ... that discussion is very helpful because it makes you relax and understand. 27yrs, female (single)1st

I’ve come to understand a lot of things concerning the way the disease is transmitted ... I knew very little ‘coz of time that I spend at the workplace, it was just too much so I’ve never had that chance to at least be exposed to teachings and discussions like this ... how to keep ourselves safe from getting the disease that is another thing that is very important. 29yrs, male (married)1st

The counselling helped me in that some things that I knew before I didn’t know them in detail so the counsellor now explained in detail what it was and what exactly it meant. 25yrs, male (single)2nd

The new knowledge and understanding gained from the counselling empowered people with the ability to look after their own health to avoid infection or to access treatment:

... before I never knew in detail how HIV and AIDS is transmitted. Though basically I could read posters, listen to the radio, but I didn’t give it much attention as I do now. From the counselling part that’s where I got much of the information as to how one is supposed to behave; conduct the sexual life so that one avoids getting infected. 43yrs, male (married)2nd

... what I think is the most important part in the testing part is the counselling part ...You would know some other means you can contract HIV and AIDS ... and how you can live your life after knowing your status. 20yrs, male (single)2nd – was only convinced to test after understanding this point in the counselling
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*It helped me in the sense that I even knew about what, about this so called window period and on how to access the uhh, RVs (sic) when you’re contracted HIV/AIDS.* 24yrs, male (single)2nd

Counselling at the VCT centre was more commonly provided on a one-to-one basis and occasionally in groups of two or more. The few that had been counselled in groups felt they had benefited more from the counselling. The amount of knowledge gained and depth of understanding appears to have been enhanced by the broader discussion facilitated by questions from others in the group:

*In my case I think I concentrated very much because the same friends who accompanied me then they also ask questions on my behalf; those that I forgot, they ask.* 27yrs, male (single)2nd

However, post-counselling understanding of transmission and hence protection was still inadequate as portrayed by the reported reasons for having escaped infection. Misconceptions still persisted with most people believing that it followed that since they were negative then the person or persons they had had sex with had also been negative at the time:

28yrs, female (divorced)1st; *Maybe because he never had sex with a sick woman ...* 28yrs, female (divorced)1st; *No it can’t happen*

36yrs, male (divorced)1st; *... maybe he is not sick either* 36yrs, male (divorced)1st; *Yes, because we were using the same woman ...*

... *I can think ...them (sexual partners) also they are negative.* 23yrs, male (single)1st

A few believed that the virus is only transmissible between people with the same blood group:
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I thought that obviously maybe it hasn’t really got into my blood because that blood maybe is different from mine. **22yrs, female (single)**

What I am thinking has saved me ... it is because our blood is different; if it was the same maybe I could have contracted the disease. **19yrs, female (single)**

Even though people acknowledged that it was not possible to identify an infected person by looks alone, they made assumptions about their partner’s HIV status based on appearance and perceived behaviour. The symptom-free period between infection with HIV and manifestation of infection when a person develops AIDS appeared to be a difficult concept to grasp. People may have known it theoretically, but did not appear to relate it to real life:

**29yrs, male (separated)**; ... it is said that you should not trust anybody, but in as far as I know them they were good people

_Int_: So you believe they didn’t have the virus?

**29yrs, male (separated)**; Yah they didn’t because if they did I should have been tested positive

**24yrs, male (single)**; ... the thing that makes me to be so comfortable was that one, that person she’s very decent so that was the thing that was making me so positive that I can’t have, I can’t be positive

_Int_: You think she was negative as well?

**24yrs, male (single)**; Yah, I think she was negative

This can have devastating consequences since the tested person will continue to have unprotected sex with their partner believing they are safe as portrayed in the following narration from a counsellor in a focus group discussion:

_There was one incident, that woman who tested negative during pregnancy on PMTCT programme then she delivered and the child became sick. So that’s when we decided to do another test but this woman refused that “no, I_

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**15** Prevention of mother-to-child transmission of HIV
tested negative”. Then we said “no, did your husband test as well” she said “no, but since I was negative, he was also negative ... and I was pregnant do you tell me that just this time my child could become positive?” Nurse, female (married)\textsuperscript{FG2}

**Attitudes**

The knowledge and enhanced understanding provided by the counselling influenced the attitude to condoms in a few people and risk perception in most people.

**Corrected misconceptions about condoms**

For some people, especially males, counselling increased understanding or corrected misconceptions about the usefulness of condoms in preventing HIV:

... I used to hear about them on the mine when they were talking about condoms but I just used to look at them, but it was at the counselling where I learnt how they help, that’s where I got to understand them ... what I learnt from the counselling is what helped me because she explained a lot of things to me and I found them to be very helpful ... When you know what they teach there that is when you will know how to go about doing things, we all just learn. 24\textsuperscript{yrs}, male (single)\textsuperscript{2nd}

... we did not really know the importance of using condoms ... So we learnt the importance of using condoms ... I think they work because mm, like the way they explained how it works ... they explained quite a lot about the condom; how it is made, how it should be stored, which ones to use, such things, not to use expired ones and the like. So I realised that, I thought that chances might be there to contract HIV but it depends on the type of condoms you use, if it’s expired or such according to the information. 20\textsuperscript{yrs}, male (single)\textsuperscript{2nd} – counselled with a friend

So that is something I learned, you don’t just wear it so long you wearing it that is not safe because it can burst when having sex and that becomes a problem ... I have learned from all that ... she explained and I’ve understood. 26\textsuperscript{yrs}, male (single)\textsuperscript{1st}
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The problem with condoms

However, the concept that condoms are not really effective in preventing infection with HIV because they do not provide a hundred percent guarantee of protection appeared to be quite resistant to change:

*Ok that information is just ok but when we consider what they say that condoms are not hundred percent I also think that if one continued using condoms, since they say they are not hundred percent one can get the disease then what next?* 28yrs, female (divorced)²nd

... on condoms I’m not for the idea because condom I don’t think it’s somehow hundred percent safe so I would say the... me what I can advise people is never to use condoms because condoms they are not so hundred percent safe. It’s better to just abstain unlike using condoms ‘coz condoms they are not hundred percent safe. 24yrs, male (single)²nd

There was a perception that condoms were meant to be used for the prevention of pregnancy:

Condoms are ... I mean even them they are not 100% safe ... If we are to have sex ... I think I’d only use condoms for the sake of like not wanting to make my girlfriend pregnant and I think that is the reason ... why they’ve been put in place. 25½yrs, male (single)¹st

We will use them to protect me from getting pregnant. 28yrs, female (divorced)¹st

I think that condoms should just be encouraged for married people so that they can prevent pregnancies. 30yrs, female (married)²nd

... it (condom) works better to prevent pregnancies than HIV. 24yrs, male (single)²nd

The health prevention messages on condoms appear to be partly responsible for this attitude as evidenced by the following quote:
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Because these health people they say the condom is not hundred percent perfect. 29yrs, male (separated)²nd

Quite a few people interviewed, both single and married, and of various ages and both sexes, were of the opinion that promoting condoms was counterproductive because they encourage promiscuity:

That is the problem with those messages instead of saying that “the world has become a difficult place you should not sleep around”, they are teaching that “you should use condoms” which is “you should sleep around but you should use condoms so that you do not get sick”. 26²yrs, male (single)²nd

... when you are saying when you use condoms you won’t contract AIDS, it’s like you are now trying to promote promiscuous (sic). 25¹yrs, male (single)¹st

The use of condoms just increases the disease ... It promotes womanising because people think it’s ok since they can use condoms if they were not there maybe they might be discouraged. 34yrs, male (divorced)²nd

They have just brought a problem with these condoms ... they have just developed prostitution; even young children are using condoms. This was not there before ... 40yrs, female (married)²nd

... the way I see it, encouraging the use of condoms is what causes the disease to be spread further ... condoms should just be encouraged for married people so that they can prevent pregnancies not for people like the young ones who are encouraged to sleep around ... they have encouraged prostitution. 30yrs, female (married)²nd

This attitude has most likely been influenced and encouraged by the religious and political stance taken on condoms in the history of the response to the pandemic (see Merson et al., 2008):

... What encouraged me was ... I read in the news paper where Dr Chiluba (former Zambian head of state) was not promoting condoms, he was saying “no we cannot promote condoms, as you are promoting condoms, that means you are promoting, we are promoting people to have sex.” 23yrs, male (single)²nd
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Increased perception of risk

Counselling enabled a better understanding and appreciation of some risks, especially relating to non-sexual behaviour such as the sharing of sharps and mother-to-child transmission. Most people’s perception of risk, having been already high prior to counselling, remained high or increased further post-counselling. This was reflected in movement from safer sexual behaviour to abstinence in a few people. Counselling appeared to facilitate a deeper appreciation of risk post counselling through increased knowledge and understanding:

... after counselling I was..., I’m more serious about it, like the way I look at it you know ‘coz it’s important, you know, and we have to be careful and at times we take things like for granted and at times you are careless because you don’t know but when you know it’s different like now I know “ok when I do this” when someone is sick and then you have sex, unprotected sex and then it’s serious. At times you think “ah maybe it’s real, maybe it’s not real” ya that’s the thing. 27yrs, female (single) 2nd

... before I tested, although I used to look after myself, this time around I know the things I am supposed to do and those I am not supposed to ... though previously I could tell myself that since I am married to this wife, or my wife, she is the only person I am supposed to know, now I know much better that I should stick to my wife. 43yrs, male (married) 2nd

I learned about how the disease is transmitted so I cannot take any of those risks because I know that if I do this or that I will get this disease that is what it has taught me. 40yrs, female (married) 2nd

That thing (counselling) has helped me to be actually more faithful to my partner. Because when you sleep around with other people that are not your partners you are at risk of contracting the disease. So it has been helpful more especially with abstinence ... we say “knowledge is power” now that we talked about this I came to know what is needed and what is not needed so having known those things I am now much aware of the dangers that are in them if I don’t actually use or rather, what can I say? If I’m not actually
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careful with the way I actually deal with these things... 29yrs, male
(separated)2nd – had reconciled with his wife.

I have come to understand the ways of transmission and the way this disease is being transmitted unto the other person ... Ya, I have been so careful ever since because the counselling was there ... it has been there to help the people and I have been lucky to at least learn something from that such that I’ve been using that in my life ... I’m taking the risks more seriously than before because at that time I wasn’t very much sure ... ever since I did the testing and the counselling especially I became so sure about this, the disease can be transmitted through the razor blade. 29yrs, male (married)2nd

Other factors influencing risk perception

However, there was also some evidence that counselling may not always have been effective in increasing risk perception. There were other factors at play that may have modified the influence of counselling.

Estimation of probability of infection based on relationship status and geographical area

The young man quoted below believed that so long it was a partner he was familiar with and she trusted him to be faithful there was no need to use condoms:

Sometimes she’s, she’s just the one you know and she trusts you, no need for condoms ... even if she’s not tested. 20yrs, male (single)2nd

The level of self-perceived risk may be dependent on people’s estimation of their chances of infection dependent on factors such as prevalence of HIV in their area of residence and factual or assumed knowledge of partner’s sexual history (Woodcock, Stenner and Ingham, 1992). The young man quoted above estimated his probability of risk depending on which town his partner hailed from and whether or not they were familiar to him. He was of the opinion that risk was higher in those towns with higher prevalence such as
the capital city and lower in his home town (Chililabombwe). He therefore felt safe engaging in unprotected sex with a girl from his home town. He had experienced more angst before his second test, after engaging in a single episode of unprotected sex in the capital city, than he had felt before his first test when he had a history of multiple unprotected sexual intercourse episodes in his home town:

"... I didn’t know that person ... she’s in Lusaka and I know Lusaka very well so I was worried that this one could be a carrier than the Chililabombwe girls. Lusaka is like... I think it gat (sic) the highest percentage of people moving with the virus than Chililabombwe. So being the town with the higher percentage of people living with HIV I thought she’s, she was also in that category, that’s why she was worrying me. 20yrs, male (single)" 2nd

Availability of ARVs

For some people the availability of antiretroviral drugs appeared to ameliorate the gravity of infection with HIV. They said they would continue having unprotected sex with their spouses even if they (the spouses) were not tested:

**Int:** ... you have mentioned condoms but you are doubting whether he will agree; if there were no ARVs would you still say that even if he refuses you can still agree to have sex with your husband?

**30yrs, female (married)** 1st; ... we would have to agree, wouldn’t that be the end of the marriage?

**Int:** So if there were no ARVs, if he refused then the marriage would be over?

**30yrs, female (married)** 1st; Yes

**Int:** ... if there were no ARVs would that have made any difference on your thoughts about that? (was unsure about using condoms with untested girlfriend)

**26yrs, male (single)** 1st; I would stop (having sex with girlfriend)

**Int:** In that case you would stop?

**26yrs, male (single)** 1st; Yes

**Int:** You would stop having sex with her?

**26yrs, male (single)** 1st; Yes
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... if there was no medicine we would have to use condoms.

40yrs, female (married)\textsuperscript{2nd}

The 40 year old female quoted above goes on to provide the rational for this position:

\begin{quote}
\textbf{Int:} ... what if he has the disease?
\end{quote}

\begin{quote}
40yrs, female (married)\textsuperscript{2nd}; If he has it? Then that is his problem doctor I don’t have it
\end{quote}

\begin{quote}
\textbf{Int:} But are you not going to get it from him?
\end{quote}

\begin{quote}
40yrs, female (married)\textsuperscript{2nd}; ... maybe he will die and I will start taking these medicines (ARVs) which have come and I won’t die
\end{quote}

\textit{Lack of self-efficacy (or sense of control)}

Self-efficacy or the belief in one’s ability to carry out certain actions is a determinant of whether or not people will pursue a particular course of action (Bandura, 1977a). Most women do not believe they can negotiate safer sexual practices with their partners (Bandura, 1994). Hence, some married women appeared to have a fatalistic attitude towards risk:

\begin{quote}
\textbf{Int:} ... Were you not afraid that you might contract the virus?
\end{quote}

\begin{quote}
30yrs, female (married)\textsuperscript{2nd}; I was scared but there was nothing I could do
\end{quote}

I can encourage him (to test) and if he is willing to come he can come now if he refuses I will just let him be, what can I do? There is nothing I can do ma’am, there is nothing that can be done. That is why I came here so that I know how I am because there is nothing else I can do.

\begin{quote}
51yrs, female (married)\textsuperscript{1st}
\end{quote}

\begin{quote}
Because sometimes you can be living with a person but it’s not easy to know that he has changed, so if he has another woman it might take some time for me to know and she may be sick so if she is sick then I will also get sick, so we will live just like that. \textit{23yrs, female (married)}\textsuperscript{2nd}
\end{quote}

This is most likely due to their lack of self-efficacy in implementing behaviour that is reliant on a male-controlled prevention tool and male
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consent. Counsellors reported similar experiences in providing support for HIV-negative married female clients even in instances where they had been counselled as a couple:

... if a man is positive and a woman is negative it’s very difficult to negotiate for safer sex. **Nurse, female (married)**$^{FG2}$

Actually it’s difficult when the woman is negative the husband is positive it’s very difficult but when it’s the other way round it works very well. **Nurse, female (single)**$^{FG2}$

... it is more actually very difficult with a negative woman with a positive husband. I’ve seen it, it’s a challenge actually where a man is positive and a woman is negative. You can give them the counselling together but you know because of that the woman is not empowered and this man is the owner of the home, he’s the one who gets a salary and all those things so you may put in measures that she can remain negative but however because she has to submit so that maybe she’s accommodated, she’s given a share of the income at home, you find that sometimes they are subjected to not maintaining the guidelines maybe that have been given to them let’s say like using of condoms. **Nurse, female (married)**$^{FG pil}$

... we had a discordant couple where the woman was negative and the husband was positive so she came to complain to the clinic that during their sexual relations the husband was deliberately tearing the condom claiming that he was taking long to ejaculate so she was very bitter about it but meanwhile we had done couple counselling previously so she just said “no sister my husband is not following what you told us, this is what is happening”. **Nurse, female (single)**$^{FG pil}$

**Provided skills in condom-use**

Learning the correct way to use condoms, during the counselling session, facilitated the adoption of condoms as a protective measure in a few people:

*I was told that if you cannot control the desire to have sex with a woman you should use a condom or the woman should use a condom then you have sex ... she even told me how to use it.* **24 yrs, male (single)**$^{1st}$
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... I said that condoms don’t work for AIDS but she (counsellor) said “condoms work but many people don’t know how to use them ... she even showed me how to put on a condom. 26yrs, male (single) 2nd

Reinforced behaviour

As expressed in the quote below counselling also appeared to reinforce behaviour by providing affirmation:

... it (counselling) has shown me that the way I tried to look after myself is the right way. 53yrs, male (married) 1st

Follow-up counselling, at the second and confirmatory test about three months later (required for all clients in the study sites), served to reinforce preventive messages from the initial counselling encouraging maintenance of non-risk behaviour:

... some of the information that was given to me in the first test, they gave me the same information so that uhh, going through the same things it’s also good because sometimes we forget. ... I think they reminded me of some of the things that I actually forgot ...you can know that you are supposed to do this but when there is no emphasis, you won’t be pushed to do that unless there is emphasis. So I think it is very helpful to emphasize the same information to re-inform the person about the whole thing. 27yrs, male (single) 2nd

... it was just like a repeat of the session and emphasis since when you are in that counselling you pay much attention. So every information tends to be very serious. 25yrs, male (single) 2nd

... for more encouragement and that one (counselling session) it will keep in my mind of doing the same thing that I am doing since I am negative I may continue being negative. 26yrs, male (single) 2nd

... just the way it (follow-up counselling) was done gave me more reason to continue abstaining because I learnt some ways in which I could keep myself even after I was tested negative so things are much better just like that from that counselling right now. 18yrs, female (single) 2nd
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8.3.2 Effect of the negative test result

Testing empowered people with knowledge of their HIV status. The negative result freed people from the anxiety and uncertainty of not knowing, enhanced their general wellbeing and provided them with a “new lease of life” facilitating a sense of control which allowed them to move on.

Reduced anxiety

The negative result relieved anxiety independent of expected test result. Words such as “peace”, “joy”, “relief” and “free” were among those used to describe the positive affect that accompanied receipt of a negative result. The quotes below refer to the feeling experienced after the initial test. The first three were expecting to be positive, the fourth was expecting to be negative whereas the last one was expecting either result:

I was always worried, so I had a discussion with him (counsellor), he tested me and I know, so now my mind is free. 28yrs, female (divorced)1st

From that time my mind has been free. 34yrs, male (divorced)2nd

I felt relieved because then I wasn’t worried. 40yrs, female (married)2nd

I just wanted to free my mind; so far I’m feeling good because the result was impressive ... I’m free as at now. 29yrs, male (separated)1st

… its more like a relief to know that you are negative, that you have information about what exactly is happening to, or what exactly about my health or my status concerning HIV and ah having that information I think gives me peace of mind … From the time I tested I have the confidence that I do not have this disease and that has brought me a lot of joy. 26yrs, male (single)2nd

From the counsellor’s perspective this was an expected outcome of knowing one’s status:
… when one gets to know their status … we say they have the free mind in a sense that they are able to make decisions basing on what they know about themselves. Nurse, female, (married)FG1

For a few people, however, the inconclusive nature of the initial HIV test result was confusing and did not relieve anxiety. Being told that they could only be sure of the negative result following a second test after three months left them in a kind of limbo. Having attended VCT with the expectation that they would know for sure whether or not they were infected, they found themselves in the same position of uncertainty as before testing:

But what I have been told is what has amazed me, because she said that she has not found the disease but that I should go back again after two, after three months and test the blood again to know the truth whether I am sick or not sick … That is what bothered me because I came so that I know the truth so that I can be free, now I have been told two things at the same time, in one day she has told me two things, she doesn’t know if I am ok then again she doesn’t know if I am sick and she doesn’t know if the virus is still moving around in my body. 22yrs, male (single)1st

She hasn’t told me the truth whether I am ok or not that is the truth that I wanted to know. 22yrs, male (single)1st

Enhanced well-being

The negative test result also appeared to have a positive physical effect. Physical symptoms experienced prior to testing spontaneously resolved or improved post testing:

I was very happy and even the pain in my abdomen became less. I think the worry also contributed to the pain. 28yrs, female (divorced)2nd

Int: You haven’t had any health problems?
29yrs, male (separated)2nd; Ah no.
Int: So those problems just disappeared?
29yrs, male (separated)2nd; Ya. Maybe I can say it was the mind because the mind is choked, everything is choked.
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I often had body pains … but these days my body is just fine. **51yrs, female (married)**

… this time most people when they fall sick they think they are positive but you will find that upon being counselled and tested they are even negative and you will see an improvement in their general condition after knowing that they are negative. **Nurse, female (married)**

Testing also appeared to improve relationships. Some people reported a closer relationship post-testing:

*My relationship more especially to my, I can say my wife, ya it’s also changed … because both of us, we are free now … I was very happy because that result, knowing it, was actually very, what can I say? It was very, it didn’t just bring happiness to myself alone but even to my partner so that’s why I was happy.* **29yrs, male (separated)**

*… since I tested my life has just been ok. Even my relationship with my husband, I tried to explain to him what I had been told here and he understood, he also went for testing. 30yrs, female (married)*

*… it’s like that was the point of the change of behaviour, he even became “born again”, he goes to church, the wife said “he never used to bring money at home” now everything, the money is given to the wife, he has changed completely because all he knew was..., he continued misbehaving because he knew that he was positive, that was in mind but without even doing the test because he had gone out with a lot of women but he was negative.* **Nurse, female (single)**

**New ‘lease of life’**

The receipt of a negative HIV test result appeared to be a pivotal moment in most people’s lives. Testing negative was perceived as being provided with a new ‘lease of life’ enhancing commitment to preventive behaviour to safeguard the negative status:

*I think uh I’ve just been like given the second chance and it is one reason why I want to like get away from all those sexual relationships because I don’t want to like start doubting my status again.* **25yrs, male (single)**
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… it was like a restoration after I tested … Just testing, again it’s a lesson on its own. It’s like you’ve made a crime, you have committed a crime and then you are sentenced to death and then fortunately the President says “this person should be released”. It’s like you have already seen the point of death there and then you are told you are free now. You wouldn’t love to go to the same, to commit the same crime. 25yrs, male (single)2nd

… since the time I tested or is it the time I knew my status my life has changed … I don’t go out and do rubbish things, you know, I mean going out with girls or doing other things which is not good ’coz I know that next time maybe when I go for VCT I can find myself positive … 19yrs, male (single)2nd

… my result in a way is a stepping stone I have got to now see and ensure that today the kind of life that I have been leading I improve upon it. 43yrs, male (married)1st

This promise of a future and regained control stimulated active reflection on one’s life and its purpose encouraging people to plan ahead:

I was thinking that now I am healthy and now I can be able even to build my own house … my life has been more focused now, I am more focused in what I am doing, ... its more like a relief to know that you are negative, that you have information ... exactly about my health or my status concerning HIV and aah, having that information I think gives me peace of mind to, even to plan ahead ... 27yrs, male (single)2nd

... when I knew that I was HIV negative, ah I began thinking like, I began making long term plans. 20yrs, male (single)2nd

Ya it feels good because you even now start planning for your future unlike people who don’t even know their HIV status because their future, they don’t penetrate to see the long future ... Planning to get some higher education ... The most influencing part for I knowing that I am HIV negative, is I’ve changed with my vision and my plans for the future. 20yrs, male (single)2nd

The plan I had now was to go to college since I did well at school. I am now working to raise money, I have even opened an account, I deposit money with Barclays. 28yrs, female (divorced)2nd
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... being HIV negative made me to be so sure of all the things that I was planning for that ... even in three to four months time I will be there so it has really influenced my doing of things ... I am focusing on things not in a short term plan but looking on the future plans. So being negative has really helped me focus on my future plans. 24yrs, male (single)

8.3.3 Provided impetus and resolve to maintain status

The desire to avoid a repeat experience of the anxiety and uncertainty motivated people to plan to either maintain or adopt safer sexual behaviour:

I shouldn’t have many girlfriends, sleep around, such things ... I don’t want to have that kind of worry again. 36yrs, male (divorced)

... that (unprotected sex) worried me so much I ... I didn’t want to take such risks again so I made a resolution, not to do that again. 25yrs, male (single)

... what I don’t want to go through again is to torment my mind. I just want to be free each and every time so that that’s why I want to each time I have sex, only that not with somebody else now. If that happened I’m not saying I’m now completely changed, just if I happened to sleep with somebody else, I would be going for the condom because this is what they call “prevention is better than cure”. Ya I want to prevent that thing from happening. That’s why I need this thing, the condom. 29yrs, male (separated)

Reported behavioural intentions

Post-VCT, almost all participants expressed intentions of reducing or eliminating their risk of acquiring HIV. The negative result provided additional motivation for those who were already abstaining or engaging in safer sex:

Just like I have been keeping myself all along, is how I would want to continue and wait until the right time ... That is in marriage, that is when I would decide to have sex with someone. 18yrs, female (single)

I feel happy that no I am very healthy and I’ll continue just being with my wife and yah no other partners only my wife. 29yrs, male (married)
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In my opinion since the results are negative I should not have sex with women I should be the same way I have been and even better, I should hold on stronger since the result is ok (negative). 26 yrs, male (single)\textsuperscript{1st}

What follows from now is total dedication, only my wife and my wife also, that’s the programme actually which we shall go through ... So safety must be first at all times, whatever I do I must take a risk assessment, that’s all the time, every time that I do things I must, I need to take some risk precautions. 35 yrs, male (married)\textsuperscript{1st} (already practising faithfulness)

27 yrs, male (single)\textsuperscript{2nd}; I have made the decision not to indulge in premarital sex or unprotected sex, if I may say so; I have made the decision to wait until I get married

\textbf{Int:} ... when did you make this decision?

