AN ETHICAL ANALYSIS OF THE RESPONSIBILITY OF THE CHURCH TOWARDS WOMEN INFECTED BY HIV/AIDS: WITH PARTICULAR REFERENCE TO ST FRANCIS CARE CENTRE AND SPARROW VILLAGE

by

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I declare that **AN ETHICAL ANALYSIS OF THE RESPONSIBILITY OF THE CHURCH TOWARDS WOMEN INFECTED BY HIV/AIDS: WITH PARTICULAR REFERENCE TO ST FRANCIS CARE CENTRE AND SPARROW VILLAGE** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

SIGNATURE
(Mrs M L Martin)

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<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<tr>
<td>Aids</td>
<td>Acquired immune deficiency syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
</tr>
<tr>
<td>NGO</td>
<td>Nongovernmental organisation</td>
</tr>
<