27 yrs, male (single)\textsuperscript{2nd}; actually even before I did the test but I think I have just like eh what can I say? I’ve just like eh, the decision has become more strongly because now that I know that I’m not positive

A few were motivated to move from safer sex to abstinence or faithfulness to one partner:

My plans now are to stay negative, ....and then to abstain and then just to use condom each and every time I have sex ... I have to have only just one partner if I want to have sex, I have to have sex with that partner. 19 yrs, male (single)\textsuperscript{1st}

The only plan I had is to stay negative ... to be faithful to one partner ... by this time I’m against condoms. The reason why I’m against that, I’ve found that maybe that’s the reason why we youths, that’s the reason why maybe we are getting infected with this HIV and AIDS because we are used that we can use each and every time condoms, condoms, condoms.

19 yrs, male (single)\textsuperscript{2nd}  

My plans are just to abstain until such a time I’ll find maybe a girl who I can marry ... the use of condoms is not as effective as abstaining. 20 yrs, male (single)\textsuperscript{2nd}

Most people reported intentions of abstaining, being faithful to one tested partner, using condoms, and not sharing razor blades. A few planned to
marry. These were not mutually exclusive categories. People had the intention of abstaining but, for many of the young men, they felt that if they were unable to abstain from sex they would then use a condom with their partners before finally marrying as a more permanent solution:

*I will protect myself just as I have been told, that is what I will do ... I was told that if you cannot control the desire to have sex with a woman you should use a condom ... If you want you can also use abstinence, just stop having sex with girls ... nowadays I just want to marry.*

*24 yrs, male (single)*

*I intend to abstain until I am married but I still know I should have alternatives and if all goes worse I must use a condom.*

*25 yrs, male (single)*

*... for me now that I know my status and I only want to maintain one relationship.*

*25 yrs, male (single)*

*I would somehow like to be very careful how to use razor blades especially that at school I’m still doing TD, ... I’m trying to like quit the whole thing about, everything, but it’s very difficult, it’s very difficult just to tell especially my girlfriend that it’s over.*

*20 yrs, male (single)*

*My plans are just to abstain until such a time I’ll find maybe a girl who I can marry maybe in five or seven years to come.*

*20 yrs, male (single)*

*I’ll make sure that I protect myself ... the most top priority that I’ll have, that I’ll use is abstinence.*

*24 yrs, male (single)*

A few of the young men who had mentioned alcohol as a contributing factor in their risk-taking reported intentions of, and attempts at avoiding alcohol consumption:

*... the other thing is to stop drinking.*

*20 yrs, male (single)*

*I was looking forward to change completely, to stop sleeping with girls, to stop taking alcohol.*

*20 yrs, male (single)*
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Most people appreciated the importance of their partners testing as well and reported intentions of requesting or encouraging them to test:

I should also encourage my husband to come for VCT and know his status so that if we are both negative then we will know how to look after ourselves. 30yrs, female (married) 1st

... if it means getting married it’s better he also comes and gets tested and then we can live together. 22yrs, female (single) 1st

At this time we cannot have sex but we can after she tests, when I see that her results are also ok. 26 yrs, male (single) 1st

I’ll just marry … I don’t know the status of the girl I’m marrying … My plan is just to bring her. 26 yrs, male (single) 1st

... when I see that she is negative and I also test, she also sees that this person is negative, then we can get married. 24 yrs, male (single) 1st

**Married women and sexual behavioural intentions**

The situation was different for married women. Most of the married women were not in a position to commit to any protective measures because they believed this was not within their control:

Unless it was him, how do I even begin to say “put this (condom) on”? 40yrs, female (married) 1st

30yrs, female (married) 1st; In the meantime I think we can just use condoms

Int: Your husband would agree?

30yrs, female (married) 1st; He is difficult! He would refuse

Int: What would happen if you suggested that you use condoms?

51yrs, female (married) 1st; Hmmm, I don’t know, it is up to him, what he would think

39yrs, female (married) 1st; She (the counsellor) told me to use condoms

Int: Do you think that will work?

39yrs, female (married) 1st; It can’t work, he wouldn’t agree
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The 30 year old and the 40 year old woman, however, explained that they would take definite and different steps to protect themselves if there were no ARVs.

8.3.4 Advocacy

Post-counselling and testing people appeared to be more interested in the health of others and reported intentions of reaching out to others so they could be equally empowered. The increased understanding of HIV issues, the experience of testing and receipt of a negative result appeared to empower and motivate people giving them the confidence to approach relatives, friends and colleagues encouraging them to attend VCT:

... I’ve been at least sensitising and encouraging my, my fellow youths to take up the, the VCT ... After the counsellor sensitised me on those issues then at least it also helped me also to teach others, from what the counsellor taught me. 24yrs, male (single)2nd

I think what I should do now is to share this information with as many people as I can manage to share with. Because before I didn’t have the information, now that I have the information I feel I cannot keep it to myself. I have got to share it with other people so that those who do not know anything about this may learn one or two things. 43yrs, male (married)2nd

... it helped me even to have that stand, to be able, rather to talk to other people and encourage them because that counselling boosted the morale in me, in my life that “ah you know I can stand and even encourage other people to do the same and also have this experience that I have had”. Whereby you are free now in mind ... 29yrs, male (married)2nd

I seized every opportunity I had to talk to people about HIV and AIDS. Actually at school I talked to the pupils, I informed them, I educated them; I gave them the information that I was given and the information that I had on my hands because we had a bit of literature at the school concerning HIV and AIDS ... what I didn’t do is that I actually wanted to form a small club at school but I didn’t do it but given a chance in the future if I have a chance or a platform I think I will do that. 27yrs, male (single)2nd
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... we can help other people also, because this is an encouragement, I have to talk to people also, at the workplace, at the church, wherever I’ll be, well I have to talk about it and share with them how the HIV needs to be done. 35yrs, male (married)

These sentiments are well summed up by one of the participants, quoting a local saying “umweyo wa nkoko waba kuli ka linda” (a chicken’s life is in the hands of its keeper) which he explained meant “the life of a person is in the hands of his neighbour” (53yrs, male (married)), in other words, “we are our brother’s keeper”.

A few went as far as to say that they wished to be trained as peer educators or counsellors (one person actually left his name and contact details with the training coordinator so he could be included in the next peer educator training).

... probably be counsellors as well. Counsel some other couples to have their HIV known to them and maybe finally they know then at least we tell the nation. 35yrs, male (married)

27yrs, female (single); ... I think I would love to help people do their test and then if they are negative I tell them to keep uhh, to keep taking care of themselves and if they are positive also advise them on how they should live... Int: So you would like to be a counsellor? 27yrs, female (single); Yes I would love to

... if I am given an opportunity to work as a peer educator, I think I can serve well now that I have this information and I understand one goes for some training so that he is equipped with the necessary information. 43yrs, male (married)

The counsellors had experienced similar reactions from some of the people they had counselled and tested:
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... when somebody maybe hasn’t sat in a session and discussed the HIV/AIDS there’s a little that they know but once you sit with them, you discuss and they’ll say “ahh I didn’t know all this so I’m going to bring another person to come here”. Nurse, female (married)\textsuperscript{FG2}

... when she reconffirmed ..., you could see someone in a jive (joyful) and encouraged to ask even a friend and she ... started sharing ..., encouraging the others also who were like sitting (not coming forward for the test). Nurse, female (married)\textsuperscript{FG1}

Nurse, male (married)\textsuperscript{FG1}; ... You sensitise the people who are positive, some will make up their mind to say “I think let’s fight together to win this battle” (HIV/AIDS epidemic) and somehow they will stand up and you train those people to be “positive preventers”

Nurse, female (married)\textsuperscript{FG1}; There are people who are ready

Community volunteer, female (divorced)\textsuperscript{FG1}; They are more than ready in fact, even the negative ones; they are more than ready to fight with us

8.4 Conclusion

The counselling and testing process appeared to provide empowerment and restore a sense of control. Most participants equated VCT to testing to know one’s HIV status, with the value of counselling only becoming apparent during the VCT process.

Counselling served to allay anxiety around testing and empowered people with enhanced HIV/AIDS knowledge and understanding. This appeared to foster increased understanding and appreciation of risk, and seemed to reassure people that testing was the right thing to do. Most of the married women appeared to have a fatalistic attitude towards risk most likely engendered by their lack of self-efficacy in sexual risk control.

Self-reflexivity, facilitated by the counselling process, provided an opportunity for a more concrete and realistic consideration of the likely
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outcome of the test and how to deal with it. The few males that had participated in group counselling reported having learned more than they would have from one-to-one counselling.

Some people, especially males, were further empowered through the acquisition of knowledge and skills in condom use thereby correcting misconceptions about, and encouraging a more positive attitude towards condoms. However, the widespread concepts that condoms are not very useful because they are not a hundred percent protective, that they are more useful for the prevention of pregnancy, and encourage promiscuity were more resistant to change.

Although counselling enhanced understanding of HIV transmission, prevention and management, misconceptions about transmission, in both sexes and all age groups, persisted post-VCT. Even though people acknowledged that they could not tell by looks alone if a person was infected with HIV, they continued to make assumptions about their partner’s HIV status from outward appearance and perceived behaviour.

Testing empowered people with knowledge of their HIV status freeing them from the anxiety and uncertainty of not knowing their status. Testing appeared to be a life event, for most, enhancing well-being, providing a new lease of life, restoring a sense of control and providing impetus and resolve for the maintenance or implementation of safer behaviour.

Post-VCT, most of the single males and females reported intentions of abstaining and using condoms when they were unable to abstain. The married men and most of those in relationships reported intentions of faithfulness and the desire to have their partners test as well. Most of the
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married women felt unable to commit to any risk reduction strategy because they believed that such a decision was not within their control.

The experience of counselling and testing appeared to inspire the desire, across all age groups and both sexes, to reach out to others and educate them about HIV/AIDS and VCT. With the current shortfall in trained health workers for the required VCT services, people who have tested constitute a potential human resource pool that can be drawn upon to enhance HIV/AIDS prevention services in the community, including VCT.
9 Findings: Challenges and needs after VCT

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Chapter 9 – Findings: Challenges and needs after VCT

9.1 Introduction

The previous two chapters have presented firstly findings related to the decision-making process people go through before attending voluntary counselling and testing (VCT) for HIV, and secondly the effect of VCT and a negative HIV test result on attitudes and subsequent self-reported sexual behaviour. This chapter describes the lived experience of people trying to safeguard a negative HIV status and the support needs that they have. These findings relate to the third and last aim:

*To gain the perspectives of people who are HIV negative on support systems and networks that would enhance their ability to remain HIV-negative*

Cross-sectional analysis of data from the initial interviews provided information on anticipated needs as reported at the initial interview whereas data generated from the follow-up interviews, six months later, provided information on actual felt needs during the six months between testing and follow-up interview. Longitudinal analysis revealed little difference between anticipated needs and the actual felt needs of individual participants. This may be a reflection of the finding that most people were already practising safer behaviour in the six months or more prior to testing and were therefore already aware of their support needs at the time of the initial interview.

The findings from chapter 8 suggest that receipt of the negative result was a significant event for most people. Being provided with a ‘clean slate’, so to speak, and the opportunity to start afresh, many attempted to guard their new lease of life with various degrees of ease, hardship, success and failure. The challenges people faced in their efforts to maintain their negative status and the various strategies that were employed to address these challenges
are presented first to provide a context for the reported felt needs that are the main subject of this chapter.

The findings presented in this chapter relate to the third and final part of Fig 6.1, p220.

9.2 Challenges in maintaining the negative status

Unsurprisingly, challenges to intentions of safer sexual behaviour were experienced more by married females and single males. Women were constrained by their culturally defined roles that placed them in a position that denied them the power to have control over their own sexuality. This was compounded by Christian values that encourage women to be submissive to their husbands. Perceptions of masculinity coupled with peer pressure worked against the young males’ attempts to implement safer sexual behaviour.

9.2.1 Cultural and religious norms

Cultural norms and lack of social support exposed some married women to potential risk of infection from unfaithful husbands even when they were well aware of what was required for them to protect themselves:

... sometimes I would refuse (sex), he would get annoyed and sometimes even chase me from the house, the elders would talk to me telling me that it’s not supposed to be like that, I should allow everything since we are married.

30yrs, female (married)\textsuperscript{2nd} (referring to time before testing)

Religious norms played a dual role depending on whether one was single or married. Christian values that were taught by some denominations served to augment the cultural norms that inhibited women from protecting themselves:
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Well, as for me, I’ll just depend on prayer, there is nothing else I can do. The Bible forbids denying sex, you cannot refuse ... Yes, otherwise I commit a sin. 40yrs, female (married)

Some values concerning pre- and extra-marital sex played a positive role in discouraging these potentially unsafe behaviours encouraging faithfulness and abstinence:

I am Christian and as far as I know I am not supposed to indulge in premarital sex. It is a sin ... so I decided not to do that; so abstinence is better for me because I am a Christian. 27yrs, male (single)

... I have to be serious and I have to be serious with my God. Especially that I have to commit my life into my God ... I’ll remain faithful to my wife. 29yrs, male (married)

However, self-professed Christianity was not always associated with abstinence:

... when I was in grade ten I became a Christian I stopped everything yah, I decide no, from that time ahhh, I can be negative, because uhh, uhh ok I didn’t go much with girls, it was just a matter of friends yah, but I didn’t go much with girls or maybe having sex with them each and every time no, maybe I can say the time when I was in grade eleven, maybe three times. 19yrs, male (single)

9.2.2 Peer pressure
Young men faced particular challenges in their effort to maintain a negative state in the face of friends with whom they no longer shared the same ideals:

... in the last six months it has been very hard ... like the way I’ve experienced after testing for HIV is that ah there are many challenges especially for youth, and you don’t just want to be like as if you are not part of them because almost everyone is out there partying and stuff so it’s really challenging. 20yrs, male (single)

It’s not an easy thing, actually it is a very challenging thing to abstain when you have peers, your friends, your close family members especially your
cousins around you talking about how their experiences, you try to deter them, you try to inform them about the real issues but they are bent on doing that, so it is quite challenging when there are people, always people in your path trying to remove you from your direction, ah it is not an easy thing ... It is all about peer pressure, the pressure from peers actually that’s where it comes from. 27yrs, male (single)

... because friends deceive us a lot “you can’t do this and that” ... sometimes when you are in a group, what I think influences is the group, and then maybe you don’t even know what the other one is thinking but you just think that “if I say this they’ll think this of me” ... some guys say that you cannot go out with a girl for one week without having sex with her ... when I was in that group it used to bother me so I was troubling the girl trying to force her this and this but she was refusing “no we can’t do this” ... when she says “no” I understand because it’s not really me and I don’t even want to do it it’s just that when my friends talk about it I just try, I say “let me try and see how she will react” but she refuses, she also doesn’t want. 19yrs, male (single)

The two people, who failed to abide by their stated intentions to abstain and to use condoms, were both young men and blamed their failure on peer pressure. One had intentions of abstaining:

I just went with friends that side in town we bought some beers, we were drunk just there in town so all I want was just like not to think about the situation (pay lower than expected) because it was very painful. So after that just there in the car, my friends brought some girls and I didn’t intend to do it but they just got them and one of my friends organised one for me that’s when we went at school. Then in the morning I just discovered that the condoms were bursting just like bursting. 20yrs, male (single)

Whereas the other had decided to use condoms with girls he didn’t know well enough:

I think it was group influence ... a lot of my friends were at Evelyn Hone (College) and they are the ones who organised everything for me ... my friend’s girlfriend and that girl they came. Then my friend took the girl out and I was left in the room with that person ... later in the morning I came to realise that oh, this is not good ... and that time I didn’t use any condom ...
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they say ahh, “this one is a coward he’s a “mbuli”” ... They say “oh you, you are a coward, this is not Chilis (Chililabombwe - small town), this is Lusaka (City) man, you have to do this, you have to do this”.

20^th yrs, male (single) 2nd

9.3 Strategies employed to counter challenges

Various strategies were employed to counter the challenges faced in implementing intentions and maintaining safe behaviour.

9.3.1 Avoidance

Most people decided to avoid situations and friends that were not compatible with what they were trying to achieve:

... all what they were doing when we are together they were just saying about those things which was negative into my mind. So I was..., they were trying to defeat me and I was trying to go in the same direction but after I realised that me I've done VCT so what I have to do is I have to pull out with these guys then I sit alone or I just be with my girl most of the time.

19yrs, male (single) 2nd

... as in our case, in Kitwe, there are..., maybe you have a group and then they make a decision of going in town and take some beers, then I just leave them...

... 20^th yrs, male (single) 2nd

I decided that I would look after myself by distancing myself from certain things even if my friend is doing it I keep away. 22yrs, female (single) 2nd

I have found something ... to be helping me like just finding entertainment and sitting and when everybody is going out you just need to do your own thing. 20^th yrs, male (single) 2nd

The young man quoted above (20^th yrs, male (single)) is one of the two that had earlier succumbed to pressure from their peers and engaged in unprotected sex acquiring a sexually transmitted infection (purulent urethral discharge) in the process.
9.3.2 Keeping busy

The adage “an idle mind is the devil’s playground” seems to apply here. Participants explained that they were more likely to engage in sexual activities if they had nothing else to think about or to occupy them. They therefore resorted to deliberately choosing not to think about sex and filling their time with other activities:

... sex is not in between the legs, it’s on the head ... when you think about sex that’s when you ... it affects now the sexual organs; that’s when you get the drive now to go and have it ... when you don’t think about it you..., the mind is ok and even the sexual organs it’s not affected in any way because you haven’t thought about it ... at the moment I’m studying theology.  
29yrs, male (married)  

... by forgetting ... and concentrate with other things.  
26yrs, male (single)  

Just kept myself busy like I had a lot of things to do ... I have found something to be ... helping me like just finding entertainment ... just to keep myself busy.  
20yrs, male (single)  

... keeping myself busy ... Through reading ... as well as being committed to church work.  
18yrs, female (single)  

I’ve a lot of activities, doing activities, maybe in the morning I’ll run ... just keeping myself busy, maybe I just study, I get a book and just read ... as I go at work that means now my mind is just in that shop (employed as salesman) ...  
23yrs, male (single)  

9.3.3 Visualisation of future benefits

Although reported by just one person in this study, visualisation has been shown to be a powerful motivation technique. This technique encourages the achievement of set goals by imagining the desired outcome to be achieved from performing or not performing an activity (Shone, 1984). Focussing on
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the future has been found to be a core component of effective adolescent HIV prevention programmes (Rotheram-Borus et al., 2009).

I have considered my future so I value most what I might find in future than what I can enjoy right now so that’s always the biggest reason ... having a good job and a good family and taking care of it, that’s what I look forward to ... I experience challenges while doing that so I keep on also reminding ... I always think about how beautiful my future will be, so visualising ... all those things I want to achieve. 25yrs, male (single)²nd

9.3.4 Talking about HIV/AIDS

Actively engaging in discussions and sensitising others about HIV and AIDS, both informally and formally, seemed to encourage adherence to reported intentions by acting as a reminder:

... mostly we talk about that especially when we gather like youths we talk about that (HIV) and I do have time to stand and then talk about that ... if you talk about something a lot you know it well and you cannot succumb to it. 19yrs, male (single)²nd

This particular young man was also encouraged by a supportive church environment:

... it’s encouraging me because in church they favour it, even our church, that time when it was VCT day whatever they announced in front by the elder and it was encouraging me all that. 19yrs, male (single)²nd

9.4 Perceived needs

Almost all participants expressed the need for some sort of on-going support. Various needs were articulated both after the first and the follow-up interviews. The articulated felt needs were broadly similar to the strategies employed to maintain the negative status. This suggests that needs were derived from experience with trying to cope with the demands of
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maintaining a negative status in an environment that was not always supportive.

At all three focus groups counsellors also considered that not enough was being done to support people who tested negative for HIV. Whereas a person testing HIV positive had a “package of care” available to them there was no similar “package” for those testing negative:

... one may go for a test and at the end of the day they come out to be negative and if you look at a lot of interventions that are there now the concentration is more on the, if one is positive … There’s the care and everything ... even the emphasis you find that the way people get the messages it’s like when one is positive that’s where the concentration is more, while the negative ones if you are to look at the main interventions that are there, there isn’t much really putting emphasis on people staying negative…. they can no longer find maybe peers, sit, “what are you doing to maintain your negative status? What have you..?” Such are not there but for the positive they’re there. When we talk to a client they are positive we’ll say there are support groups, there are what have you and they begin to share ... It’s like it’s left to an individual to begin that behaviour change on their own.

Nurse, female, (married)\textsuperscript{FG1}

But I think our concentration has been on looking after the positive than the negative … There has been a gap in following up the negative ones, I think it’s a weakness in our service because we’ve been just concentrating on the positive ones and following them up.

Nurse, female (married)\textsuperscript{FG2}

... we are more concerned with the positive, we have neglected actually the negative (general agreement). It’s the part that we have neglected for long so it’s good that we should also come up with ideas to help these people.

Nurse, female (married)\textsuperscript{FGpil}

VCT counsellors felt that there was need for guidance from the national level on support strategies for people testing negative:

I think the problem again even in the national guidelines they are silent on the negative people what to do with those, that group. Even their focus has
been on positive ones (general agreement). But I think there should be a deliberate policy where we need to look at negative ones, how do we look after them so that we maintain., they maintain their negativity?

Nurse, female (married) FG2

... we just leave them (negative clients) just like that so at least the Government should look into it. Nurse¹, female (married) FGpil

Two main themes thus emerged from the clients and counsellors relating to suggestions to meet the perceived needs of the people that participated in this study:

1. Reinforcement of behaviour change
2. Access to recreational activities

Fig 9.1 provides a diagrammatic representation of the relationship between these main themes and the sub-themes.

**Figure 9.1: Relationship between main themes and sub-themes of perceived needs**
9.4.1 Reinforcement of behaviour change

A general need was frequently expressed for some form of reinforcement or encouragement to implement and maintain desired behaviour change. The various needs articulated in this theme were either related to the concept of “reminders” or the acquisition of additional HIV/AIDS knowledge including HIV/AIDS related life-skills.

Reminders

Most people felt the need for regular reminders to encourage maintenance of safer behaviour. These took many forms but what they had in common was the need for some form of regular contact with either the counselling service or other people who had also been through VCT and tested negative. It seemed that passage of time leads to decline in levels of perceived threat of HIV infection therefore the felt need for regular reminders that would sustain immediate post-test levels of vigilance:

... sometimes as you go along the brain becomes I don’t know if it gets weaker, you start to take things less seriously but when you go for counselling at least they tell you how things are and what you should do.

20 yrs, male (single)

I do need very much support ... constantly reminding you about the devastating effects of this disease, yes, that can be very much helpful just reminding ....just continue that it can be helpful to me because when I hear it reminds me that “ah no I am negative so I have to be faithful and remain faithful to my wife so that I don’t get the disease”.

29 yrs, male (married)

Ongoing contact with counselling services

Contact with the counselling service could take the form of either face-to-face contact with counsellors or through some other means such as printed material or telephone contact:
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... if I have the desire to come and have a talk I come and learn more and be encouraged, it would be like I am just being reminded.  
28yrs, female (divorced)²nd

... something that can empower me just to be negative ... That would just be in the form of discussions even reading books even posters, maybe monthly you send me something. 23¹rs, male (single)²nd

... if there are tapes that are recorded and they talk about this. They can be so helpful, so that I just put it on the radio and start listening.  
29yrs, male (married)²nd

... although I have said I am honest it does not mean I will always be like that, so having something to remind me that this is what I should do would be helpful … if everybody had that privilege of having maybe land phones. Just phone them “ah how are you doing now? How’s things there? Take care” something like that. Something with being informed or rather reminded and even know that “ah there’s somebody who cares about me”. 29yrs, male (separated)²nd

... because it is like a baby, he or she needs to be fed, so after counselling I still feel you supposed to go back maybe after one month again just to see how things are going, just like that. 20²rs, male (single)²nd

As suggested by the last two quotes, ongoing contact with the counselling service may serve an additional purpose. Maintaining some form of contact may send the message, as stated by 29yrs, male (separated)²nd, that someone cares about whether or not they maintain their negative status thereby encouraging adherence to planned actions.

From the counsellors’ perspective ongoing contact in the form of follow-up visits was an ideal way of supporting people testing negative:

… maybe what could be helpful is even for the negative ones if we want them to maintain their status, emphasis should be continued on them being negative by following them up and continue giving them information and guidance. Laboratory technician, female (widowed)¹FG1
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Maybe if we can start enrolling them now and maybe seeing them once or maybe quarterly you follow them up, it can work. **Nurse, female (single)**

... the review should not end just at three months. Maybe after three months we should say come after six months or one year so that at least it will be continuous. **Nurse, female (married)**

I think here we have a problem where you are negative usually we wean them off very early we don’t even know where they go to (general agreement) so what we need is maybe some follow-ups somehow ... **Nurse, male (married)**

From the counsellors’ view such contact would also enable them to confirm the status of those who do not return for testing and monitor the effectiveness of the VCT service through repeat testing:

... we are emphasising on the window period and the importance of them coming back to have a re-test. So if they are not able to come back already it’s indicating something to us that something is not ok. **Nurse, female, (married)**

... we need to come up with a deliberate policy on how we can track these negative results clients because the information we are providing to them is not as bulky as it is for the positive ones, we just briefly talk about the positive living, this and that, then the client will be told to come back after three months. I think we need also to develop certain strategies which will keep these people to continue within their duration of coming back. So if we can develop such a strategy it can strengthen the prevention part of VCT. **Nurse, male (married)**

It’s very difficult actually, most of them they don’t come back but a few will come back. Then actually we don’t really like follow them but maybe if we can have a system like following them maybe it can also help ... We just give them an advice on how they should live and from there we don’t know what happens thereafter because we don’t follow them. **Nurse, female (married)**
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The counsellors emphasised the importance of the second and subsequent follow-up HIV tests. They appeared to consider that regular testing would be supportive of efforts to maintain a negative status; a proposition, as pointed out by Kalichman and Cain (2008) in their study on repeat HIV testing and risk behaviours, that may be true for some but not for others. The clearest articulations of this perception came from the second focus group:

... to be coming in possibly every year for testing so that at least they know where they are and they would be able to know if things go wrong along the line they’ll be able to access care and support. Nurse, female (married)\textsuperscript{FG2}

... follow them up every three or six months just to find out if there is any change in their status or they’ve maintained that and continue supporting them. Nurse, female (married)\textsuperscript{FG2}

... to be coming for tests not only after three months but even after some other time to come ‘coz it is important that they should maintain that negative status. Nurse, female (married)\textsuperscript{FG2}

The focus group discussions confirmed the poor availability of information and education materials for clients in general, and especially for people testing negative:

We don’t have material … we get support from the ZPCT\textsuperscript{16}, they bring when they have the material but not straight from the Government, it’s a rare thing, without this supportive partners we don’t even have materials, the pamphlets to give the clients. Nurse, female (widowed)\textsuperscript{FGpil}

It’s like you can have the material and it’s like it’s flooded on the market and when it disappears it will disappear for good and when you have it again it will be flooded on the market, just like that so those are the scenarios but there is no continuous like each time you have a client you have some material to give them. Nurse, female (married)\textsuperscript{FGpil}

\textsuperscript{16} Zambian HIV/AIDS Prevention, Care and Treatment partnership
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Even the leaflets, the information, they should produce some for negative people … handouts or leaflets or brochures on how one should live if found negative specifically for negative people so that at least as they come through you give them handouts. Nurse, female (married)\textsuperscript{FG2}

… IEC materials they should come out also specifically encouraging the people that are negative, that would also be another thing that would be good and also the drama part of it let it come out clearly encouraging the person who is negative to maintain his status. Nurse, female, (married)\textsuperscript{FG1}

Support groups

Clients felt that the opportunity to discuss with and learn from the experiences of others having the same goal as they themselves would help them to maintain their negative status:

\begin{quote}
I need positive people, people with the same view that I have, people that I can discuss the views that I have with so that I remain strong.
\end{quote}

25\textsuperscript{yrs}, male (single)\textsuperscript{1st}

Interestingly even people such as the 23year old married female, who considered themselves not to be at risk of infection (believed husband was negative and faithful), felt they needed further support:

\begin{quote}
… we can just agree when to meet, even once a month or twice in a month. Those who are negative can meet and learn about this so that we distance ourselves from those things and do not get infected.
\end{quote}

23\textsuperscript{yrs}, female (married)\textsuperscript{2nd}

Support groups or clubs were also identified by the counsellors as a good and practical strategy for encouraging and empowering people testing HIV negative:

\begin{quote}
…maybe we can come up with some support groups where we enrol them in these groups where they are coming to meet regularly maybe..., possibly three every three months, we have a discussion with them. Nurse, female (married)\textsuperscript{FG2}
\end{quote}
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... for the youths that are testing negative we need to find them like a group where they can be meeting to encourage themselves if we have to prevent the HIV and AIDS. Nurse, female (married)FGpil

The ideal support for an HIV negative person; we need to continue to empower the client with the current and more knowledge in terms of HIV, support groups and clubs. Social worker, female (single)FG1

... its better we have a group like the one we have alcohol AA so we can have also NN, negative, negative. Nurse, female (widowed)FGpil

Involvement in VCT centre activities

A few people felt that being involved in the activities of the counselling centre such as community sensitisation would help to remind them of the need to safeguard their status:

Maybe if I can join some groups which are sensitising the HIV and AIDS to the people ... Maybe it can be remembering me each and every time. 20yrs, male (single)1st

Such involvement may be considered, by some, as endorsing the decision to test and thereby provide motivation:

... so just to make us feel that what we are doing is good or to encourage those who are yet to make a decision. It’s good maybe to organize functions there you go out in the open. You tell other people that “I tested”, “I did this”, “I know” like the adverts that we have “we know now- how about you -, do you know?” 27yrs, male (single)2nd

Counsellors also believed that including people who had tested in outreach activities of the VCT centre would be supportive of their efforts to remain negative:

Even to involve them in these campaigns it can be good because I’ve heard a lot of people when they come, you test them, they’ll ask you “now madam that I’ve tested and I’m negative, what next? How are you going to help me?” or others will just come out to say “I also want to join you now to be
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maybe a counsellor or a peer educator”. So I feel it’s important that we, this should be used as a strength to maybe recruit those people, train them as peer educators so that they can be going in the field or on the community to sensitise others… ……Community volunteer, female (divorced)FG1

They also felt that community involvement should include more than the client alone, suggesting a strategy that is reminiscent of “diffusion of innovation” (Rogers, 1995), recruiting parents and influential people in the community such as church and traditional leaders to sensitise their children and members respectively:

… we need to start from the base and give this information at the family level where parents will be free to discuss sexuality issues with the children … involve traditional leaders and all the clergy, sometimes if these people are involved in certain programmes like the prevention of HIV, you know the mindset of people, most of it when they hear it from the pastor … the priest they will get it as a gospel truth. So these leaders should be trained also. They should become trained counsellors or trained peer educators so that they are able to disseminate quality information to the people because if they get it from their spiritual leaders … because this information is not coming only from the medical inclined people, because most of these information they’ll say “ah because they are coming from the medical department no wonder they are talking about these things”. If it comes from their local people I think they will get it to be a serious matter because they will know “even the local people they are aware about this, let’s also do this” I feel it can help us a lot in the preventing of these infections. Nurse, male (married)FG1

Additional knowledge about HIV/AIDS

Most people expressed the desire for more information on HIV and AIDS beyond what they had received in the counselling. It seemed that knowing their status increased the need to know, in more depth, about transmission of the virus and prevention of infection:

I just want to know any other uh, any other tool or way in which you can, can contract the disease. 23yrs, male (single)1st
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I would like to continue learning … ways in which I can look after myself.

31yrs, female (single)^2nd

… what I need now is that I want to learn more, a lot more, because there are some things I don’t know … I just know the surface that’s what I can say.

19yrs, male (single)^2nd

… one can never stop learning and things change every day so even if I know something we can still discuss so that I learn more.

28yrs, female (divorced)^2nd

… what other encouragement you can give ... just on how I can protect myself … 34yrs, male (divorced)^1st

I would like something to follow, like if you come here and they test you and find you are negative, it’s better there is some way in which they continue to teach us so that we do not get that disease. 23yrs, female (married)^2nd

… you know they say that “isukulu talipwa” (education never ends) it’s all the same with these things as well, I might be thinking I know everything but I don’t so I can be coming they teach me more. 26yrs, male (single)^2nd

Counsellors admitted rushing through the post-test counselling for negative people and felt that they should take time to provide more information:

… do post-test objectively that is give a lot of information because if someone is HIV negative we just rush to give them their results and off they go without giving them a lot of information about the prevention of HIV.

Nurse, female (married)^FG1

… I’ve seen some counsellors who think giving out a negative result is the best thing you just say “no you are negative so maintain your negative what, what, what” and you forget about the other steps to be taken.

Nurse, female (married)^FG2

… if they are negative I should be able to spend more time with such a one in explaining to them how to maintain their status not only saying because you are negative you just pass through it blah, blah but I should also take time to explain more insights on their being negative.

Laboratory technician, female (widowed)^FG1
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**Life-skills training**

Life-skills that would help participants protect themselves and to know how to approach issues of HIV testing with partners and how to manage relationships were among the felt needs articulated by some people:

*You can tell me what is required or what to do in different circumstances.*

22yrs, female (single)\(^1\)st

*I will come and ask him (counsellor) questions so that he can help me with how I can live and what I can do because I don’t want to get married. I have thought about it a lot and I know that all men do not behave … Those are the questions I would like him to help me with.*

28yrs, female (divorced)\(2\)nd

*… I would like to learn so that I am fully equipped with information … how to deal with these, you know, to deal with people of different sex because there are times when you don’t mean something. You mean well but you end up maybe seducing the other person.*

25\(3\) yrs, male (single)\(2\)nd

*I don’t know how to take (her) in also to know her status and how to tell her that “you should do this and that”.*

231 yrs, male (single)\(2\)nd

**9.4.2 Access to recreational activities**

To be kept busy was the cry of most of the young single people, especially males. With nothing else to do, engaging in sex appeared to fill the vacuum created by the absence of social amenities that can provide leisure time activities for young people:

*... when I was in grade ten there was that World Vision\(^17\), yah, this … organisation it was at least helping the young boys (here at the) branch in town, pool, whatever, so those things were keeping us busy because we are not uhh, we were not thinking, ahhh, about girls because we were just thinking about games, whatever, so at least those things if they bring them back it can help us because here in Chililabombwe we don’t have where to go afterwards just have mu ma bar (bars) drinking beer, whatever.*

19yrs, male (single)\(1\)st

\(^{17}\) A VCT project run by World Vision International, a Christian relief, development and advocacy organisation
... a lot of people lack recreation at the right time, recreation facilities, and they only find sex as the only work, I mean the only thing to do when they are not like., like in employment and when you are not doing other things it’s the only thing that can like sort of entertain them apart from like, I mean they haven’t got the chance to be in school right now or something to keep them busy. If there were some recreation facilities that, I mean, if some recreation facilities were put in place I think that would really help. Because a lot of people will have, I mean will find, I mean they will have something to keep them busy and then there will be little time to think of like having sex ...

25\text{yrs, male (single)}^{1}\text{st}

I think what would have helped me to..., my life to be easier is like um maybe going out sporting like uh just find some sport to do, having a lot of organisations around like YMCA$^{18}$ and stuff, those organisations they help a lot so that at least if there were more of those, more of games to play just to keep me busy. 20\text{yrs, male (single)}^{2}\text{nd}

Other options to fill the time included continuing education and work:

... just having a lot of things to do like giving a lot of work ... so that just to keep you busy. 20\text{yrs, male (single)}^{1}\text{st}

... if you are like fully active in education, I don’t think you would pay much attention to these uhh, in ehhh relationships, you would want to have relationships but you wouldn’t want to, I mean you wouldn’t be having a..., involved in a number of I mean high number of relationships because you’ve got something to keep you busy. 25\text{yrs, male (single)}^{1}\text{st}

9.4.3 Needs peculiar to married women

As can be expected (see de Zoysa, Sweat and Denison, 1996, Exner et al., 2002, Killewo et al., 1998, Krishnan et al., 2008) the felt needs of most of the married women centred around getting help to get their husband’s tested and/or sensitised on HIV and AIDS:

I can be given a call-out slip for him so that he also comes and tests. 51\text{yrs, female (married)}^{1}\text{st}

\footnotesize{$^{18}$ Young Men’s Christian Association – a charity that works with young people especially those in need}
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... when I have convinced him then we can come to the VCT room he tests and then they can try to help him by explaining to him how he should live.  
30yrs, female (married)1st

You should be teaching the men, yes, you teach them. You should just arrange seminars for all the male miners and teach them, mmm, tell them, tell them, mmm, so that they know and have some fear. Mixing women is not good.  
40yrs, female (married)1st

Most married women found themselves in a particularly difficult position due to cultural and traditional norms which dictate that initiating sex is the preserve of men and a married woman should never deny her husband sex (except during culturally approved periods of abstinence such as post-childbirth) (Gupta, 2000, UNAIDS, 1999a). Since these norms are perpetuated during initiation and marriage ceremonies, counsellors were of the opinion that this is where the change should begin to give women more of a voice in the marriage relationship and shift the focus from sex to a more holistic view of marriage:

I think we need to improve counselling especially in marriages. We should try and change the teaching whereby like you know you are a woman you are told just to submit, to submit, to submit and that is the thing that is killing most of the women. She can be quite negative (HIV-negative) quite alright but with those submission, submission I think that is the thing that is making them to be susceptible to these other things. Nurse, female (married)FGpil

... when we (traditional marriage counsellors) are teaching, the emphasis is on sex as if that’s the prime thing in marriage, no wonder we are having a sex mad world. Now this girl she just has to know this ... and the husband is being told it must be like this ... those are contributing factors, we see that when a friend is sick the other one won’t refrain now they’ll go out looking because they’ve been told it (sex) must happen so as counsellors who get involved in marriage counselling I think we are the right people to educate our fellow counsellors to say let’s not put the emphasis on this (sex) because this is what is bringing a problem ... So I think the traditional way of teaching marriage couples should change because sex is not the prime thing
in a marriage there are so many factors involved in a happy marriage.
Nurse\textsuperscript{2}, female (married)\textsuperscript{FGpil}

9.5 Post-test testing behaviour (confirmatory test)

As per Zambia National AIDS Council testing protocol all individuals testing HIV-negative must be re-tested three months after the initial test to confirm the negative status.

Close to half did not return for the confirmatory test. Of the thirty-one that were interviewed a second time sixteen had returned either to the same centre or to a different one for their confirmatory test. Two of these did not test, one did not find a counsellor at the VCT centre and the other did not find her preferred counsellor. Counsellors indicated that few clients returned for the confirmatory test although they did acknowledge that some may have been going elsewhere for their second test:

... when your session is over it’s rare that the negative client come back.  
Nurse, female, (married)\textsuperscript{FG1}

Because if you test maybe four maybe one would come.  
Nurse, female (married)\textsuperscript{FG2}

Others will just be celebrating their first test saying they are negative, they are negative. Nurse, female (married)\textsuperscript{FG2}

... some clients fail to come back for the second test not because they have the fear of the result or what, it’s because some people move from place to place. I’ve met a lot of clients who have come from..., like they did their first test in Lusaka, in Kasama, some even from Tanzania, Mozambique, they come and do their second test here. Community volunteer, female (divorced)\textsuperscript{FG1}

The most common reasons for not returning for the confirmatory test were lack of time or forgetfulness:

I don’t have time to go there for another test. 23\textsuperscript{yrs}, male (single)\textsuperscript{2nd}
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I didn’t have time because I went to Samfya ... I usually used to knock off at 18:00 to 19:00 so I had no chance of going there. 29yrs, male (separated) 2nd

I was busy with my child’s problem. 30yrs, female (married) 2nd

I had forgotten ... because I had a lot of things to do. 24yrs, male (single) 2nd

I just forgot. 40yrs, female (married) 2nd

A few people felt it was not necessary to do the second test because they knew they were negative:

... before that test I had not had sex for about five months and afterwards I only had sex with the one I was engaged to so I thought there is no problem. 26yrs, male (single) 2nd

I can do it just because of the procedure which is there (VCT protocol) not necessarily that I want because I know that this time that I am negative. 29yrs, male (married) 2nd

This may be justified for those who understand the concept of the window period, but not for those who may go on believing they are negative when they may not be.

The focus group discussions and sentiments voiced by some participants suggest that people do not return for the confirmatory test because they do not wish to ruin the happiness and security provided by the negative result (if they were to test positive on the confirmatory test):

Because it’s like they are scared when you tell them “no there is the window period so this time that you’ve tested you should come back after three months to make sure that the result was negative. And then this person will go and start thinking about “mmm, I was tested negative at least my mind is clear and now I go back today to be told that I’m positive”. Nurse, female (married) FG2
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I think uhh most people don’t usually make it for the second, I can tell that because most of the people I have actually interviewed, my friends, those who ever, because I have opened doors to my friends that I went to voluntary counselling and testing, I got a negative result. Now most of them told me that they have also been there now they haven’t been there for the second time; why? Because the fear of maybe destroying that good feeling in the first test where they tested negative. They fear maybe they’ll test positive in the second one. 27yrs, male (single) 2nd

... because the way she was telling me, she was telling that “no maybe it is in window period” so that is why I was also thinking, mmm, maybe after three months I will be positive ... And I can’t even go back because I don’t want to be positive. 29yrs, male (separated) 1st

Of the sixteen clients who returned for a second test nine had been expectant of a negative result more than a positive or either result at the time of initial testing. This gives some credence to the statement that people do not return for the second test because they do not wish to run the risk of their initial negative test being over-turned. It may be that these individuals were quite sure that they would test negative after having tested negative the first time, so they could go for a second test with the confidence that they will test negative again. Five of those who returned had been expecting a positive result and three of these had been symptomatic. The remaining two had been expectant of either result.

**Self-testing**

It may be that those who do not return may prefer to self-test if this option were available. On being asked if they would prefer to test themselves at home most of those that returned for the follow-up interview responded that they wouldn’t mind testing themselves for the confirmatory test but not for the first test as demonstrated by the following quote:
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... after I know my status I can be able to test myself because I will not have that fear that I had the first time. 24yrs, male (single) 2nd

Sixty-nine percent (11/16) of those that had returned for confirmatory testing said they could have tested themselves and 80% (12/15) of those that didn’t said the same. Of these, 45% (5/11) of those that returned and 33% (4/12) of those that did not return would have preferred to test themselves citing lack of time and confidentiality as reasons for preferring a self-test:

... it would be a good thing ... because it would provide confidentiality. 25yrs, male (single) 2nd (did not return for confirmatory test)

In fact testing at home would even be better because most of the time we are busy so it is better one is taught how to do the test and you test yourself so that you know how you are and if I find that I have the virus I can come back before the virus attacks deep inside my body. 24yrs, male (single) 2nd (did not return for confirmatory test)

I think that way it could be confidential, totally confidential. 20yrs, male (single) 2nd (returned for confirmatory test)

I would like to test myself because I am busy and it is not easy to come here. 28yrs, female (divorced) 2nd (returned for confirmatory test but did not find preferred counsellor)

One of those that returned and three of those that didn’t felt it would be a bad idea to self-test:

I think it will be, the state of mind; the mind will always expect to get the same result and when I get a different result it will be very shocking and it is not good to be shocked. 27yrs, male (single) 2nd (returned for confirmatory test)

I think it is not good. 26yrs, male (single) 2nd (did not return for confirmatory test)
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The counsellors were of the same opinion voicing concerns about the psychological impact of a positive result when a client may have been expecting a negative one based on the previous test, disposal of sharps, quality of testing and the need to repeat positive tests:

... looking at the consequences surrounding the testing I think it is not a good idea for the client to test himself in the absence of a counsellor because anything can happen. Nurse, male (married)\textsuperscript{FG1}

And for self-testing you have to look at the aspect of infection prevention because you are also going to give them the needle and syringe ... So I think self-testing is not good. Nurse, female (married)\textsuperscript{FG1}

I think under self testing there are a lot of things which can go wrong during the testing due to fear and anxiety in these clients. They may mix reagents wrongly (agreement) and they may get the false positive they may get a false negative due to wrong combination of these reagents. Another point which may come here is how are we going to monitor quality? Or how are we going to monitor exactly whether this client really tested positive because as the entry point for ART they have to test positive and there is a proof to say actually this person tested positive. If they test at home then they come back to the hospital facility are we also going to repeat the test just to confirm whether it’s true positive or not? Then it will be wasting of resources ...

Nurse, male (married)\textsuperscript{FG1}

\textbf{Int:} What about for your clients, ... self-testing for the clients?  
Nurse, female (married)\textsuperscript{FG2}; It’s scary, it’s very risky. ... it’s not advisable.  
Nurse, female (single)\textsuperscript{FG2}; The clients it’s dangerous  
Nurse, female (married)\textsuperscript{FG2}; The clients, no, I wouldn’t allow if let’s say the next one tests positive they would hide you

9.6 Conclusion

In the six months post-testing, most people claimed to have maintained and implemented intentions reported at initial interview. Maintenance or implementation of desired behaviour was challenging for some, especially married women and young single men. Cultural and religious norms and
values impeded the risk reduction efforts of some married females whereas perceptions of masculinity and peer pressure impeded those of some young single males. Various strategies such as avoidance, keeping busy and visualising future benefits were used, with varying levels of success, to implement and maintain desired intentions.

Almost all participants expressed the need for on-going support with most wanting additional in-depth information on HIV/AIDS transmission, prevention and treatment. Most single young men and women reported a need for regular reminders to reinforce intended and implemented behavioural changes, and recreational activities to take up idle time. Ongoing contact with and involvement in activities of the counselling services and support groups were identified as possible means of providing reminders. The needs of most married women centred on getting help to get their husbands sensitised about HIV/AIDS and to test.

The focus groups confirmed the lack of support for people testing HIV-negative and corroborated support measures identified by the interviewees.
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*It is vital for scientists to answer locally generated research questions to gather the evidence upon which local prevention and clinical care decisions are based … local studies are needed to inform international guidelines that are often handed down to low- and middle-income countries from international and multilateral health agencies, such as WHO and UNAIDS (Mandel and Brickley, 2008)*

10.1 Introduction

Voluntary counselling and testing (VCT) has the potential to impact HIV incidence at population level. However, this is dependent on people adopting and maintaining safer behaviour (Weinhardt et al., 1999, Coates, Richter and Caceres, 2008). Examining the process from the time a person becomes aware of personal risk to infection with the human immunodeficiency virus (HIV) through to how they go on to access VCT and their subsequent behaviour provided an opportunity to explore how VCT can be made more effective for people testing negative (see International HIV/AIDS Alliance Asia and Eastern Europe team, 2004).

The findings from this study provide insight into the interaction between HIV-test decision making, behaviour pre-test, VCT, receipt of a negative result and behaviour post-test in an area with one of the highest HIV prevalences in Southern Africa. Such insight provides useful context-specific information for understanding how VCT and receipt of a negative result, influence self-reported risk behaviour, and the felt support needs of people testing negative. Such understanding is essential for the design of a VCT service that is optimally responsive to the needs of its users thereby achieving desired outcomes.
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Chapter outline

The chapter begins with a discussion about my disclosing to participants that I was a medical doctor doing a research study and the influence of that decision on the type and quality of data generated. I next discuss the strengths and limitations of the methodology utilised in this study. These two sections provide the context within which the findings are discussed. A summary of the main study findings is then provided followed by a discussion of the findings structured around the three study aims. The findings are interpreted and related to the existing literature highlighting, where appropriate, similarities and differences, and their practical and theoretical implications.

Reflexivity and ethical considerations were integral components of the process guiding both data generation and analysis as reflected in the methods chapter. This permitted the co-generation of data that more closely reflected the interviewees’ perspective while being sensitive to their needs.

10.2 Positioning of self in the study and impact on generated data

The position a researcher takes in an interview interaction determines to a certain extent the type of interaction and data generated (Lofland and Lofland, 1995). Helen Richards, a General Practitioner, and Carol Emnlie, a Sociologist, compared their experiences of the respondent/interviewer interaction while working on similar qualitative studies. Richards disclosed her professional background and Emnlie identified herself as a researcher, due to perceived difficulties with understanding of the term ‘Sociologist’. They found that while some interactions were common to both others seemed to be related to the professional background of the interviewer.
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(Richards and Emslie, 2000). If a researcher decides, like I did, to reveal their professional background they need to be aware of the influence this will have on the respondent and actively work at clarifying their current position in the research. I have discussed my decision to disclose my professional status and how I proceeded to manage the interview interactions within that framework in section 5.9.3 and 5.9.7.

It is not only the perception of the interviewer by the interviewee that is affected by disclosure or non-disclosure of professional background. Splitting of the professional from the researcher may produce conflict in the researcher making them ill-at-ease and thereby impacting negatively on the quality of the data that is generated in such an environment. Being oneself in an interview avoids this conflict and allows one to be their more natural self enabling the use of previously acquired skills to enhance the interaction (Colbourne and Sque, 2004, Hoddinott and Pill, 1997). Disclosing my professional background may have led to generation of data influenced by interviewees relating to me as a doctor and therefore part of the system, to be treated with deference and told what people belonging to the system would want to hear, as stated by Richards, “who participants think you are affects what you get told” (Hoddinott and Pill, 1997, Richards and Emslie, 2000). In particular, responses related to the usefulness and quality of services and reports about risk behaviour and safer sex may have been different to what may have been reported to an interviewer perceived not to be part of the system and not too knowledgeable about the topics under discussion (see Richards and Emslie, 2000). On the other hand their reports of behaviour may have been more candid than they would have been with someone who was unknown to them and was not a medical person, people to whom they
are accustomed to giving information they would not normally give to a complete stranger (Hoddinott and Pill, 1997). Thus disclosure of professional background may have facilitated the generation of the rich data obtained from this study. However, similar to Richard’s experience some people when asked for any further comments or questions responded by requesting for health-related information. Therefore, knowledge of professional background may have also precluded the spontaneous discussion of wider issues which participants might think were outwith the interest of doctors.

10.3 **Strengths and limitations of the methodology**

This thesis was conducted in a systematic manner beginning with a focussed research question which guided the selection of the research approach and study design. The whole process of the research including theoretical assumptions; fit between question, method, approach and theoretical perspective; the holistic context within which data were generated; and methods of data generation and analysis has been clearly described in the interests of transparency, allowing the reader to come to their own conclusions about the validity and usefulness of the findings (Willig, 2004).

10.3.1 **Strengths**

A particular and rare strength of this study is its qualitative longitudinal design (with a follow-up rate of 74 percent) which allowed for an in-depth exploration and understanding of the process of change over time and factors facilitating and hindering this process (see Holland, Thomson and Henderson, 2006, Murray et al., 2009). Similar to a study of the poor in East London (Cornwell, 1984), I found that with time, as trust developed, either within the same interview or in the follow-up interview, people tended to
open up and provide more valid “private” accounts rather than the “public” accounts initially provided with the underlying desire to appear “normal”.

In addition, this study utilised a multiperspective approach. This allowed for the comparison of service users’ and service providers’ perceptions of the service and the needs of users, facilitating the identification of areas of concordance (validation) and discordance. This is potentially useful information for the improvement of services (Kendall et al., 2009).

Credibility of the findings was enhanced by the independent coding of a randomly selected subset of the transcripts (Creswell, 2007, Willig, 2004).

The study was focussed on an understudied and underserved group, clients testing HIV negative at VCT. Facilitating a focussed in-depth examination and understanding of this largest group of post-test clients is potentially very useful research.

The recruitment strategy maximised variation of perspectives by enrolling a diverse group of participants from both private and public VCT facilities in different geographical areas (Creswell, 2007).

Prior observation of counselling sessions facilitated a full understanding and description of the VCT procedure in this study. This enables the reader to interpret the findings in their appropriate context and facilitates comparison with other studies and their own situations (Denison et al., 2008, Glick, 2005, Solomon et al., 2004, Weinhardt et al., 1999).

The researcher was familiar with the language, cultural, religious, social and political context of the study area, and the people, and conducted all the interviews herself and transcribed almost all of them (verbatim). These
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factors enhance the validity of the generated data and accuracy of transcription and interpretation (Lofland and Lofland, 1995).

Findings contradictory to emerging explanatory concepts were deliberately sought to facilitate the refinement of the proposed explanatory framework and have been presented. A plausible and comprehensible explanation of the findings has been presented with ample evidence in terms of quotations, and will be related, in this chapter, to what is already known about this subject area.

10.3.2 Limitations

The major limitation of this study is the reliance on self-reports of behaviour and behaviour change. Apart from re-call bias people may not tell the truth in such an interview due to various reasons, such as social desirability, where people provide answers that they perceive to be more socially acceptable or what they think the interviewer is looking for (see National Research Council (U.S.), 1996). The validity and reliability of self-reports of sexual behaviour have been questioned since the first sexual behaviour surveys were conducted by Kinsey in 1948 (Weinhardt et al. 1998). Stigmatised behaviours may be under-reported whereas socially desirable behaviours may be over-reported. Weinhardt et al (1998) conducted a systematic review of the literature assessing the “reliability and validity of self-report measures of HIV-related sexual behaviour”. The review covered research published between 1 January 1990 and 31 December 1995. The authors of this study found that self-reports of sexual behaviour varied according to the method of data collection and conclude that there is “little consensus among researchers” as to which method provides the “most reliable and valid sexual behaviour data”.

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Plummer, Ross and Wight (2004) conducted a study assessing the validity of adolescent sexual behaviour data collected in a rural area in Tanzania. This study compared “the reliability and validity of sexual behaviour data” collected using five different methods in a single population of adolescents: biological markers; face to face questionnaire; self-completion questionnaire; in-depth interview; and participant observation. This study found that participant observation provided the most reliable data. Participants, especially girls, were secretive (cf Helle-Valle, 2004) and under-reported sexual behaviour in face to face and self-completion questionnaires, and in-depth interviews.

However, self reports of behaviour may be reliable in health promotion and specifically in sexual health. Amos, Currie and Hunt (1991) compared the consistency of self-reported behavioural change, for five different behaviours (diet, cigarette smoking, alcohol consumption, weight control, and physical activity), between postal interviews and home interviews. In general, there was consistency in self-reports of behaviour change in that change did occur, but there was inconsistency in the details of change in terms of the rate of change and timing of change dependent on the type of behaviour. The authors suggest that this may be due to the saliency of other factors associated with the behaviour change which could influence recall. James, Bignell and Gillies (1991) also recorded consistency between self-administered questionnaire and interview self-reports of sexual behaviour.

In a study examining the impact of intervention components on HIV risk-taking in female sex workers in Nairobi, Kenya (Kaul et al., 2002), self-reported sexual behaviour was compared to incidence of sexually transmitted infections (STIs). Reported changes in high-risk behaviours
correlated with a reduction in STIs providing some evidence for the validity of self-reports. A multi-centre randomised controlled trial assessing the efficacy of VCT in individuals and couples in Kenya, Tanzania and Trinidad (The Voluntary HIV-1 Counselling and Testing Efficacy Study Group, 2000) had similar findings. Furthermore, agreement between self-reports of sexual behaviour within couples who were interviewed separately was also found to be high.

Overall, in the current study, accounts of behaviour change given in the first interview (pertaining to behaviour prior to testing) were consistent with those given six months later providing some evidence for validity of the reports. In addition, people that had failed to implement their stated intentions did not conceal this in the second interview even though they could recall what they had said in the first interview (see Kipp, Kabagambe and Konde-Lule, 2001). As mentioned in sections 5.9.7 and 10.2, disclosure of my professional background may have introduced bias in the type of data collected. This may have been compounded by the fact that the interviews were conducted in a health facility and immediately following VCT – when issues of safe sex were uppermost in the participant’s mind. Within such a context it is possible that people would be unlikely to criticise the VCT service, would be unlikely to report reduced perception of risk to HIV and may under-report sexual risk behaviours. A deliberate effort was made to minimise under-reporting of sexual risk behaviour by assuring participants of confidentiality and anonymity, informing them that the study might involve the asking of sensitive personal questions about their sexual life which they did not have to answer but that it would be very helpful if they would. The establishment and maintenance of rapport before and during the
interview was also sought after and largely achieved (see section 5.9.3). Thus I consider that these data are useful accounts and that the interpretations drawn are sensible and robust.

Self-selection bias cannot be ruled out since the risk characteristics of those that declined to participate were not available. As presented in section 6.2.1, a sub-analysis of the risk profile of VCT clients attending at three of the study sites suggests that the study may have differentially recruited people of higher risk behaviour. The three study sites included in this sub-analysis had data available in a format that could be used to calculate the proportion of people attending who test negative and give a history of multiple partners. In 2007, the year when most of the participants were recruited, the proportions at the three sites were four percent, six percent and twelve percent. Among the people interviewed 36 percent gave a history of multiple partners. It therefore seems unlikely that the group that did not participate may have been composed of more high risk people than the group interviewed. However, this difference could be due to participants providing different information to the counsellor and to the researcher which may have been due to differences in the way the information was elicited, interviewee and interviewer relationship dynamics (as discussed in section 10.2) or differing frames of reference for ascribing multi-partnership. Examination of a subset of the total sample, from two of the study sites that recorded information on individual VCT forms, showed that out of the 17 interviewees for whom a completed form was available, four had reported multiple partners in the counselling session. An additional six reported multiple partners in the interviews (all the four that reported multiple partners in the counselling did so in the interviews as well). The self-selection of higher risk
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people would not, in essence, create an undesirable bias in this case since this is the group of primary interest in the prevention of HIV (see Nyblade et al., 2001) and for whom effective prevention interventions are particularly pertinent.

Attrition bias is unlikely because there was no major difference between the two groups although it may be that the people who returned for the second interview may be more compliant than the ones who did not (Watts et al., Unpublished). This may be an underlying trait (see section 2.2.1) which could explain why they returned for the second interview and why they claimed to have initiated and maintained safer behaviour. If this is the case then any intervention to improve VCT effectiveness would have to take into account issues of increasing compliance.

Focussing on a single model of VCT delivery and HIV-negative people has the disadvantage of not allowing for comparison with other models and with people testing positive. This limits the population to which the results may apply. Since the purpose of the study was to understand better the interaction between VCT, a negative result and sexual behaviour, we are unable to say from this study whether the interaction observed is unique to people who self-refer for VCT and test HIV-negative or not. The results of this study may only be generalisable to people self-referring to health-centre affiliated voluntary counselling and testing services and testing negative.

Pre-test risk behaviour, attitudes to risk and the decision to test preceded knowledge of HIV status. The design of the study was such that interviews were conducted after the client had been made aware of their negative status and this may have influenced recall of risk behaviours and attitudes, and of
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the decision making process (cf Siegel et al., 1989). Ideally people self-presenting for VCT would have been approached pre-VCT and an initial interview conducted. Immediate post-test and follow-up interviews would then be conducted with those testing negative. However, resource constraints, in particular time, did not permit such a design as it would have meant recruiting from only one facility per day which would have further limited the number of people that could have possibly been recruited within the available time frame.

It is possible that risk behaviour post-test may have been influenced by the initial research interview. The initial interview may be considered an intervention as it provided people with an opportunity, additional to the counselling, to reflect on their susceptibility to risk, behaviour and intentions (Bowling, 1997, Rice and Ezzy, 1999). The interview is something that is normally not available to people accessing VCT and so we cannot rule out the possibility that it may have influenced post-test behaviour by acting as an additional ‘counselling session’, given that it may have provided additional motivation to some to implement or maintain safer sexual behaviour. It should be noted that most people were already practising safer sex before VCT and it seems plausible that, for most, continuing to do so was probably a result of the motivating effect of the negative result rather than the interview. What could be done in a future study, designed as suggested above, is to have a comparison group of people who would be interviewed pre-test and at six months (excluding the immediate post-test interview) to assess any additional effects that may be due to the first post-VCT interview (Hawthorne effect).
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In the systematic review, presented and discussed in chapter 3, exclusion of papers focussing exclusively on pregnant women, adolescents, men-that-have-sex-with-men (MSM) and injecting drug users may have resulted in missing some studies that could have been useful in answering the review’s questions. This has been partially addressed by relating the findings from the current study to some of these studies highlighting similarities and differences.

Cross-sectional analysis of the data and thematic coding, provided a comprehensive coverage of the common themes in relation to the research aims, but resulted in some fragmentation and loss of detail of the individual accounts and experiences over time. The use of a case study approach would have better preserved the integrity of individual’s accounts and experiences, including over time (Silverman 2005).

10.4 The decision-making process around going for VCT

Little is known about the decision-making process involved in testing for HIV in sub-Saharan Africa (Solomon et al., 2004). The current study identified a three-staged decision-making process, beginning with the recognition of susceptibility followed by emotional and cognitive engagement with the problem of testing for HIV, and concluding with the desire to know status irrespective of test result. This section begins by discussing the theoretical implications of the findings and then discusses the three stages in relation to the literature.

10.4.1 Theoretical implications

Some commonly accepted theories of behaviour change have been presented in section 2.2.2. The presented theories are similar, the basic difference
between them being the emphasis placed on the different mechanisms and determinants of behaviour change (Kalichman, 1998).

VCT is considered as a catalyst for behaviour change, reducing the threat of HIV infection or reducing the severity of infection (see section 1.5 & Fig 1.1, p18) (see UNAIDS, 2002). Therefore, according to these models, attending VCT should precede and then encourage behaviour change.

However, the decision-making process conceptual framework generated from the findings of this study (Fig 10.1 — corresponds to the first part of the framework presented in Fig 6.1, p220.), suggests that for most people behaviour change occurred before attending for VCT.

The following is a discussion of the fit of the proposed framework to the earlier discussed behaviour change models (section 2.2.2). The theoretical implications for the behaviour change model providing the closest fit are
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discussed in more detail. This study did not set out to test any of the
behaviour change models. The design of this study would be inappropriate
for such a task. This section merely attempts to broadly relate the study
findings to the currently available behaviour change models.

The central constructs and explanatory framework of the health belief model
(HBM) (Rosenstock, Strecher and Becker, 1994) provided the closest fit to the
conceptual framework.

The next closest fit was with the AIDS risk reduction model (ARRM)
(Catania, Kegeles and Coates, 1990) and the stages of change (SOC) model
(DiClemente and Prochaska, 1982). Both of these models emphasise self-
perception of risk as the initial step but do not emphasise socio-demographic
characteristics. In addition, the ARRM emphasises commitment and
enactment of change and unlike the study framework does not highlight the
cognitive and emotional engagement process as a core construct. This is
similar to the SOC model whose core constructs provide a framework for the
behaviour change process rather than the decision making process (see
Kalichman, 1998).

The theory of reasoned action and the theory of planned behaviour (Ajzen,
1988, Ajzen and Fishbein, 1980) emphasise the role of subjective norms in
decision-making which were not prominent in this study, do not emphasise
self-perception of risk and do not have a ‘cues’ construct.

The information-motivation-behavioural skills model (Fisher and Fisher,
1992) focuses on factors influencing risk reduction such as AIDS risk
reduction information, motivation to change and possession of skills which were not main concepts in the study framework.

The social cognitive theory (Bandura, 1977b) focuses on the concept of self-efficacy positing that people will only engage in a particular behaviour if they believe that they are capable of implementing the behaviour. This model does not consider ‘cues’ and does not emphasise self-perception of risk as the initial step.

**Comparison of the health belief model to the proposed conceptual framework**

According to the HBM (an abbreviated version of which is provided in Fig 10.2 for ease of reference, the complete model is available in section 2.2.2, p43) behaviour is influenced by individual socio-demographic factors. As described in section 2.2.2, according to this model, people will take action to protect their health if they feel that they are able to perform the required action or behaviour (self-efficacy), believe that the condition is serious, and feel susceptible to it (threat). They should also believe that they have access to the available means of reducing their risk of getting the infection or reducing its severity and that the benefits of any preventive action(s) outweigh anticipated losses (expectations). The protective action or behaviour may be motivated by cues which may be internal personal states or events in the external environment.
The conceptual framework proposed by this thesis is by and large in agreement with this model. However, according to the proposed framework, for most people, risk reduction or behaviour change preceded the decision to test, and hence VCT. In addition, cues were not only ‘cues to action’ but also ‘cues to recognition of susceptibility’, and aversive emotional states played a central role in the decision-making process.

Fitting the conceptual framework to the health belief model results in the modifications (in circles and italicized words) reflected in Fig 10.3.
Socio-demographic factors such as gender, marital status, cultural beliefs and social network played a role in influencing the decision-making process. Recognising self-susceptibility to a disease which was believed to be life-threatening, anxiety, feeling out of control, realising that being HIV-positive was not the end of life, and that it was better to know and access help led people to test. Most people had adopted safer sexual behaviour to reduce threat of infection before testing. For these people attending VCT can be considered an additional action to further reduce threat — to access medication if HIV-positive or to further protect themselves from infection if negative. In this study cues not only potentiated action but also served to facilitate perception of risk.

The HBM does not adequately explicate the cue-to-action construct (Aspinwall et al., 1991, Rosenstock, Strecher and Becker, 1994). It is not very clear which cues exist and what is their relative efficacy in influencing behaviours related to prevention of HIV/AIDS (Rosenstock, Strecher and...
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Becker, 1994). Salient cues in this study included physical signs and symptoms both internal and external, media, and social networks. In addition the HBM does not explicitly acknowledge the influence of aversive emotional states such as fear and anxiety (Bowling, 1997) which were found to play a prominent role in the decision making process. Aversive emotional states have been shown to be associated with reductions in high risk behaviours and increases in safer behaviour (Catania, Kegeles and Coates, 1990). The roles of social and environmental influences are not given much attention and past behaviour is not taken into account in this model. Research does suggest that past behaviour predicts future behaviour (Ogden, 2007, Bowling, 1997).

10.4.2 Relating the findings to the literature

The discussion now turns to the findings in relation to the literature and will be guided by the conceptual framework presented in Figure 10.1, p346

Stage 1 – Recognition of susceptibility

The HIV-test decision making process was complex for most people with the recognition of risk being the initial step. It is accepted that people will take action to protect their health if they believe that they are susceptible to the condition threatening their health (Rosenstock, Strecher and Becker, 1994). Several studies, in Africa and elsewhere, have shown that perception of self-susceptibility is positively associated with testing (Ickovics et al., 1994, Myers et al., 1993, Jereni and Muula, 2008, Maman et al., 2001, Fylkesnes and Siziya, 2004, deGraft-Johnson et al., 2005, Siegel et al., 1989). However, a significant body of literature suggests that knowledge of risk is not necessarily sufficient to drive an individual to take action (Woodcock, Stenner and Ingham, 1992, Stein and Nyamathi, 2000, Siegel et al., 1989, Rimal, Creel and Keulder, 2006,
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Fylkesnes et al., 1999, Stolte et al., 2007); they must also feel a need to test (International HIV/AIDS Alliance Asia and Eastern Europe team, 2004). For example, a person may recognise that they have been exposed to risk of HIV infection but may not feel the need to test until faced with a situation that triggers the need to know, such as, signs and symptoms suggestive of HIV infection, the death of a close friend, relative or spouse, or until they perceive some benefit to testing. On the other hand some people will test in order to confirm their negative status even if they do not perceive themselves to be at risk of infection (Thierman et al., 2006, Lupton, McCarthy and Chapman, 1995) like the young man in this study who tested to prove he was negative. A participant in a study investigating the motives of gay men for taking or not taking the HIV test (Siegel et al., 1989) also reported that he had tested to prove to himself and his partner that he was negative, though he turned out to be positive.

Hindrances

A phenomenon that may hinder recognition of risk but has received little attention in the literature is that of inferred negativity. People may believe they are negative because their partner is negative or they assume they or their partner have been tested for HIV, when blood specimens were collected when they visited a health facility for other personal health concerns or routine health checks. Others may believe their partner is negative (and therefore faithful) because they themselves have tested negative (cf Morrill and Noland, 2006, Ryder et al., 2005, Exner et al., 2002). This is important to consider, as education can address this.

A related phenomena that may equally lull people into a false sense of security is the notion that chances of contracting HIV are lower in areas
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where perceived prevalence is low and higher in areas where perceived prevalence is high (cf Woodcock, Stenner and Ingham, 1992). This perception of risk was also identified by Worthington and Myers (2003) in their study on factors underlying anxiety in HIV testing; people believed themselves to be negative because as far as they were concerned they did not belong to a high risk group.

Such beliefs may have unfortunate consequences as people will unknowingly continue to expose themselves and others to risk and will not feel compelled to test until they begin to experience signs and symptoms which then act as cues to recognition of risk.

Facilitators

Recognition of susceptibility was aided by high levels of awareness and knowledge about HIV/AIDS achieved mostly through mass media information and education material (Central Statistical Office, Ministry of Health and MEASURE Evaluation, 2002). As in most countries in Africa, radio is the main source of information for most Zambians (Falobi et al., 2002). The 2007 Zambia Demographic and Health Survey (ZDHS) estimates that 71 percent of households in urban areas and 50 percent of those in rural areas own a radio (Central Statistical Office et al., 2009). Judging from the reasons that people gave for labelling themselves as at risk, it would seem that the mass media campaigns have been successful in relaying messages on risk. Reported sources of risk included both sexual and non-sexual such as sharing of razor blades. Such a response is desirable in countries with generalised epidemics and high prevalence since the chances of infection are higher. In countries with low prevalence and epidemics concentrated in particular high-risk groups a policy of testing every person including those
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at low risk, may not be cost-effective. In addition, it may do more harm than
good to the HIV/AIDS prevention response by drawing resources from other
HIV/AIDS programmes that already need additional support (see Lupton,
McCarthy and Chapman, 1995). Considering that levels of comprehensive
knowledge (see section 4.4.1) are low, radio has the potential to further
increase understanding of HIV/AIDS transmission, prevention and treatment
issues (Falobi et al., 2002, Maman et al., 2001).

High levels of awareness and visibility of HIV/AIDS also facilitated increased
perception of risk (cf Siegel et al., 1989). Due to the high HIV prevalence,
especially in urban areas, most people in Zambia have personal experience of
HIV and AIDS. Seventy-two percent of respondents in the 2000 ZDHS knew
someone who was either living with HIV or had died from an AIDS related
illness (Central Statistical Office, Ministry of Health and MEASURE
Evaluation, 2002). The availability heuristic (Slovic, Fischhoff and
Lichtenstein, 1982, Tversky and Kahneman, 1974) suggests that events that
are more vividly remembered or more frequently experienced are more
likely to influence judgement about the probability of experiencing the same
event than those that are not. This heuristic may be useful in explaining why
personal experience of HIV/AIDS appeared to heighten perception of risk to
HIV infection.

Similar to findings from other studies (Ickovics et al., 1994, Jereni and Muula,
2008), married women in the current study were more likely to feel at risk
due to their partner’s extra-marital behaviour. The Malawian study by Jereni
and Muula (2008) found that 22 percent (13/60) of the female participants
primarily presented because of their partner’s infidelity. The participants in
the Ickovics study were all women and more than a quarter of them (42/152)
felt they were at risk due to their partner’s behaviour. Most of the women in the current study only labelled themselves as at risk when they developed physical signs and symptoms that were suggestive of HIV/AIDS even though they had been aware of their partner’s behaviour before the development of the symptoms and signs (cf Nyblade et al., 2001). Although Jereni and Muula report that 23 percent requested testing because of current illness, they do not provide information as to whether these women were also at risk due to their partners’ extra-marital sexual behaviour. It is important to determine which of the two precedes the other since married women, as this study suggests, may be waiting until they begin to experience signs and symptoms suggestive of HIV/AIDS before presenting for testing. This may be too late for them to fully benefit or to benefit at all either from the counselling if they test negative or the treatment that may be available to them if they do indeed test positive.

A qualitative study (in-depth interviews with 15 females, 17 males and 15 couples) in Tanzania also found that women were seeking testing to confirm their (perceived) positive status following their own sickness or the sickness or death of a child or spouse. This study also found that fear of a partner’s reaction was the most common barrier to testing (Maman et al., 2001). This fear was not expressed by the eight married women in the current study. However, the current study does present some evidence that reduced economic dependency on their husband’s may encourage women to test. This supports Nyblade et al’s (2001) findings in a study examining participation in population-based counselling in rural Uganda in which women who were economically independent were more likely to test than those who were not (see table 10.1).
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Table 10.1: Receipt of voluntary testing and counselling by occupation status (females)

<table>
<thead>
<tr>
<th>Occupation</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bar worker/owner/home-brewing</td>
<td>136</td>
<td>36.8</td>
</tr>
<tr>
<td>Homemaker (no pay)</td>
<td>370</td>
<td>23.0</td>
</tr>
<tr>
<td>Subsistence agriculture</td>
<td>4,068</td>
<td>32.1</td>
</tr>
<tr>
<td>Commercial agriculture</td>
<td>155</td>
<td>36.1</td>
</tr>
<tr>
<td>Government/clerical/teaching/housekeeper/military/police</td>
<td>317</td>
<td>35.7</td>
</tr>
<tr>
<td>Shopkeeper</td>
<td>180</td>
<td>37.8</td>
</tr>
<tr>
<td>Trading/vending</td>
<td>235</td>
<td>34.9</td>
</tr>
<tr>
<td>Student</td>
<td>224</td>
<td>17.4</td>
</tr>
<tr>
<td>Other/unemployed</td>
<td>501</td>
<td>29.5</td>
</tr>
</tbody>
</table>

p < 0.001 (from $\chi^2$ showing differences in voluntary testing and counselling receipt among categories of the specified variable)

Source: Modified from Nyblade et al, 2001

**Stage 2 – Emotional and cognitive engagement**

Diagnostic testing for any potentially fatal disease is accompanied by anxiety (Worthington and Myers, 2003). This study highlights that the reasons commonly given for wanting an HIV test belie the often protracted and anxiety-laden process preceding attendance for voluntary counselling and testing, and give a simplistic picture of why people feel a need to test for HIV. An unexpected finding in this study was the wide variability in duration and depth of angst that generally characterised the decision to attend for VCT.

Some people, especially those expectant of a negative result, appeared to have little cause for concern believing that their chances of infection were low since they were either in a monogamous relationship, had no history of sexual risk or simply did not think their previous behaviour was risky, even if it was. These were testing because they felt it was the right thing to do according to the health messages. An Australian study which examined the reasons for testing in low-risk people also found that most of those
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presenting for testing were expecting a negative result and reported minimal anxiety about testing (Lupton, McCarthy and Chapman, 1995). Such people may take the negative result as a confirmation of the safety of their previous behaviour or partners (see Ryder et al., 2005).

Hindrances

Emotional and cognitive engagement with VCT was commonly deterred by the fear of a positive HIV test result, prolonging the angst of living with uncertainty of personal HIV status (cf Siegel et al., 1989, see Catania, Kegeles and Coates, 1990). Other studies in the USA, South Africa, and Scotland also recognise this fear (Siegel et al., 1989, Meiberg et al., 2008, Flowers, Duncan and Knussen, 2003, Ransom et al., 2005, Kalichman and Simbayi, 2003). Siegel et al (1989) identify HIV antibody testing as “problematic behaviour ... because of the momentous psychological and social risks, and benefits associated with testing.”

Stigma is an ongoing challenge and serves to discourage people from testing. Stigma as defined by Goffman (1963: p13) is “an attribute that is deeply discrediting”. The term ‘stigma’ originates from the ancient Greek who used it to describe a symbol put on a person’s body exposing something “unusual or bad about the moral status” of the individual. In the present day the word is applied to the discrediting attribute itself rather than to a physically observable sign. The stigma related to HIV infection can be classified as a “blemish of individual character” or a moral weakness. Stigma is socially constructed and society will ostracize anyone that does not satisfy the accepted attributes. Being infected with HIV is synonymous to engaging in socially undesirable sexual activity or belonging to a group that is not accepted in that particular society thus creating a barrier to testing (Lupton,
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McCarthy and Chapman, 1995, Ransom et al., 2005, Siegel et al., 1989, Rassjo et al., 2007). In a study on stigma as a barrier to HIV testing at a South African University, Meiberg et al (2008) found that though the majority of participants said they did not believe they could get HIV from casual contact such as shaking hands and sharing utensils they frequently expressed fear of HIV transmission through such contact. This is similar to the fear of infection from such contact, expressed by one of the study participants. Residual fears such as these perpetuate the stigma attached to HIV/AIDS.

Denial, a coping strategy employed by some people, hinders progression through the decision-making process. Siegel et al (1989) found that people used denial as a coping strategy so they could continue life with some semblance of normality. The current study also suggests this may be a common coping mechanism (Perry, Baranowski and Parcel, 1990: p174-175), preventing people from confronting their risk and dealing with it, that it is better not to know than to know that one is HIV positive. People believed that knowing that one is positive is inviting worry about death (cf Meiberg et al., 2008, Rassjo et al., 2007).

**Facilitators**

Normalising HIV, so that it is perceived just like any other disease, may help to reduce stigma and encourage testing as suggested by interviewees in the current study. It is postulated that as more people test, testing for HIV would become a norm in the society further reducing stigma (UNAIDS, 2001b). This appears to be the case in the study area with people encouraged to test because they see their peers testing. This may be further facilitated by the active sensitisation that tested individuals appeared to engage in post-testing.
This study and others provide encouraging signs of reducing levels of perceived HIV/AIDS stigma in Zambia. Normalisation of HIV has most likely been facilitated by the advent of ARVs as suggested by findings from a study by two of my thesis supervisors, Grant et al (2008) on adherence to antiretroviral therapy in Ndola, Zambia, and from the 2007 ZDHS. Participants in the Grant et al (2008) study reported that “People are more accepting ...” and “The illness is common now, it is in the open”. The ZDHS findings, indicate increasing levels of acceptance of HIV-infected people (Central Statistical Office et al., 2009). However, there is still much that needs to be done as evidenced by a recent report of an HIV-positive woman who committed suicide because of intolerable social discrimination in a rural town in the Southern Province (Chibulu, 2009).

**Stage 3 – Need to know status regardless of test result**

Increasing anxiety about their HIV status and feelings of not being in control, coupled with the understanding of the possibility of life even with a positive HIV-result, made possible by the availability of ARVs, can tip the balance in favour of testing (cf Siegel et al., 1989).

Although sensitisation and promotion activities targeted at the community may be effective in raising awareness and encouraging self-perception of risk, this study suggests they may not provide sufficient information for the individual person to understand to the level that motivates testing (see International HIV/AIDS Alliance Asia and Eastern Europe team, 2004). Some people required the one-to-one counselling session to understand issues to a level where they saw testing as beneficial and then decided to test. Believing that one cannot do anything about AIDS, if one has it, discourages testing. Such people cannot be reached through VCT, since they will not attend.
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Therefore, such perceptions need to be addressed through community interventions that help people to understand and accept that it is possible to live positively with HIV infection (Meursing and Sibindi, 2000). Provision of face-to-face community-based opportunities, for discussing and learning about HIV/AIDS, which are not necessarily linked to testing, may facilitate understanding, encourage testing, behaviour change and reduce stigma (Kipp, Kabagambe and Konde-Lule, 2001, Woodcock, Stenner and Ingham, 1992).

This study has shown evidence of delay, often prolonged, between recognition of risk of HIV infection and presentation for testing (see section 7.3). This delay works against both prevention and treatment goals of VCT. The problem of timely identification of those who are infected has been partially addressed through the introduction of provider initiated counselling and testing (C&T) (see section 1.6). However, this strategy will only capture those that regularly use health care services. As pointed out by Asante (2007), weak health systems and poor health services utilisation in Africa generally, mean that many people will still not be captured by this strategy. In addition, this strategy does not address the primary prevention role of VCT. Since the majority of people will not come to health facilities or VCT centres, information and education need to be provided in the communities where people live.

Problems with accessing the VCT service may have resulted in missed opportunities. The Alma Ata declaration on primary health care recognises the need to make health services as easily accessible as possible to facilitate uptake (Declaration of Alma-Ata, 1978). Services must be provided at times convenient to most people, but even more important, service providers must
be available during the stated service operational hours. Although VCT services are said to be available in all health facilities in the study area, availability is dependent on whether there actually is a nurse-counsellor or other counsellor on duty and the number of staff available to attend to patients requesting other primary health care services.

10.4.3 Risk behaviour change before attending VCT

Most people in this study were practising safer sex before attending for VCT and close to half of these said they adopted safer behaviour at some point during the decision making process, before finally committing to testing. Studies investigating the effect of VCT on behaviour have suggested that tested individuals may have been practising safer behaviour prior to testing (Ickovics et al., 1994, Jacobsen, Perry and Hirsch, 1990). However, there is a dearth of studies specifically examining the temporal relationship between deciding to attend testing and behaviour pre- and post-testing. In addition, the phenomena of behaviour change before VCT has not been incorporated in behaviour change models with the predominant current thinking being that VCT initiates behaviour change.

The time taken in making the decision to test appears to provide a space for reflection, introspection and understanding of what it is that one wants from life (see Ransom et al., 2005). People who went through this process initiated self-protective behaviours before they finally made up their minds to test. In one of the studies in the Jacobsen, Perry and Hirsch systematic review (1990), the authors found that before knowing their status most HIV-negative men, who opted to be informed of their HIV status in a study on the natural

19 Nurse-counsellors are employed as nurses and are responsible for other nursing duties
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history of HIV, had discontinued a behaviour (unprotected receptive anal intercourse) that put them more at risk of infection while fewer had discontinued one that would put their partner more at risk than themselves (unprotected insertive anal intercourse) before knowing their results. The authors of the systematic review speculate that “in the absence of direct knowledge of their antibody status, individuals will be more likely to act in a self-protective manner than in a manner associated with greater concern for the protection of others” (Jacobsen, Perry and Hirsch, 1990). This may explain why people in this study adopted safer behaviour even without knowing their status and were more centred on the self in their decision to test and only exhibited concern for others after they were aware of their status.

It is possible that people changed behaviour and waited for six months before testing to ensure that the test would be definitive since they would have had a six month or more risk-free period. One person did report not testing earlier because they wanted to make sure they were past the window period. Most, however, had been practising safer sex or abstaining for two or more years before testing and when asked about the necessity of a second test most did not relate this relatively risk-free period to increased probability of initial test being definitive and reported that they felt a second test was necessary to confirm their status. In addition, if they had been waiting for the window period before testing then they would not be expected to return for the confirmatory test. However, almost all of those that returned for the confirmatory test had been practising safer sex or abstaining in the six months prior to their first test.
Ickovics et al (1994) (see section 3.2.1) found that although tested women had proportionately more partners, who were also more risky, more of them were practising protected sex, before testing, than the untested women. They concluded that previous behaviour was “a better predictor of current behaviour than receiving counselling and a negative result.”

### 10.5 Influence of counselling and HIV test result on HIV & AIDS knowledge, perceptions and attitude

Knowledge and perception of VCT will determine the purpose for which the service is accessed, when it is accessed, and the benefits expected. This section begins with a discussion of the participants’ perception of VCT followed by a discussion of the effect of counselling and testing on knowledge, understanding, risk perception and post-test risk and testing behaviour.

#### 10.5.1 Perception of voluntary counselling and testing

The literature is relatively silent on users’ understanding of VCT. A qualitative study in Western Uganda, (Kipp, Kabagambe and Konde-Lule, 2002) found that HIV counselling and testing sessions were primarily viewed as an opportunity to know HIV status rather than as an opportunity to learn more about how to prevent the transmission of HIV. Behaviour change workshops, which had been conducted in the district, were seen as the primary source of such information. A Zambia VCT Partnership report (2003) notes, from a review of documents and literature on VCT in Zambia, that people’s understanding of VCT was narrowly limited to provision of sero-status and locations for testing.
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The findings from the current study support these previous studies suggesting that the concept of counselling may not be well understood by people in the study area. VCT was perceived as “testing for HIV”, implying that people attended VCT primarily to test and so the decision-making process was targeted at the testing rather than counselling. If people understood that counselling alone may be available (without having to test), to clarify some of the questions they battle with in the decision-making process, they may decide to attend VCT sooner rather than later. Earlier understanding of the advantages of testing may lead to earlier testing (cf UNAIDS, 2001b). This is perhaps an unintended consequence of the way VCT has been marketed. VCT is set up for those who are seeking testing (cf Ikechebelu et al., 2006), as evidenced by the health information, education and communication materials that encourage people to go for VCT to know their status.

Siegel et al (1989) define three competing social constructions of the HIV test; the psychosocial, public health, and medical constructions. The psychosocial definition evolved during the early years of the epidemic when stigma and discrimination were rife and there was no treatment for the disease thereby creating a situation where it was of greater benefit not to test than to test. In those early days, the gay rights and civil liberties movements actively advised people not to test for fear of the unfavourable social and psychological consequences. The public health definition was later championed by public health officials and policy makers who were looking to the test to provide them with HIV surveillance data and for control of transmission through counselling of tested people whom it was hoped would then adopt safer behaviour. Finally the medical construction of the
test came into existence with the discovery of medication for the treatment of HIV/AIDS. This construction subscribes to the idea that knowing one’s status is advantageous for the purpose of accessing treatment and prolonging life. This was the predominant construct in the Siegel et al study (1989) which was examining motives for testing or not testing in men-who-have-sex-with-men (MSM) in New York. The authors predicted that this construct would become even more popular with increasing evidence of the benefits of treatment.

This was indeed the finding in this study and also in a recent other Zambian study (Grant et al., 2008) where people referred to how seeing others recover convinced them that there is life with an HIV-positive result, encouraging them to attend VCT for the primary purpose of testing to know their status so they could access ARVs if positive. A study at the University of Limpopo, in South Africa (Meiberg et al., 2008), examining the effects of stigma on testing at a time when ARVs were not available, found that most students were not prepared to test because of perceived stigma and discrimination post-testing, with no tangible benefits. These findings support the supposition that the psychosocial construct of testing will predominate when perceived disadvantages of testing outweigh benefits whereas the biomedical construct predominates when access to therapy is perceived to be available providing the benefit of improved quality of life and longevity.

In order to reap the desired benefits from VCT the Public Health concept needs to be promoted such that people attend VCT for the primary purpose of protecting oneself or others from infection. Marketing VCT as a potential source of further information and not necessarily a testing tool may help encourage earlier contact for information that can aid in the decision-making
process and/or adoption of safer behaviour even without testing (UNAIDS, 2000b). Some participants in the Ugandan study (Kipp, Kabagambe and Konde-Lule, 2002) did mention the need for counselling without having to take an HIV test.

10.5.2 Influence of counselling

The influence of counselling will depend a great deal on how the counselling is conducted, whether didactic or client-centred (Solomon et al., 2004, Kamb et al., 1998). Findings from the current study suggest that the counselling provided in the study area leans more towards a didactic form in that little time was spent on defining and addressing the clients’ problems and risk behaviours. The procedure of the counselling itself followed the laid down protocol as reflected in participants’ reports on the content of the counselling and testing session, that is, assurance of confidentiality, informed voluntary consent, and assessment of readiness to receive their result.

It is difficult to unravel the influence of counselling as distinct from testing. The design of the current study (see section 5.8.2) meant that people were interviewed post counselling and testing. Therefore, their responses may have been influenced by either. Most studies have assessed the effectiveness of counselling and testing together, rather than counselling or testing alone (Holtgrave and McGuire, 2007). The RESPECT study (Kamb et al., 1998) conducted in the USA (see section 2.5.4) showed that counselling with testing achieved better results than testing with information-provision. As noted by Holtgrave and McGuire (2007) it would not be ethically possible to replicate such a study now since the RESPECT study provided a standard of care in HIV counselling which would have to be the minimum provided for any participant in an intervention trial. It would be possible though to assess the
immediate effects of counselling alone in areas where rapid HIV testing is not being practised since counselling and receipt of HIV results do not occur on the same day. Mattson (2002) conducted such a study and investigated the impact of HIV test counselling on college students’ perceptions of risk and disease severity, and risk behaviours on a large South Western University in the USA. Counselling had no effect on perceptions of disease severity but, as in the current study, increased perceptions of susceptibility encouraging adoption of safer sexual behaviour.

In the current study counselling provided an enhanced understanding of HIV/AIDS issues pertaining to transmission, prevention and treatment (cf Coyle, Knapp and O'Dea, 1996). This was beneficial in: enhancing appreciation of risk; allaying anxiety about receipt of a positive result; and encouraging the sharing of information about HIV/AIDS and VCT with family, friends and colleagues. However, as evidenced by the reported rationales for testing negative, understanding of transmission was still not sufficient even after counselling. This suggests the need for continued education post counselling.

Allaying anxiety about testing prepared people to receive the result whatever it would be (cf Maman et al., 2001). Counselling provided people with the opportunity to reflect on their past behaviour, their probability of infection and their future. The process empowered people with knowledge that enabled them to consolidate or conceptualise plans of how to cope with a positive result or to safeguard a negative status. Being asked to verbalise these plans seemed to provide some measure of confidence in their ability to cope with whatever result they would get (cf Meursing and Sibindi, 2000).
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Even though people presented to a VCT centre with a request to be tested for HIV, actually involving them in the decision on the timing of the test and receipt of results gave them the perception of control over what can and cannot be done (cf Coyle, Knapp and O'Dea, 1996). Involving people in making decisions about their care, especially in an environment where health personnel are considered as the ultimate authority on health matters and expected to dictate what will be done and when, may help VCT be more effective. Research on compliance has shown that people who are involved in the decision-making process are more likely to follow guidelines and advice (Cameron, 1996). Conversely, people that feel threatened by feelings of lack of control in the patient-provider interaction may seek to gain control by means that counter the intended goals of the interaction. In a study examining factors underlying anxiety in HIV testing, Worthington and Myers (2003) found that people who felt a lack of control in the test interaction with providers, experienced higher levels of anxiety and employed various techniques to enhance feelings of control including withholding information which may be useful for the development of risk reduction plans. Therefore, enhancing feelings of control in the VCT interaction may promote openness in discussing risk factors and adherence, indeed concordance with health promotion messages.

10.5.3 Influence of testing

In common with other studies receipt of the negative result was associated with reduced anxiety (Jacobsen, Perry and Hirsch, 1990, Flowers, Duncan and Knussen, 2003, Siegel et al., 1989, Lupton, McCarthy and Chapman, 1995). Knowledge of HIV status with the resultant resolution of uncertainty and anxiety empowered people to take control of their lives and health and make plans and decisions about their future. The negative result was seen as
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providing a ‘clean slate’ (cf Flowers, Duncan and Knussen, 2003, Lupton, McCarthy and Chapman, 1995) with the opportunity to start afresh and resolve not to put oneself in a position that would recreate the anxiety and necessitate further testing (cf Lupton, McCarthy and Chapman, 1995, Coyle, Knapp and O'Dea, 1996).

Earl and Albarracin (2007), in their meta-analysis of the short and long term outcomes of HIV-prevention interventions, discuss the hypothetical effects of resolving fear through HIV counselling and testing. They hypothesise that when a person’s fear of testing, with the possibility of testing positive, is resolved by the receipt of a negative result they are more likely to pay attention to recommendations that will enable them to maintain this positive affect: “the positive affect induced by this fear resolution may increase the motivation to never experience the fear again, thus reducing risky behaviours and increasing associated knowledge”. Their findings of significant decreases in self-perception of risk and increases in both knowledge and use of condoms post HIV counselling and testing compared to fear-inducing arguments supported this hypothesis.

The current study suggests that the test experience for an HIV-negative person:

1. Is a life event (defined as an “event that changes somebody’s status: an event such as marriage, birth of a child, or disability ...” (Encarta®, 2009)
2. Stimulates positive emotions that people wish to hold onto
3. Improves attention to health promotion information
VCT may therefore provide a ‘teachable moment’ for enhancing and influencing behaviour (Jacobsen, Perry and Hirsch, 1990). A ‘teachable moment’, although not adequately developed as a concept “has been intuitively accepted as an important focus for both clinicians and researchers interested in promoting health and wellness” (Lawson and Flocke, 2009). Lawson and Flocke (2009) conducted a systematic review in an attempt to define the ‘teachable moment’. They identified three categories in which the term is usually used: unpredictable opportunities that may arise in an interpersonal interaction; specific events or contexts that provide conditions conducive to change; and cueing events which increase perception of risk and negative or positive outcome expectations, produce a strong emotional response, and constitute a life event. Kamb and colleagues noted that “timing may be an important element for intervention success; it is possible that individuals who seek STD testing and treatment are particularly amenable to behaviour change” (Kamb et al., 1998). Therefore, the post-test counselling session appears to be an ideal time to discuss and enhance knowledge and understanding about HIV, consolidating resolve and encouraging maintenance and implementation of safer sexual behaviour.

**10.5.4 Risk perception post-VCT**

The literature review (section 2.4), highlighted concerns that a negative result may result in increased risky behaviour (Fernyak et al., 2002, Solomon et al., 1996, Sherr et al., 2007, Matovu et al., 2007, Minga et al., 2005). Generally, in this study, perceptions of risk after VCT increased or remained at the pre-test level. This is encouraging and has important implications for the implementation or maintenance of safer sexual behaviour post-testing. A reduction in level of perceived risk would portend an inclination towards performing the risk behaviours that come to be considered as ‘not so risky
after all’. Post-test focus group participants in the Ryder et al study (2005) (see section 3.2.1) reported that the negative test result had confirmed that their previous behaviour was low risk thereby encouraging them to continue the same risk behaviour, ultimately resulting in sero-conversion. Perceptions of vulnerability may be lowered by receipt of a negative result. The study by Ickovics et al (1998), on the long term effects of counselling and testing for women, found lowered perceptions of vulnerability post-testing. The authors suggest this may be due to the negative test result reinforcing belief in the effectiveness of protective measures and self-efficacy based on effectiveness of previous behaviours.

**ARVs and perception of risk post-testing**

The current study provides worrying evidence of lowered perception of risk and disease severity post-testing due to the availability of ARVs. Some people were prepared to, and did engage in risky behaviour (post-testing) because they were aware of the availability of medication that can be taken to ameliorate the effects of the disease. This finding echoes that of Dilley et al (1997) in their study, in MSM, on advances in treatment and changing views about high-risk sex in the USA. Although most people in their study did not reduce their level of perception of risk even with the advent of new treatments, twenty-six percent (14/54) were “less concerned about becoming HIV positive” and thirteen percent agreed that they were “willing to take a chance of getting infected when having sex”. These findings are consistent with the findings from the systematic review by Crepaz, Hart and Marks (2004) (see section 2.4). This is an unfortunate consequence of the observed benefits of ARVs which can be countered by providing balanced information and education on the benefits and implications of antiretroviral therapy in the counselling session and IEC materials (Crepaz, Hart and Marks, 2004).
10.5.5 Risk behaviour post-VCT

People seeking VCT may be more motivated to change behaviour than those that don’t attend or are referred by a health worker (see Solomon et al., 2004, Watts et al., Unpublished, Weinhardt et al., 1999). As reported in section 2.5.4, the Higgins et al (1991) systematic review concluded that risk reduction may have been due to factors associated with the decision to test and to receive results rather than the counselling and testing. The findings from this study support this conjecture. The decision making process and decisions taken pre-test appear to have played a central role in risk behaviour and behaviour post-test. Voluntary counselling and testing appeared to be just one among other strategies that most people used in their pursuit of control over their own health and well being.

The most commonly reported post-test behavioural intentions were faithfulness and abstinence. This is similar to findings from studies in Zambia, Namibia, Kenya and Uganda (Kelly, 1993, Rimal, Creel and Keulder, 2006, Muller et al., 1992, Arthur et al., 2007). These behaviours entail reduction in number of sexual partners breaking up sexual networks and effectively reducing transmission as evidenced by the Ugandan experience (USAID, 2002c, Kirby, 2008).

Similar to findings from other sub-Saharan countries (National Research Council (U.S.), 1996) condoms were not a popular option in the current study. Most of the people who planned to use condoms planned to use them as an interim measure before knowing their partner’s HIV status when they would use faithfulness as their preventive strategy. Unlike an Australian study (Lupton, McCarthy and Chapman, 1995) and a study in New York (Siegel et al., 1989) avoidance of condoms was not reported as an explicit
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reason for testing. Testing for the purpose of avoiding condom use is a safe strategy so long as both partners have tested negative (taking into account the window period) and practice mutual fidelity. However, for some people in stable relationships monogamy may be providing a sense of false security which may hold them back from testing or practising safer sex (de Zoysa, Sweat and Denison, 1996, Solomon et al., 2004). The prevalent negative attitude to condom use needs to be addressed by appropriate community and individual level interventions.

The assumption that counselling and testing initiates behaviour change has been challenged by inconsistent findings of the effectiveness of VCT for primary prevention. This has led to suggestions that people attending VCT may have already changed behaviour with the result that change cannot be demonstrated post-test. The current study shows that most people who had a history of higher risk behaviour at various time periods in their past had adopted safer behaviour in the six months or more prior to making the decision to test. For such people, the enhanced understanding provided by the counselling served to consolidate their previous behaviour whereas the negative result with its connotation of ‘a new lease of life’ provided impetus and resolve to maintain their negative status. Therefore, rather than being a catalyst for behaviour change, VCT was, for most, a boost to previously adopted behaviour. This finding is corroborated by findings from longitudinal studies which have shown that risk reduction took place in gay communities before HIV counselling and testing became widely available (Doll et al., 1990, Wiktor et al., 1990). Doll et al (1990) suggest that other motivating factors such as frequent access to risk-reduction information, and watching one’s friends become ill and die may provide sufficient impetus for
behavioural change. Macintyre, Brown and Sosler (2001) also suggest that visibility may play a more central role in encouraging behaviour change. Modelling data from three demographic and health surveys from Uganda, Kenya and Zambia to predict behaviour change, they found that personal experience of AIDS was a significant predictor of behaviour change in Zambia and Uganda. It was marginally significant in Kenya. Findings from the current study support this supposition and so do those of Palekar et al (2008) who found an association between knowing someone who had died of AIDS and condom use in South African youth.

Challenges to behaviour change

Both women and men faced gender specific challenges to implementing safer behaviours. Part of the reason for the low acceptability of condoms as a preventive measure was the widespread view that condoms are not 100 percent safe, are for prostitutes and encourage promiscuity. Issues of trust and faithfulness then come into play constraining people from suggesting or insisting on the use of condoms since this might be seen as a sign of unfaithfulness, promiscuity or lack of trust (Morrill et al., 1996, de Zoysa, Sweat and Denison, 1996, Taegtmeyer et al., 2006).

Women faced problems related to their subordinate status in relation to men and their economic dependence on men (St Lawrence, Eldridge and Brasfield, 1998, de Zoysa, Sweat and Denison, 1996). Young men faced problems related to the pressure to conform to socially constructed perceptions of what it means to be a ‘man’ (Selikow et al., 2009, Ndubani and Hojer, 2001, Foreman, 2000).
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Culture and religion further contrive to disenfranchise women. Due to cultural constraints most women in the current study did not venture to suggest the use of condoms in their relationships (cf Taegtmeyer et al., 2006, Lupton, McCarthy and Chapman, 1995). Other factors such as self-efficacy and relationship status may also be determinants of initiation and maintenance of safer behaviour in women. Morrill et al (1996) found that women in more committed relationships were less likely to adopt safer sexual behaviours presumably because they felt they could trust their partners.

The majority of the study’s interviewees were self-confessed Christians but, overall, Christianity appeared not to influence sexual risk behaviour. This is similar to the findings of two other African studies. Masatu et al (2009) investigating the predictors of risky behaviour among adolescents in Tanzania, found that Christian adolescents engaged in more risky sexual behaviour than non-Christian adolescents, a difference they could not explain. Similarly, a study in Zambia, by Agha, Hutchinson and Kusanthan (2006), found no association between religious affiliation and sexual risk behaviour in young women aged 13-20 years. Although they found that affiliation with conservative religious groups, Seventh Day Adventists, Jehovah’s Witness and New Apostolic Church, was associated with delayed sexual initiation this was cancelled by the lowered likelihood of condom use at first sex in the same group. Motivations for not initiating sexual intercourse and not using a condom at first intercourse were different depending on affiliation. Seventh Day Adventists reported non initiation of sex due to fear of pregnancy and the desire to complete schooling while Jehovah’s Witnesses reported the fear of God as the reason for non initiation
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of sex. Seventh Day Adventists did not use a condom during first sexual intercourse due to lack of awareness, access to and skill in using condoms. Jehovah’s Witnesses reported religious or partner related reasons for not using a condom at first intercourse.

The findings on the influence of peer pressure on risk behaviour mirror those of Selikow et al (2009) from focus group discussions with young adolescents in Cape Town, South Africa. Young people in particular have the desire to conform to peer norms and this may put them at risk of HIV infection as reflected in the myths about young men and sex reported in the current study (see section 7.2.1, p228) (cf Kalunde, 1997, Longfield, Cramer and Sachingongu, 2003). These myths highlight what may be low levels of comprehensive understanding of HIV/AIDS and sexuality especially in the young.

Alcohol has been associated with reduced self control and increased risky sexual behaviour (National Research Council (U.S.), 1996, Kalichman et al., 2007). Participants in the current study acknowledged this association (cf Hingson et al., 1990) and reported intentions of abstaining from alcohol. Novel approaches to motivate young people to drink responsibly should improve self control and decrease risky behaviour.

10.5.6 Testing behaviour post-VCT
Fifteen out of the 31 participants did not return as requested for the confirmatory test at three months post-test. This test is important to rule out false negative results due to testing in the window period when antibodies to the virus may not be at a level high enough to give a positive result. Failure to confirm the result, with a history of risky behaviour in the three months
prior to testing, may lead to false beliefs of a negative status and exposure of others to risk of infection if positive.

A study exploring the reasons for seeking an HIV test, conducted by Lupton and colleagues (1995) in Sydney, Australia, found that although people said they understood that the first test was not definitive they rarely returned for the confirmatory test. The authors suggest this may be due to the fact that people were testing to confirm a negative status and therefore did not feel the need to return for a re-test (Lupton, McCarthy and Chapman, 1995). Findings from the current study resonate with those of Lupton et al (1995). A few people appeared to understand the window period and did not return because they surmised that the first test was done after the prescribed three month period since their last risky sexual contact and they were therefore definitely negative. However, it may be that some people did not return because they did not wish to have the negative result overturned at subsequent testing and preferred to go with the results of the first test, a proposition supported by the fact that most of those who returned for their confirmatory test had originally been expectant of a negative result.

Alternatively, it may be a sign of poor understanding of the ‘window period’ concept. This problem can be addressed by the provision of adequate post-test information both verbal and written and by active follow-up and engagement of tested people in post-test activities, as suggested by many study participants (see section 9.4.1).

10.6 Felt needs of people after testing HIV negative

People may have intentions of adopting safer behaviour but fail to do so (Ogden, 2007). An understanding of why they fail to do so is essential for the identification of which behaviour change constructs would best aid the
development of interventions that could help move them through this intention-behaviour gap. Others may be able to implement desired change but with some difficulty and may require some form of support to ensure maintenance of behaviour change. The current study provides insight into why intentions to practice safer sex may not be implemented and perceived support needs of HIV-negative people.

Few studies have examined the felt needs of HIV-negative people. A UNAIDS report on the impact of VCT presents a table entitled “care needs following VCT” listing findings from studies on main concerns of those testing negative as opposed to needs. Among the listed concerns are: safer sex and staying negative, future fertility, sharing result with partner, continuing risk of exposure, and caring for relatives (UNAIDS, 2001b: Box 12, p36). These do not shed light on what HIV-negative people need in order for them to address the listed concerns.

10.6.1 Support groups, further knowledge and community outreach
A qualitative study from Uganda (Kipp, Kabagambe and Konde-Lule, 2002) offers some insight into the actual felt needs of users of VCT services. Focus group participants in this study reported the need for further counselling sessions to encourage behaviour change. The felt needs reported in the current study are in line with this finding. Continued contact to remind people about the need to stay safe and the desire for further HIV/AIDS knowledge were recurrent themes. Additional counselling sessions, as they are currently offered, do not appear to be what is required as reflected by the poor return rates for the confirmatory VCT session. Judging by the suggestions put forward for additional support, it would appear that more informal and interactive interactions with an element of sensitising others to
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the dangers of HIV/AIDS and the benefits of testing would be preferred. Baggaley et al, (quoted in UNAIDS, 2001b) found that, in Lusaka, Zambia, only six percent of HIV-negative people returned for further post-test counselling. When interviewed, people said they had found other informal sources of support in the community. Incentives may also need to be provided to get people to attend and participate in certain activities. Training in the basics of HIV/AIDS transmission, prevention and treatment, and involvement in HIV/AIDS prevention activities may provide sufficient incentive to retain people in post-test activities such as support groups. The AIDS Information Centre in Uganda has recorded success with a “Post Test Club” that draws its membership from tested people who, after learning more about HIV/AIDS, go out encouraging others to go for VCT using various IEC strategies. Moses, a member of the Post Test Club, had decided to join the club after he tested negative “in order to get more complete and accurate information about HIV/AIDS, and to encourage people who might be living with the same fear he had, to come forward and be tested” (USAID, 2002b). However, careful consideration and evaluation of the potential stigma-potentiating effects of support groups or post test clubs composed solely of those testing negative, as suggested by participants in the current study, has to be undertaken.

Mobile health technology

The high return rate for follow-up interviews in the current study was made possible by the availability of mobile ‘phones. Almost all the participants had a mobile ‘phone and these were used to set up appointments and remind participants about the appointment closer to the agreed date and time. Such widespread availability provides an opportunity for novel ways of providing ongoing support and education to encourage implementation and
maintenance of safer sexual behaviour. Mobile health technology (mHealth) offers exciting new avenues for reaching out to people and encouraging them to adhere to disease prevention advice or treatment. Project Masiluleke, a South African project, working with MTN\(^{20}\) uses “a form of text messaging similar to sms” encouraging recipients to telephone the national AIDS hotline with the aim of increasing HIV test uptake. The project has been well received and response is said to be “spectacular” (Economist.com, 2009). Similar interventions have proved to be successful elsewhere, in weight loss programmes (Patrick et al., 2009) and smoking cessation (Rodgers et al., 2005).

10.6.2 Life-skills training

There is a need for life-skills training such as communication and negotiation skills for both women and men. Women more than men find it difficult to negotiate safer sex options with their partners and to get their partners to test. How to maintain a negative status in an environment where a man dictates how sex will be practised and with the possibility that a once faithful man may become unfaithful is an ongoing concern for women who test negative (Were, 2002, De Zoysa et al., 1995). Intervention programmes need to recognise that many women may be at risk due to the behaviour of their partners. Programmes need to be targeted at empowering women, educating both women and men, changing attitudes about cultural and religious beliefs and practices that put women at risk and providing social and structural support to facilitate change (De Zoysa et al., 1995). Churches may have an important role in facilitating change.

\(^{20}\) Mobile Telephone Networks – a large cellular network provider in South Africa
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The recent adoption of a resolution by the United Nations (UN) General Assembly to support the creation of a new agency to specifically deal with the rights and needs of women world-wide is a welcome development and will serve to focus and coordinate efforts for the mitigation of the effects of HIV/AIDS on women, especially in developing countries where women carry a disproportionate burden of the epidemic, both as carers and people living with HIV/AIDS (see UN News service, 2009).

10.6.3 Education-entertainment

Edutainment, “a form of entertainment designed to educate as well as to amuse” (Wikipedia, 2009), has been shown to be successful in influencing sexual behaviour in Zambia, South Africa and other developing countries (Yoder, Hornik and Chirwa, 1996, Singhal et al., 2002, Bertrand et al., 2006). Successful examples include the following:

Soul City, a multi-media intervention with specific interventions for specific age groups produced and broadcast in South Africa and other countries in southern Africa (Singhal et al., 2002), has been shown to be successful in influencing attitudes and behaviour. An impact evaluation conducted by the Soul City Institute found that exposure to Soul City intervention materials improved knowledge about HIV/AIDS and anti-retroviral therapy, increased condom use, increased HIV test uptake and encouraged reduction in number of sexual partners. Cross sectional studies were conducted in all the countries that had implemented Soul City programmes using stratified cluster samples from both urban and rural areas. Multivariate analysis was conducted to take into account confounding effects of socio-demographics and other media (Soul City, 2008).
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Whizzkids United programme, a brainchild of Africaid, an HIV/AIDS children’s trust registered in the UK and South Africa, teaches children 12 – 15 years old the life skills needed to help protect them against HIV using football. The programme is currently running in South Africa, Ghana and Uganda and there are plans to launch it in seventy-two High schools in the UK in 2009, and in either Zambia or Botswana. External evaluation of the programme is yet to be conducted (The Africaid Trust, 2009). A programme along these lines would neatly resolve the need for involvement, recreation, knowledge and skills training among the youth and young adults. Older adults could also benefit by being involved in the running of such programmes and mentoring.

World Vision International\textsuperscript{21} run a similar programme in one of the study sites (Chililabombwe) providing HIV/AIDS education with football, training youth peer educators, running support groups for people who had tested for HIV and providing other recreational facilities at their VCT testing site. These activities proved to be quite popular with adolescents and young adults. The programme could not continue due to withdrawal of donor support when the project to which the programme was affiliated came to an end (P. Sichalwe, personal communication, 2006).

10.7 Linking back to theory

To explain the relationship between the HIV-test decision making process, VCT, receipt of a negative result, and subsequent risk behaviour and felt needs, I have used the conceptual framework of VCT intervention components and outcomes proposed by Denison (2008) (see Fig 1.1, p18). This framework posits that counselling and knowledge of HIV status

\textsuperscript{21} A Christian relief, development and advocacy organisation
provide motivation for individuals to adopt safer behaviour that will prevent transmission of the virus by influencing knowledge of HIV risk reduction, attitudes, and beliefs.

Although findings from some in the current study are consistent with this framework, generally the findings depart from this framework at two points. Firstly, the current study suggests that the decision to test is in most cases made before attending VCT, since VCT appears to be perceived as “testing for HIV”, counselling serves to confirm this decision as having been the right decision to make and the person therefore tests. Secondly, reduction in risk behaviours and adoption of safer behaviours, in most people, seems to have occurred prior to counselling and testing. The fact that decision making at both levels — to test and to reduce risk behaviour — appears to occur mostly pre-VCT has important implications for the provision of VCT services. If most people are presenting when they have already adopted safer behaviour and are knowledgeable about HIV/AIDS transmission and prevention then the time required for pre-test counselling could be reduced and more time spent on post-test counselling when most HIV-negative people may be better able to engage with the counsellor. In addition, provision of appropriate health education and health promotion interventions in the community may improve understanding thus influencing behaviour change and testing behaviour leading to increased VCT uptake and effectiveness, and reducing the need for prolonged pre-test counselling. This suggestion is supported by findings from the current study whereby a few people, who appeared to have gained an adequate understanding of HIV/AIDS, felt that HIV counselling was not necessary. Kipp et al (2001), documented similar findings in a study on the impact of counselling and testing in a rural area in
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Uganda. Time spent on pre-test counselling would be tailored to the client’s information needs as assessed by appropriately trained counsellors. The revised framework adapted for those testing HIV-negative and incorporating the conceptual framework used to explain the findings of the current study (Fig 6.1, p220), is as shown in Fig 10.4. The concepts in circles and italicized words in the boxes reflect the modifications.
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Figure 10.4: HIV-test decision-making process & VCT components & outcomes for those testing HIV-negative

Interactive community IEC programmes

Recognition of risk

Emotional and cognitive engagement

Risk reduction

Decision to seek testing

Pre-test counselling:
The test process, Risk prevention
Implications of testing
Risk assessment, Coping strategies

Confirm decision to test/decision
to test & informed consent
↑Knowledge, ↑Understanding,
↑Self-efficacy, ↓Anxiety,
↑Perception of risk (added text)

Yes, HIV test is performed

Post-test counselling
Test result given, risk reduction reinforced, discussion
about disclosure, discussion about onward referral

Individual psycho-social outcomes: Empowered & in control, ↓Anxiety, ↑wellbeing,
impetus and resolve to maintain or

Relational level outcomes:
Disclosure to/sensitisation of sexual partners, family, friends & colleagues, partner testing

Community level outcomes:
Disclosure to/sensitisation of communities, reduce stigma, ↑demand for CT

Individual behavioural outcomes: Maintain/implement safer sexual practices and behaviour.

Reduced HIV/STD transmission
Improved health
Reduced unintended pregnancies
Reduced HIV transmission to infants

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10.8 Conclusion

This study provides useful insight into the interaction between attendance for HIV voluntary counselling, testing, receipt of a negative result and self-reported risk behaviour in a Zambian population. Useful information on the felt support needs of an underserved and understudied group is also provided. Such understanding is essential for the enhancement of VCT services.

The conduct of interviews by a health professional in a health care setting and immediately following VCT may have resulted in the generation of data that was unduly influenced by these factors. To mitigate the effects of these factors, careful attention was paid to the establishment and maintenance of rapport and analytical interpretation of the interview data.

An in-depth exploration and understanding of the decision-making processes and behaviour over time was facilitated by the qualitative longitudinal design. The multiperspective approach provided potentially useful information for the improvement of services.

The validity and reliability of self-reports of sexual behaviour change has been questioned, however, studies have shown that such reports may be reliable if careful attention is paid to the methods of data collection.

Currently available behaviour change theories failed to provide an adequate framework for the explanation of the study findings.

Inferred negativity and perception of risk based on perceived prevalence are hindrances to recognition of susceptibility — which is widely recognised as a pre-requisite to testing — that have received little attention in the literature.
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Health promotion activities targeted at the community may not provide sufficient information to enhance understanding and motivate testing. Poor understanding of HIV/AIDS and the benefits of testing appeared to contribute to the delay in attending VCT. Provision of interactive community-based opportunities to learn about HIV/AIDS may better facilitate understanding and earlier testing.

VCT is generally considered a pre-requisite to behaviour change. This is contrary to the experience of most of the participants in this study who reported changing their behaviour before attending for VCT. It has been suggested that studies investigating the effectiveness of VCT may have failed to show a positive result because individuals may have been practising safer behaviour before testing. However, this is an understudied area.

The findings of this study and those of a Ugandan and another Zambian study suggest that VCT is generally viewed as a diagnostic opportunity rather than a learning opportunity. This may be an unintended consequence of the VCT marketing strategy which encourages people to go for VCT to know their status.

Since the test experience, for most, constituted a life event, stimulated positive emotions and improved attention to health education messages it may provide a “teachable moment” for enhancing and influencing behaviour change decisions.

As suggested by other studies, access to risk-reduction information, personal experience of AIDS and the pre-test decision-making process appear to have played a central role in risk behaviour pre- and post-test.
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In line with findings from a study in Uganda, continued contact with the counselling service and the desire for further HIV/AIDS knowledge were recurrent themes. Programmes designed to educate and entertain, “edutainment”, would be an ideal solution for the younger participants’ need for recreational activities.
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11.1 Conclusions

In the literature review little evidence was found that voluntary counselling and testing (VCT) was effective in changing or challenging the behaviour of people who had tested negative. Knowledge of how VCT influences behaviour and knowledge about the needs of people recently tested HIV-negative was also found to be limited. To address this, people who had tested negative at VCT were interviewed immediately after their first VCT session, after they had received their test result, and around six months thereafter, to elicit their perspectives on HIV counselling and testing, any expressed planned or actual behaviour change, and any suggestions to improve the process from their perspective. Serial qualitative interviews were used to capture any change in behaviour over time, and so that a relationship could be built up which might promote open disclosure (Murray et al., 2009). Focus groups of counsellors were also held to gain their perspectives on the process of VCT, and their suggested improvements.

At initial interviews, most participants reported that before they attended for VCT they had already adopted safe or safer sexual behaviour and close to half of these reported changing their behaviour in response to their own assessment and perception of risk. This finding was so important as VCT, as an HIV prevention tool, has consistently been constructed as a trigger to behaviour change. It was decided to formulate a new study aim to add to the two prior aims. The aims thus were:

1) To gain an understanding of the decision making process that precedes VCT attendance and its role in moderating the influence of VCT on subsequent sexual behaviour
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2) To gain the perspectives of people who are HIV negative on how voluntary counselling and a negative result influence their attitudes, intentions and subsequent sexual behaviour

3) To gain the perspectives of people who are HIV negative on support systems and networks that would enhance their ability to remain HIV negative

The information gathered in this study allows an understanding of the experiences of people testing negative in a specific urban Zambian setting. It is recognised that these findings are specific to a group who have self referred to a VCT centre, and who have tested negative. It is also recognised that there will be a further set of influencing factors for those who test positive, nevertheless the findings may be useful to inform changes to VCT services to make them more accessible to people at risk of having HIV, and more effective at encouraging a behaviour change to minimise HIV risk. This chapter presents the conclusions and recommendations drawn from the findings and discussion.

This study thus concludes that in this sample of HIV-negative people:

1) The majority appeared to have made life changes before attending VCT and used VCT to know their status. Rather than initiating safer sex choices, the process of counselling and testing affirmed these choices and appeared to consolidate resolves to remain negative. HIV testing and receipt of a negative result may constitute a life-changing event, potentially a “teachable moment”. For a number of people, it may well be an opportune time for a particular focus on reinforcement and affirmation of the safer sex choices that they have earlier started
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to embrace. It is also recognised that for others the teachable moment may provide an opportunity to influence subsequent sexual risk behaviour.

2) VCT was primarily perceived and used as a diagnostic tool (similar to the way the screening of blood at blood banks was used for knowing one’s HIV status when the HIV test first became available in the USA and Uganda (UNAIDS, 1999b, Kalichman, 1998).

3) Understanding about HIV and AIDS, especially related to HIV transmission, remained inadequate in spite of the counselling and high levels of knowledge about HIV and AIDS.

4) Even though the community based information, education and communication (IEC) programme was passive, with limited participant or community involvement, the programme still had an impact on decision making. There was demand for a more interactive programme.

5) There was a felt need for a more comprehensive HIV/AIDS information and behavioural support strategy that goes beyond the VCT encounter (both before and after), and a felt need to share the HIV/AIDS knowledge that had been acquired, with others within the immediate social network and wider community.

6) There was no clear post-test support “package” for those testing HIV-negative, in comparison with those testing positive.
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7) Young people, especially those out of school and unemployed, expressed a need for recreational activities to take up the time that they might otherwise fill with activities that may expose them to risk of HIV infection such as frequenting bars and drinking alcohol.

8) The current behavioural change models do not fully explain the staged changes in behaviour and decision making before, during and after VCT in this study.

11.2 Recommendations

The Zambian Ministry of Health, through the Permanent Secretary, granted permission to proceed with this study with the mandate to disseminate findings to all the relevant stakeholders (see appendix 8). The implications of the study findings for HIV counselling and testing policy, VCT services and practice, training, and research are as follows:

11.2.1 Implications for HIV counselling and testing policy

Recommendations are targeted at various levels in the health service:

1. National policy guidance should promote VCT as a component of a comprehensive package of diagnosis, care and support, not only for HIV-positive people but also for HIV-negative people. VCT should be provided within an accessible environment of interactive community-based and community-led IEC programmes. Referral systems to well-organised, relevant, evidence based post-test support services for the provision of foregoing and ongoing preventive counselling and other intellectual, emotional, social and psychological support should be developed (see Piot et al., 2008).
2. The National AIDS Council (NAC) should facilitate the availability of and ensure adequate IEC materials, especially leaflets and brochures, in all common local languages, which should be offered to all clients post test, both positive and negative. Innovative delivery of IEC and motivational messages by mobile telephones should be piloted.


4. The national level should review and then provide guidance on appropriate training, support and incentives to be offered to community volunteers (both those working in HIV specific or integrated programmes) to avoid disparities across the country. The provision of these will provide motivation and assist retention.

5. The national policy addressing equity and gender sensitivity should be expanded to provide more detailed guidance on combating the socio-cultural norms and practices related to gender roles and responsibilities that put both women and men at risk of HIV infection. As these norms and practices are reinforced by both men and women, the proposed guidance must be inclusive and integrated (see Berer, 1996, Ottawa Charter for Health Promotion, 1986).

6. The provincial level should coordinate the design and development of appropriate information, education and communication (IEC) materials (provinces are generally composed of people of similar traditional and
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Producing these materials at this level takes advantage of economies of scale and is in the interests of ensuring consistency and quality. As there is a great need for more materials specifically targeting the needs of those testing negative, the materials should address issues of particular relevance to those testing negative, such as transmission and prevention of HIV, the window period and the need or not of a repeat test. Myths and misconceptions identified by various studies should be addressed in these materials to complement the counselling and reinforce delivered messages. These materials should be developed in collaboration with the target population and rigorously evaluated before mass production and distribution.

7. Provincial level monitoring and evaluation indicators could include VCT-process quality indicators to encourage the development and implementation of VCT-process quality procedures.

8. District Health Management Teams (DHMTs), the private sector, non-governmental organisations (NGOs), faith based organisations (FBOs) and community based organisations (CBOs) providing HIV prevention services, should involve community members in the identification, design, development, implementation, and monitoring and evaluation of interactive community based HIV IEC strategies (see Chopra and Ford, 2005, The Nairobi Call to Action, 2009, Ottawa Charter for Health Promotion, 1986). This will relieve the burden on the health system, encourage community ownership and promote sustainability, and early uptake of the services. Communities may be those in defined residential areas, schools, churches, workplaces or any other socially, culturally or economically defined group of people (see WHO, 2004). Such an
approach should cover some of the information gap between knowledge gained from the mass media IEC campaigns and the understanding required to change behaviour and accept testing. Persisting knowledge gaps post counselling and testing can also be addressed by the community IEC programme. This approach has previously been proposed by Kipp, Kabagambe and Konde-Lule (2001) and Woodcock, Stenner and Ingham (1992) (see section 10.4.2, p360). It has been suggested that personal experience of the effects of HIV/AIDS facilitates behaviour change (see section 10.5.5, p374). Therefore, correcting misconceptions and improving understanding of HIV/AIDS should work synergistically with such an environmental context to encourage the adoption of safer behaviour and testing for HIV. In addition, improving understanding prior to attending VCT may lessen the time required for counselling thus increasing throughput while improving effectiveness and reducing cost (see UNAIDS, 2000b).

9. DHMTs, the private sector, NGOs, FBOs and CBOs should develop VCT-process quality assurance procedures based on guidelines provided by NAC to ensure, among other requirements, adherence to the principals of client-centred counselling.

11.2.2 Implications for VCT services and practice

This study further recommends that:

1. VCT should emphasise counselling more than testing. Counselling and testing should be de-linked in the public’s mind to correct the misconception that VCT equates only to HIV testing. Materials marketing VCT should be designed to encourage attendance at VCT which should
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*always* provide information and should only provide the HIV test *if* then considered necessary and desired by the individual person.

2. There should be a reorientation of information-giving and counselling. The amount of time spent on providing basic information on HIV/AIDS in the pre-test counselling could be reduced and more time spent on risk identification and risk reduction planning with goal setting inclusive of the need or not of a confirmatory test if the client tests negative. Most people in the current study appeared to be already quite knowledgeable about HIV and AIDS and were practising safer sex. Counsellors would need to assess the client’s information needs and misconceptions and proceed accordingly (this is supposed to be the current practice according to the training provided and the VCT guidelines). There is need for counsellors to appreciate that the purpose of counselling is primarily to empower people to be responsible for their own health and requires a client-centred approach. The post-test session should concentrate on preventive counselling.

3. Group counselling should be emphasised as an option in VCT sensitisation materials and when conducting VCT sensitisation sessions, taking care to emphasise that if the client is tested, the test result will be given individually and in confidence (see UNAIDS, 1999b). Interaction within the group may be more effective (and more cost-efficient) than individual counselling in enhancing understanding (cf Ickovics et al., 1994), and thus should be an option where practical. Personal risk identification and risk reduction planning may then be done in a shorter one-to-one pre-test counselling session before blood is drawn for the HIV test (NAC, 2006d), and confirmed in the post-test counselling session.
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4. Exploration of innovative options for the provision of counselling (and sometimes testing) at times and locations that will ease accessibility for as many as possible should be considered. The provision of counselling in the community or in health facilities by community volunteers may facilitate accessibility and acceptability.

5. Pilot studies to assess provision of follow-up prevention counselling sessions as a component of a more comprehensive preventive health visit, to encourage re-attendance should be considered. The follow-up visit may include screening, advice and referral for common medical conditions such as hypertension, diabetes mellitus and obesity.

11.2.3 Implications for training

1. The national level should facilitate and ensure continued education of counsellors. This may be done by requiring annual re-certification of counsellors based on a continuing education points system similar to the one in place for medical practitioners.

2. National church leaders should be informed of the importance of overcoming various cultural aspects of sexual behaviour that are both against their religious teachings and which encourage the spread of HIV. The churches can have a much greater role in encouraging voluntary counselling and referring for testing, and supporting behaviour change in the community.

3. DHMTs, the private sector, NGOs, FBOs and CBOs should prioritise the retraining of counsellors. The dynamic nature of HIV/AIDS knowledge requires continuing education to keep up to date with developments in the field thereby enhancing the ability to provide appropriate information
and assistance to VCT clients. Continuing education is also necessary for counsellors to further improve their counselling skills.

4. DHMTs, the private sector, NGOs, FBOs and CBOs need to scale up recruitment and training of volunteer community peer educators and counsellors. The success of a community-based IEC programme will depend on adequately trained and motivated community volunteers. Volunteers should primarily be recruited from among those attending VCT as they may be a more motivated group. The community volunteers should be supervised by health workers at the closest health care facility.

5. Training of psychosocial counsellors should emphasise the purpose of counselling and be directed at imparting skills in client-centred counselling to facilitate an interaction that is more relevant to the client’s risk profile and needs. The need for such an approach was highlighted in the current study by the relative non-relevance of currently advocated and propagated prevention advice for married women who had no control over their own sexuality. This may explain why these women were attending VCT primarily to access ARVs as it had little else to offer them.

11.2.4 Implications for research

1. The finding that many people self-referring for VCT, and who subsequently test negative, have already started to change behaviour should be tested in other settings. This study focussed exclusively on people self-referring to a health facility affiliated VCT centre. Clients attending VCT may be either referred by a health-worker, self-referred or actively recruited (see Obermeyer and Osborn, 2007). The motivation behind the decision to test may be different in the different groups and
Chapter 11 – Conclusions and recommendations

this may change behaviour, as found in the current study, both before and after VCT. One may consider that those actively recruited such as during community testing campaigns, door-to-door services and health facility visits technically voluntarily accept VCT, but may have had less time to change behaviour before testing. People may accept VCT when approached directly because of various factors other than that it is something they really want to do. In a study on informed consent, in a peri-natal HIV transmission study, Abdool Karim et al (1998) found that more than 80% of the women had consented to testing because they felt compelled to do so.

To test the validity of this finding of behaviour change prior to the VCT, the dynamics of the decision making process, perception and experience of VCT, behaviour pre-test and behaviour post-test of people self-referring and those referred or actively recruited for VCT should be explored. Such a study should utilise serial interviews to assess the decision making process and behaviour pre-test, prior to counselling and testing, so as to obtain reports that are not influenced by the potential modifying effects of counselling, and knowledge of status.

2. To address the context specific influences present in this study, similar research should be conducted by researchers that have a different professional background and interviews could be conducted in other settings such as people’s homes.

3. Trials, randomised or cluster randomised where possible, of post-test intervention strategies, such as post-test clubs, IEC materials, support groups, mobile health technology and ‘edutainment’ (see section 10.6.3) should be done. Such studies should focus on the delivery of the
Chapter 11 – Conclusions and recommendations

necessarily complex intervention and on maintenance of the HIV-negative status over a prolonged period.

4. Trial and evaluation of individual versus group counselling to assess acceptability, feasibility and cost effectiveness should be carried out.

5. Studies should be conducted, especially in sub-Saharan Africa, an area where close to sixty percent of those living with HIV are women (UNAIDS, 2008a), to investigate further the HIV-test decision-making process of women to determine barriers, facilitators and potential solutions (see Ransom et al., 2005).

6. The phenomenon of inferred negativity (see section 10.4.2, p352) should be investigated further as it may be a reason for non-testing and continued exposure to risk. The epidemiological description of this phenomenon would determine its prevalence and distribution ascertaining, firstly, whether it is indeed a problem and secondly, which particular groups of people would benefit from a targeted intervention.

7. The extent and consequences of treatment optimism in Zambia, considering that some people in this study appeared to have a reduced perception of the severity of HIV infection due to the availability of antiretroviral drugs, should be investigated.
Chapter 11 – Conclusions and recommendations

11.2.5 Summary of the main recommendations

Table 11.1: Main recommendations

<table>
<thead>
<tr>
<th>AREA</th>
<th>RECOMMENDATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Policy</td>
<td>The components of VCT should be promoted as parts of the comprehensive package of care and support that extends from before attending for the actual moment of “VCT” to post counselling and testing for both HIV-negative and HIV-positive people.</td>
</tr>
<tr>
<td></td>
<td>IEC materials specifically targeted at HIV-negative people should be made readily available in all VCT facilities and offered to all who test negative.</td>
</tr>
<tr>
<td></td>
<td>The training, support and retention strategies for community volunteers for an expanded interactive community-based IEC programme should be standardised.</td>
</tr>
<tr>
<td></td>
<td>Social policies and a legal framework that will underpin interventions aimed at supporting young people to better avoid infection and addressing equity and gender issues should be put in place.</td>
</tr>
<tr>
<td>2. Service and practice</td>
<td>Counselling and testing should be de-linked in the public’s mind encouraging earlier attendance for counselling, and testing only if desired.</td>
</tr>
<tr>
<td></td>
<td>VCT should be reoriented to provide relatively more prevention counselling than information giving. The information provided should be tailored to the individual client’s needs.</td>
</tr>
<tr>
<td></td>
<td>VCT should be an integral component of an interactive community-based IEC programme. Such an approach would enhance knowledge acquisition and understanding before attendance for VCT and should facilitate earlier testing and behaviour change. Group or individual counselling, without testing, could be provided in the community and referral to testing sites offered.</td>
</tr>
<tr>
<td></td>
<td>Community-based interactive IEC strategies must be designed and implemented in collaboration with target communities and should use people that have attended VCT as a human resource pool for volunteers.</td>
</tr>
</tbody>
</table>
Chapter 11 – Conclusions and recommendations

| 3. Training                                                                 | Continued education of counsellors should be prioritised and enforced to ensure that all counsellors are kept abreast of developments in HIV/AIDS and counselling.
|                                                                            | Recruitment and training of community peer-educator and counsellor volunteers should be scaled up to provide additional human resources for an expanded interactive community-based IEC programme.
|                                                                            | A forum should be provided for the regular updating of church leaders on research findings that have a bearing on their religious teaching on sexual behaviour.

| 4. Research                                                                 | The validity of the finding that most people, in this study, presenting for VCT have already started to change behaviour should be investigated. The dynamics of behaviour change pre- and post-testing should be explored in diverse groups, VCT models and settings.
|                                                                            | Trials should be considered to compare the acceptability and cost-effectiveness of individual versus group counselling.
|                                                                            | Randomised or cluster randomised trials of post-test intervention strategies such as sms ‘phone messaging should be conducted.

VCT services are playing a valuable role in HIV prevention. However, the capacity of VCT to influence behaviour has not been exploited to its full potential. Providing VCT within a comprehensive package of care that takes into account the information needs of the pre-counselling, the counselling and post counselling and testing stage should create an opportunity for enhancing VCT effectiveness. If adapted as described above, VCT could create opportunities for earlier testing and earlier enhancement or implementation of behaviour change (see Coates, Richter and Caceres, 2008).

... it could be that the question that needs to be explored ... is not so much whether VCT is effective for primary or secondary prevention in African contexts, but rather, under what specific conditions it is effective. (Solomon et al., 2004)
References

12 References


References


References


References


References


References


References


References


References


References


References


References


References


References


References


References


References


References


References

References


References


References


Richards, H. & Emslie, C. (2000). The 'doctor' or the 'girl from the University'? Considering the influence of professional roles on qualitative interviewing. *Family Practice*. 17(1), 71-75.


Saldana, J. (2003). Longitudinal qualitative research: analyzing change through time, Walnut Creek, California, USA, AltaMira Press.


References


References


Thompson, C. (1999). If you could just provide me with a sample: examining sampling in qualitative and quantitative research papers. Evidence Based Nursing. 2(3), 68-70.


References


References


References


References


References


References


13 Appendixes

13.1 Appendix 1: Systematic literature review search strategies

Medline, EMBASE, Global Health, PsychINFO (Ovid platform)
1. HIV.mp. or exp HIV-1/
2. VCT.mp.
3. "voluntary counsel?ing and testing".mp.
4. ("C&T" or "counsel?ing and testing").mp. [mp=title, original title, abstract, name of substance word, subject heading word]
5. "test counsel?ing".mp.
7. 6 or 4 or 3 or 2 or 5
8. 1 and 7
9. (HIV adj5 VCT).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
10. ((HIV adj5 C&T) or (HIV adj5 (counsel?ing and testing))) or (HIV adj5 (voluntary counsel?ing and testing))).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
11. ((HIV adj5 "test counsel?ing") or (HIV adj5 "risk reduction counsel?ing")).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
12. 11 or 10 or 9
13. exp Sexual Behavior/ or sexual behaviour.mp.
14. exp Health Behavior/ or Risk-Taking/ or "behavio?r change".mp. or Behavior/
15. sexual partner?.mp. or exp Sexual Partners/
16. Unsafe Sex/ or Extramarital Relations/ or extramarital partner?.mp.
17. Prostitution/ or sex worker.mp.
18. *Condoms/ut [Utilization]
19. Sexual Abstinence.mp. or Sexual Abstinence/
20. monogamy.mp.
21. (monogamy or "faithful$ adj5 partner").mp. [mp=title, original title, abstract, name of substance word, subject heading word]
22. (abstain$ adj5 sex$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
23. (risk adj5 behavio?r).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
24. (sex$ adj5 behavio?r).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
Appendixes

25. (behavio?r$ adj5 modif$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
26. (behavio?r$ adj5 chang$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
27. 26 or 24 or 20 or 25 or 16 or 19 or 14 or 13 or 21 or 17 or 23 or 22 or 15 or 18
28. 8 or 12
29. 27 and 28

CINAHL, IBSS (EBSCO platform)

S5 and S6

S6  S3 or S4
S5  S1 or S2
S4  TX "unprotected sex"
S3  TX behavio* n3 chang* or behavio* n3 modif* or sexual n3 behaviour or sexual n3 behavior or sexual partners or multiple partners or concurrent partners or safe sex or safer sex or risky n3 behavio* or sex* near3 abstain* or condom
S2  TX hiv n3 "risk reduction counselling" or "HIV test counseling" or "HIV test counselling"
S1  TX HIV N3 VCT or "HIV C&T" or ( "HIV counseling and testing" ) or ( "hiv voluntary counseling and testing" ) or ( "HIV counselling and testing" ) or ( "hiv voluntary counselling and testing" ) or HIV n3 C&T or ( HIV N3 "VOLUNTARY COUNSELLING AND TESTING" ) or ( HIV N3 "VOLUNTARY COUNSELING AND TESTING" ) or ( HIV N3 "counseling and testing" ) or ( HIV N3 "counselling and testing" ) or hiv n3 "risk reduction counseling"

WoS

<table>
<thead>
<tr>
<th>#3</th>
<th>#2 AND #1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Topic=(&quot;behavio* same change&quot; or &quot;behavio* same modif*&quot; or &quot;sexual behavio*$r&quot; or &quot;sexual risk behavio*$r&quot; or &quot;sex* same partner*$&quot; or &quot;condom same use&quot; or &quot;sexual abstinence&quot; or &quot;risk behavio*$r&quot; or &quot;risk taking&quot; or &quot;safe$ sex&quot; or &quot;multiple partners&quot; or &quot;concurrent partners&quot; or monogamy or &quot;unprotected sex&quot; or &quot;protected sex&quot;)</td>
<td>#2</td>
</tr>
<tr>
<td>Topic=((HIV AND CT) OR (HIV counsel$ing and testing) OR (HIV voluntary council$ing and testing) OR (HIV and &quot;risk reduction counsel$ing&quot;) OR &quot;HIV test counsel$ing&quot;)</td>
<td>#1</td>
</tr>
</tbody>
</table>
Appendixes
Cochrane Database of Systematic Reviews and Database of Abstracts of Reviews of Effects
“HIV counselling and testing” AND “HIV prevention”

Digital Dissertations
HIV AND (risky sexual behaviour OR sexual behaviour)
### Appendix 2: Quality assessment tool

**QUALITY ASSESSMENT TOOL**

<table>
<thead>
<tr>
<th>Ref ID:</th>
<th>Author:</th>
<th>Year: ______________</th>
</tr>
</thead>
</table>

#### A) REPORTING

(Q1) Is the hypothesis/aim/objective of the study clearly described?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

(Q2) Are the main outcomes to be measured clearly described in the introduction or methods section?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

(Q3) Are the characteristics of the subjects included in the study clearly described?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

(Q4) Is the intervention clearly described?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

(Q5) Are the main findings of the study clearly described?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

(Q6) Have the characteristics of subjects lost to follow-up been described?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

#### B) SAMPLING

(Q1) Is the method of sampling described?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

(Q2) Are the individuals selected to participate in the study likely to be representative of the target population?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

(Q3) What percentage of selected individuals agreed to participate?

- 80 - 100%
- 60 – 79%
- Less than 60%
- Not Reported
- Not Applicable

(Q4) Have the characteristics of those who refused to participate been described?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>
C) ALLOCATION BIAS
Study Design

RCT  Quasi-Experimental  Qualitative  Case-control, Before/After study,  
(go to i) (go to D) (go to D) No control group, or Other:________  
(go to D)

(i) Is the method of random allocation stated?
    Yes  No

(ii) If the method of random allocation is stated is it appropriate?
    Yes  No

(iii) Was the method of random allocation reported as concealed?
    Yes  No

D) CONFOUNDERS
(Q1) Prior to the intervention were there between group differences for important  
confounders reported in the paper?
    Yes  No

Relevant Confounders reported in the study:
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

(Q2) If there were differences between groups for important confounders, were  
they adequately managed in the analysis?
    Yes  No

(Q3) Were there important confounders not reported in the paper?
    Yes  No

Relevant Confounders NOT reported in the study:
_____________________________________________________________________
_____________________________________________________________________

E) BLINDING
(Q1) Was (were) the outcome assessor(s) blinded to the intervention or exposure  
status of participants?
    Yes  No  Not Reported  Not Applicable

F) WITHDRAWALS AND DROP-OUTS
(Q1) Indicate the percentage of participants completing the study.
    80 -100%  60 - 79%  Less than 60%  Not Reported  Not Applicable
Appendixes

G) ANALYSIS
(Q1) Is there a sample size calculation, power calculation or description of methods used to analyse the data?
   Yes    No
(Q2) Is there a statistically significant difference between groups?
   Yes    No    Not Reported
(Q3) Are the statistical or data management methods appropriate?
   Yes    No    Not Reported

H) INTERVENTION INTEGRITY
(Q1) What percentage of participants received the allocated intervention of interest?
   80 -100%   60 - 79%   Less than 60%   Not Reported   Not Applicable
(Q2) Was the intervention measured in the same way in all groups?
   Yes    No    Not reported    Not Applicable

Comments
____________________________________________________________________________________
____________________________________________________________________________________

I) DOES THE STUDY MAKE A USEFUL CONTRIBUTION TO UNDERSTANDING THE REVIEW QUESTION?
   Yes    No

## Appendix 3: Data extraction form

**Data extraction form**

<table>
<thead>
<tr>
<th>Ref No.</th>
<th>Author/Yr/ Source</th>
<th>Title/ Country/ Study Site</th>
<th>Aim</th>
<th>Target Pop/Age Range</th>
<th>Incl Criteria</th>
<th>Excl Criteria</th>
<th>Recruitment Procedures (including Participation rate)</th>
<th>HIV-/HIV+ No. in Interv Arm</th>
<th>No. in Control Arm</th>
<th>?Comparable Baseline Measures</th>
<th>Outcome Measures</th>
<th>Analysis Results</th>
<th>Study Recommendations</th>
</tr>
</thead>
</table>


### Appendix 4: Reasons for excluding studies

#### Primary reason(s) for exclusion of studies

<table>
<thead>
<tr>
<th>No</th>
<th>Author</th>
<th>Study country</th>
<th>Main reason for exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>(Arthur et al., 2007)</td>
<td>Kenya</td>
<td>Did not identify VCT mediating factors. Focus – impact of VCT on behaviour. Did not discuss results by serostatus</td>
</tr>
<tr>
<td>2</td>
<td>(Bentley et al., 1998)</td>
<td>India</td>
<td>Did not identify VCT mediating factors. Did not analyse data by serostatus</td>
</tr>
<tr>
<td>3</td>
<td>(Christianson, Lados and Johansson, 2007)</td>
<td>Sweden</td>
<td>Did not identify VCT mediating factors. No information on C&amp;T format. Wrong focus – reasons for testing</td>
</tr>
<tr>
<td>4</td>
<td>(Corbett et al., 2007)</td>
<td>Zimbabwe</td>
<td>Did not identify VCT mediating factors.</td>
</tr>
<tr>
<td>5</td>
<td>(Denison et al., 2008)</td>
<td>Various</td>
<td>Meta-analysis – did not identify VCT mediating factors</td>
</tr>
<tr>
<td>6</td>
<td>(DiFranceisco et al., 2005)</td>
<td>USA</td>
<td>Did not identify VCT mediating factors. Focus – condom use post-testing</td>
</tr>
<tr>
<td>7</td>
<td>(Elwy et al., 2002)</td>
<td>N/A</td>
<td>Systematic review - did not discuss VCT mediating factors</td>
</tr>
<tr>
<td>8</td>
<td>(Exner et al., 2002)</td>
<td>USA</td>
<td>Did not identify VCT mediating factors.</td>
</tr>
<tr>
<td>9</td>
<td>(Gresenguet et al., 2002)</td>
<td>Central African Republic</td>
<td>Did not identify VCT mediating factors</td>
</tr>
<tr>
<td>10</td>
<td>(Holtgrave and McGuire, 2007)</td>
<td>Various</td>
<td>Review of evidence for effectiveness of VCT</td>
</tr>
<tr>
<td>11</td>
<td>(Ickovics et al., 1994)</td>
<td>USA</td>
<td>Study conducted in 1991/92</td>
</tr>
<tr>
<td>12</td>
<td>(Ickovics et al., 1998)</td>
<td>USA</td>
<td>Study conducted in 1991/92</td>
</tr>
<tr>
<td>13</td>
<td>(Kalichman and Simbayi, 2003)</td>
<td>South Africa</td>
<td>Study assessing attitude to testing</td>
</tr>
<tr>
<td>14</td>
<td>(Kamb et al., 1998)</td>
<td>USA</td>
<td>Did not identify VCT mediating factors</td>
</tr>
<tr>
<td>15</td>
<td>(Kwachai et al., 2004)</td>
<td>Thailand</td>
<td>Did not identify VCT mediating factors</td>
</tr>
<tr>
<td>16</td>
<td>(Kipp, Kabagambe and Konde-Lule, 2001)</td>
<td>Uganda</td>
<td>Did not identify VCT mediating factors. Cross-sectional study</td>
</tr>
<tr>
<td>Appendixes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17 (Matambo et al., 2006)</td>
<td>Zimbabwe</td>
<td>Wrong focus – need for repeat test</td>
<td></td>
</tr>
<tr>
<td>18 (Matovu et al., 2007)</td>
<td>Uganda</td>
<td>Did not identify VCT mediating factors</td>
<td></td>
</tr>
<tr>
<td>19 (Matovu et al., 2005)</td>
<td>Uganda</td>
<td>Did not identify VCT mediating factors</td>
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</tr>
<tr>
<td>20 (Merson, Dayton and O'Reilly, 2000)</td>
<td>Developing countries</td>
<td>Review of HIV prevention interventions Did not discuss VCT mediating factors</td>
<td></td>
</tr>
<tr>
<td>21 (Metcalf et al., 2005)</td>
<td>USA</td>
<td>Did not identify VCT mediating factors</td>
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</tr>
<tr>
<td>22 (Morrill et al., 1996)</td>
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<td>Did not identify VCT mediating factors Focus – determining predictors of behavioural change</td>
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<tr>
<td>23 (Ryder et al., 2005)</td>
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<td>Cross-sectional Focus – repeat testing</td>
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</tr>
<tr>
<td>24 (Sherr et al., 2007)</td>
<td>Zimbabwe</td>
<td>Did not identify VCT mediating factors</td>
<td></td>
</tr>
<tr>
<td>25 (St Lawrence, Eldridge and Brasfield, 1998)</td>
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<td>Cross-sectional study Did not identify VCT mediating factors</td>
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<tr>
<td>26 (The Voluntary HIV-1 Counselling and Testing Efficacy Study Group, 2000)</td>
<td>Kenya Tanzania Trinidad</td>
<td>Did not identify VCT mediating factors</td>
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<tr>
<td>27 (Watts et al., Unpublished)</td>
<td>Malawi</td>
<td>Did not identify VCT mediating factors</td>
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<td>28 (Weinhardt et al., 1999)</td>
<td>Various</td>
<td>Meta-analytic review Did not identify VCT mediating factors</td>
<td></td>
</tr>
<tr>
<td>29 (Wiktor et al., 2004)</td>
<td>Cote d'Ivoire</td>
<td>Not CDC VCT model</td>
<td></td>
</tr>
<tr>
<td>30 (Wolitski et al., 1997)</td>
<td>Various</td>
<td>Systematic review - did not discuss VCT mediating factors</td>
<td></td>
</tr>
<tr>
<td>31 (Xu et al., 2002)</td>
<td>Thailand</td>
<td>Did not identify VCT mediating factors</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix 5: KCM CT data collection form

#### CT Data Form

<table>
<thead>
<tr>
<th>Activity Number:</th>
<th>VCT Counsellor:</th>
<th>District:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>VCT ID No:</th>
<th>Testing Centre:</th>
<th>Company:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>CHAMP VCT Card No:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Test used for training purposes
- Workplace
- Community
- Married
- Single-Not disclosed
- Single-Widower
- Single-divorced
- Single-Never married
- Abbot Determine 1&2
- Gonio II
- Unigold
- Other

#### Employment status:
- Employed - FT
- Employed - PT
- Seasonal Worker
- Self-employed
- Student
- Unemployed

- Industry
  - Agriculture
  - Commerce
  - Education
  - Energy
  - Finance
  - Healthcare
  - Insurance
  - Manufacturing
  - Mining
  - NGO
  - Tourism
  - Trading
  - Transport
  - Not disclosed

#### If employed, Job/Position

#### Type of VCT:
- Couple
- New
- Old
- Multiple Partners:
  - Yes
  - No

#### Reason for visit:
- Sick
- Partner HIV Positive
- ANC / Pregnant
- Just to make sure
- Just to know
- Partner tested and advised
- Worried about partners behaviour
- Planning to get married
- Planning to have baby
- Other

#### Location:
- Urban
- Rural

#### Post test:
- Result available same day
- Attended post-test counseling
- Result collected
- Referred to post-test service

#### Test result:
- Positive
- Negative
- Indeterminate
- No Result

#### Referred to:
- Hospital
- Faith-based organisation
- District clinic
- Rural Health Centre
- NGO
- Other

#### Signature of counsellor:

---

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13.6 Appendix 6: University of Edinburgh REC consent

The University of Edinburgh
School of Health in Social Science

SCHOOL OF HEALTH IN SOCIAL SCIENCE

APPROVAL BY RESEARCH ETHICS COMMITTEE

<table>
<thead>
<tr>
<th>Name/s of Researcher/s:</th>
<th>Janet P Banda Sikasote</th>
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<tbody>
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<td></td>
<td></td>
</tr>
<tr>
<td>Proposed Title of Research:</td>
<td>Factors influencing behaviour change in HIV negative individuals in an urban mining area in Zambia</td>
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<tr>
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<td></td>
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The above research proposal has been approved by the School of Health in Social Science Research Ethics Committee.

Signed: .................................. (Kath M Melia)

Date: .................................
13.7 Appendix 7: University of Zambia REC consent

THE UNIVERSITY OF ZAMBIA
RESEARCH ETHICS COMMITTEE

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

Assurance No. FWA00000338
IRB00001131 of 1ORG0000774

18 October, 2007
Ref.: 020-06-07

Dr Janet P. Banda Sikasote
Division of Community Health Sciences: General Practice
University of Edinburgh
20 West Richmond Street
Edinburgh EH8 9DX

Dear Dr Sikasote,

RE: RESEARCH PROPOSAL ENTITLED: “FACTORS INFLUENCING BEHAVIOUR CHANGE IN HIV NEGATIVE INDIVIDUALS IN AN URBAN MINING AREA IN ZAMBIA”

The above research proposal was presented to the Research Ethics Committee meeting held on 7 June, 2007 where changes were recommended. We would like to acknowledge receipt of the corrected version with clarifications. The proposal has now been approved.

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).

Yours sincerely,

[Signature]

Dr E. Munafula-Nkandu
CHAIRPERSON

Date of approval: 18 October, 2007 Date of expiry: 17 October, 2008
Appendix 8: Ministry of Health authorisation letter

14th September, 2007

Dr. Scott A. Murray
University of Edinburgh
20 West Richmond Street
Edinburgh EH8 9DX

Dear Dr. Murray,

RE: AUTHORITY FOR DR. JANET P. BANDA SIKA SOTE TO CONDUCT Ph.D FIELD WORK IN SELECTED PUBLIC HEALTH FACILITIES

The letter serves to grant Dr. Janet P. Banda Sikasote, permission to conduct her Ph.D field work in selected public health facilities.

The aim of this study: “to determine the influence on sexual behaviour of an HIV negative test result given in the context of VCT, in order to inform the development of a model to enhance post-test behaviour change strategies”, is indeed important and in line with the current Ministry of Health strategy to provide quality health services on HIV/AIDS prevention and control.

In this regard it will be important that findings of this study are effectively communicated to all stakeholders so that they inform policy and action.

Please ensure that the student obtains necessary ethical clearance from the University of Zambia Ethics Committee.

Let me also emphasize on the need for Dr. Janet P. Banda Sikasote to consult and work through the relevant provincial and district health offices when conducting her field work in the facilities.

I wish her success in her studies

Dr. S. K. Miti
Permanent Secretary
MINISTRY OF HEALTH

All correspondence should be addressed to the
Permanent Secretary
Telephone: +260 1 2530415
Fax: +260 1 253344
Appendix 9: Interview pro-forma

HIV/AIDS Prevention study

Demographics pro-forma (Interview participants)  No:_______

Age (at last birthday):  ______years  Sex: M/F

Marital status:  Single/Married/Divorced/Widowed/Separated

Religion:  Catholic  Baptist
          Pentecostal  Jehovah’s Witness
          SDA  Methodist
          Evangelical  CMML
          UCZ  Salvation Army
          Other___________________

Educational level:  Primary/Secondary/Tertiary/None

Occupation:____________________________________

D.O.E:___/___/___  Permanent/Temporary/Contract
Appendixes

HIV/AIDS Prevention study

Demographics pro-forma (Focus group participants)  No:_____

Age (at last birthday): _______years  Sex: M/F

Marital status:  Single/Married/Divorced/Widowed/Separated

Religion:  Catholic  Baptist
          Pentecostal  Jehovah’s Witness
          SDA  Methodist
          Evangelical  CMML
          UCZ  Salvation Army
          Other_________________

Educational level: Secondary/Tertiary

Occupation/Position:____________________________________

Counselling experience: _______Years _______Months

Average number VCT counselling sessions: ______ per month _______per week

Experience of VCT as client: Yes/No  HIV status known: Yes/No
13.10 Appendix 10: Initial interview schedule

Interview Schedule
You went through the process of thinking about, then deciding to come and finally coming for VCT and getting the test done and now you know your result and you have your future in front of you. I would really appreciate it if you would share with me as freely and as honestly as you can what it has been like for you, going through all this, and what your plans for the future are. You will be doing most of the talking since it is your experiences and plans that I would like to learn more about.

1. I know it is not easy to come for VCT, so how did you start thinking about coming and what finally made you come?
   - Clarify perception of HIV prevention programmes terms and words used by participant e.g. Voluntary, Counselling, Testing, Window period, HIV/AIDS, Risky behaviour, Safe sex, Positive living, ARVs/ART (This will be done throughout the interview whenever the participant uses such terminology for the first time)
   - Explicate underlying reason(s) for testing
     - What prompted contemplation, role of HIV/AIDS prevention messages
     - Duration of contemplation
     - What prompted the visit
     - When did they decide they would actually have the test done – before counselling or convinced during counselling session
     - Determine influence of availability of ARVs on decision
     - Perception of risk of contracting HIV relative to their sexual practices (Ask about sexual practices if information is not volunteered)

2. You’ve come out of the VCT session with a negative result, what are your feelings about the result and were you expecting it?
   - Establish reaction and attitude to result
     - ?disbelief
     - ?Relief
     - ?Expected
   - Why do they think they have escaped infection, influence of religion
   - Determine appreciation of non-conclusiveness of test at this time – need for re-testing/confirmation
Appendixes

3. What effect do you think the negative result will have in your life?
   - Future plans
     - Sexual behaviour changes, influence of religion
     - Self-efficacy
     - Perceived support/assistance required
     - Share result, why/why not
     - Influence of ARVs availability

4. I’ve always found changing old habits to be very hard, how easy do you think it will be, for you to change your sexual habits? (If there is a need to change)
   - determine underlying reasons for answer given and perceptions influencing the reasoning

5. Have you heard or seen any HIV/AIDS prevention messages on TV, radio, billboards or read any pamphlets or leaflets?

6. How useful or how helpful have you found these messages?
   - Feelings and perceptions about HIV/AIDS prevention messages
     - helpful in making decisions – to test, to change
     - threatening
     - pressure to test
     - Deficiencies

7. What do you know about treatment for HIV/AIDS? (If ARVs have not come up already in the discussion)
   - Of all the things you have told me today, is there anything you would have done or would do differently if there was no treatment for HIV/AIDS?
   - determine perceptions about ARVs, prevention, cure

8. How helpful or useful has the Voluntary Counselling and Testing session been for you today and do you think the experience and what you have learnt from it will help you in doing all the things you’re planning to do?
   - Perceptions about VCT
   - Areas of improvement

Summarise discussion

9. Is there anything else that we have not discussed that you feel might be important?
Appendices

13.11 Appendix 11: Follow-up interview schedule

Interview schedule
Thank you so much for coming back for this discussion, I really appreciate your commitment to the study. Our last discussion was very helpful and I am looking forward to learning more from you.

1) What has life been like for you in the last six months or so after the first test compared to before the test?
2) Can you just tell me again what made you decide to come for an HIV test?
3) How did you feel getting the negative result?
4) How helpful would the second visit and test be or do you feel it is unnecessary?
5) Why do you think you are still negative?
6) What were your plans for the future following the test?
7) What has been your experience with putting these plans into action?
8) What changes would you have liked to make but couldn’t? Why? Experience of influencing partners’ behaviour? (Coming for test and safer sexual practices) Lacking skills?
9) What have you found to be of help in putting your plans into action? Is there anything else that you think might have helped you to put your plans into action? Would follow-up or support help, if so how could that best be done?
10) In what way has knowing your status influenced decisions you’ve made in the last six months?
11) What is your understanding of; (i) safe sex? (ii) unsafe sex?
12) What do you consider to be a risk for acquiring HIV infection? (Pre-test / post-test)
13) What risks have you been exposed to in the last six months?
14) Which risks do you consider to be more dangerous than others? (Pre-test / post-test)
15) What risks are you (i) prepared to take? (ii) not prepared to take? (Pre-test / post-test)
16) Which risks would you be prepared to take if there were no ARVs? (Refer back to comments on ARVs in first interview)
17) What messages would you like to see on condoms? (How do you feel about condoms?)
Appendixes

18) Has your understanding of risk changed in any way since you were first tested?
19) Do you think being married protects you from acquiring HIV? Why / why not?
20) Now I would like you to look back at the entire counselling and testing process, in what way or ways do you feel that things could have been done better or differently?
21) If you were given a choice between a blood test and a saliva test for HIV, which one would you prefer? Any particular reason why you would rather have that type of test?
22) What do you think of the following methods of getting your HIV test done if they were available in the future;
   (i) test yourself with a kit at home
   (ii) have a test done on demand followed by counselling if you want it
   (iii) go to a VCT centre and be counselled and tested as per the current practice
23) In what way if any have you, personally, found the HIV prevention messages on radio, TV, posters or in pamphlets, leaflets or magazines to be helpful to you in the past six months?
24) How do you think these messages can be made more useful for an HIV negative person?

Summarise discussion

25) Is there anything else you would like to say or ask?

Clarify inconsistencies between this and previous interview. Provide transcript for verification.
INTERVIEW PARTICIPANT INFORMATION SHEET - HIV/AIDS PREVENTION STUDY

My name is Janet Sikasote, I am a specialist in Public Health. I am inviting you to participate in this research study.

Before deciding whether or not to take part, please take time to read the following information. This information will help you to understand what your participation will involve.

Please feel free to ask if there is anything that is not clear or if you would like more information.

What is the purpose of the study?
In order to provide effective HIV/AIDS prevention services we need to know how well the current services are performing and how we can improve them.

Why am I being invited to participate?
I need to talk to people like you, who have gone through the Voluntary Counselling and Testing process. Sharing your experience of this process and life after knowing your HIV status will be very useful in helping me identify which areas require improvement and the type of improvement required.

What will I have to do and how long will it take?
If you do decide to take part in the study you will be asked to sign a consent form. This is to show that you understand what the study is about and what it involves and that you have agreed to take part.

I will ask you to take part in two discussions with me. These discussions will be recorded in order to provide an accurate record. The recording will be securely stored for 5 years after which it will be completely destroyed. The first discussion will be today and will take about an hour.

The second will be 6 months after the first one and will take about one hour.
Below is a timeline of all these activities:

Today

1. Reading information sheet, understanding study & involvement
2. Sign consent form
3. 1st discussion Will take about 1hr
4. 2nd discussion Will take about 1hr

(Repeat HIV test at 3 mths)

These discussions may involve sensitive personal questions about your sexual life. You do not have to answer these questions, but it would be very helpful if you would.

You do not have to take part in this study and if you decide not to, your rights to health care services will not be affected in any way.

Privacy and confidentiality procedures
Any information provided in these discussions will be kept strictly confidential and will only be viewed by myself and my supervisors at the University. It will not be revealed to anyone else without your written permission.

Your name or any other identifying feature will not appear on any discussion records. No individual taking part in the study will be identified in any publication or presentation of the findings.

What are my rights in this study?
If you take part in the study:
1. You have the right to refuse to answer any question that you do not wish to answer
2. You have the right to review the write-up of the discussion if you wish to do so
3. You have the right to withdraw from the study at any time
4. You have the right to a summary of the finalised study findings

Researcher’s Name: Dr Janet P.B. Sikasote

Signature: _______________ Date: __/__/__

Contact details:
Cell phone No: 0977 771451
Address: P.O Box 210367, Chililabombwe

For any ethical queries please contact:
The University of Zambia
Research Ethics Committee
Ridgeway Campus
P. O. Box 50110
Lusaka.
Telephone: 260-1-256067
E-mail: unzarec@zamtel.zm
FOCUS GROUP PARTICIPANT INFORMATION SHEET

HIV/AIDS PREVENTION STUDY

My name is Janet Sikasote, I am a specialist in Public Health. I am inviting you to participate in this research study.

Before deciding whether or not to take part, please take time to read the following study information. This information will help you to understand what your participation will involve.

Please feel free to contact me at the address or telephone number on the last page, if there is anything that is not clear or if you would like more information.

What is the purpose of the study?
In order to provide effective HIV/AIDS prevention services we need to know how well the current services are performing and how we can improve them.

Interviews have been held with clients who have undergone voluntary counselling and testing and tested negative, to try and gain an understanding of what kind of influence VCT has on the perceptions and attitudes to behaviour related to HIV transmission and determine the existence of any unmet needs for clients testing HIV negative.

Why am I being invited to participate?
I need to talk to people like you, who are providing Voluntary Counselling and Testing services. Sharing your experience of and views on this service and on the findings from the interviews will be very useful in identifying areas that require improvement, the type of improvement required and its feasibility.

What will I have to do and how long it will take
If you do decide to take part in the study you will be required to sign the attached consent form and send it back to me by ___/___/___. This is to show that you understand what the study is about and what it involves and that you have agreed to take part. I will follow you up with one phone call or visit if I do not get the signed consent form by the date mentioned above.

You will take part in a focus group discussion with 5 – 9 other counsellors and facilitated by myself. These discussions will be recorded in order to provide an
accurate record. The recording will be securely stored for 5 years after which it will be completely destroyed.

The focus group discussion will take place on ___/___/___ at ______________ ________________________________ from 14:00 hrs to approximately 16:00 hrs.

These discussions may involve sensitive topics. You do not have to contribute on these if they make you uncomfortable, but it would be very helpful if you would.

You do not have to take part in this study and if you decide not to, your rights and privileges as a counsellor and health services user will not be affected in any way.

Privacy and confidentiality procedures
Any information provided in these discussions will be kept strictly confidential and will only be viewed by myself, my supervisors and the other members of the focus group. It will not be revealed to anyone else without your written permission.

Your name or any other identifying feature will not appear on any discussion records. No individual taking part in the study will be identified in any publication or presentation of the findings.

What are my rights in this study?
If you take part in the study:
5. You have the right to refuse to answer or comment on any question
   6. You have the right to review the write-up of the discussion if you wish to do so
   7. You have the right to withdraw from the study at any time
8. You have the right to a summary of the finalised study findings

Researcher’s Name: JANET P.B. SIKASOTE  Researcher’s Signature:_________
Contact Details: 35 Kamenza Way, P.O.Box 210367, Chililabombwe
Mobile: 0977 771451
Date:  /  /
INFORMED CONSENT FORM

HIV/AIDS Prevention Study

Site: ______________________  Patient identification number: ______

Name of researcher:  Dr Janet Sikasote

1. I confirm that I have been given and have read and understood the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights to health care services being affected in any way.

3. I agree to the discussion being recorded and I understand that I will be given an opportunity to review the write-up if I so wish. I understand that the recordings will be erased after 5 years.

4. I understand that this study requires my participation in two discussions which are 6 months apart.

5. I understand that the researcher will hold all information and data collected from this interview and from my VCT records in confidence, and that all efforts will be made to ensure that I cannot be identified as a participant in the study. I give permission for the researcher to hold and have access to relevant personal data.

6. I agree to take part in the above study.

________________________    ______________________          ______________
Name of participant       Signature/Thumb print       Date

_________________________    ______________________          ______________
Name of researcher        Signature                     Date
## INFORMED CONSENT FORM

**HIV/AIDS Prevention Study**

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1. I confirm that I have been given and have read and understood the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights to health care services being affected in any way.

3. I agree to the discussion being recorded and I understand that I will be given an opportunity to review the write-up if I so wish. I understand that the recordings will be erased after 5 years.

4. I understand that the researcher will hold all information and data collected from this interview and from my VCT records in confidence, and that all efforts will be made to ensure that I cannot be identified as a participant in the study. I give permission for the researcher to hold and have access to relevant personal data.

5. I agree to take part in the above study.

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Appendixes

3. Focus group discussions

INFORMED CONSENT FORM

HIV/AIDS Prevention Study – Focus Group Participants

Site: ______________________  Counsellor identification number: ______

Name of researcher:       Dr Janet Sikasote

1. I confirm that I have been given and have read and understood the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights and privileges as a counsellor and to health care services being affected in any way.

3. I agree to the discussion being recorded and I understand that I will be given an opportunity to review the write-up if I so wish.

4. I understand that this study requires my participation in a focus group discussion on the ----/---/----.

5. I understand that the researcher will hold all information and data collected from this discussion in confidence, and that all efforts will be made to ensure that I cannot be identified as a participant in the study. I give permission for the researcher to hold and have access to relevant personal data.

6. I agree to take part in the above study.

________________________  ______________________  ______________
Name of participant        Signature                     Date

________________________  ______________________  ______________
Name of researcher          Signature                     Date
Appendixes

4. Photograph consent form

I, Dr Janet P Banda Sikasote would like to use a photographic image of you in the write-up of the HIV prevention study that I am conducting.

Please note that your name will not be published with the images.

I need your permission to take/use any photographs of you.

Please complete this form and sign below.

I _________________________________ give my permission to Dr Janet P. Banda Sikasote to take photographs of me and use them in the study write-up.

Signature: __________________________ Date: __________________________
13.14 Appendix 14: List of initial themes and notes

1. Themes/Notes
   Organised according to areas of interest;

1. Contemplation/Action triggers
   – Personal illness
   – Personal contact with infected/sick relatives or friends
   – Sensitisation materials and programmes
   – Personal or partners’ risky behaviour

2. Perception of /Feelings about VCT
   – Personal choice
   – Testing for HIV
   – To know health status
   – Gives courage to test
   – Allays fears about consequences of positive result
   – Teaches about the disease
   – Very useful/helpful

3. Perception of risk
   – Killer – no life after infection
   – Life continues
   – Negative status confirmation of partners negative status even if unknown
   – Condoms not trusted
   – Condoms work
   – Dislike condoms – uncomfortable
   – Abstinence preferred

4. Reaction to result/life event
   – Joy
   – Disbelief
   – Disappointment – due to inconclusive nature of first test

5. Reason for testing negative
   – Partner negative
   – God’s protection
   – Safe behaviour
   – Luck
Appendixes

6. Kinds of additional support required
   - Reading material
   - Training as counsellor/community educator
   - Additional counselling sessions
   - More information through seminars
   - Couple sensitisation

7. Perceptions about prevention messages
   - Useful/helpful – serve as warning, encourage to test, give information on prevention
   - Not very useful for those who cannot read English and those who cannot read at all, do not provide opportunity for interaction
   - Should present the real face of HIV/AIDS

8. Perception about ARVs
   - Prolong life but do not cure
   - Serves as motivation for testing
   - Not very useful since they don’t cure
   - Has no influence on decision to test

9. Future plans
   - Abstinence
   - Marry
   - Condoms
   - Faithfulness
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Appendixes

13.16 Appendix 16: Initial thematic map
Appendixes

13.17 Appendix 17: Field work photographs

Nchanga Health Centre (Private) MCH clinic/ VCT centre, Chingola

Kakoso Government Clinic VCT centre (undergoing renovation), Chililabombwe
Appendixes

Konkola Mine Hospital (Private) VCT room, Chililabombwe

Follow-up interview 29yrs, male (married)
Appendixes

Follow-up interview 19yrs, female (single)

First focus group discussion, Konkola Mine Hospital meeting room, Chililabombwe
Appendixes

Second focus group discussion, Nchanga South Hospital nurses’ tea-room, Chingola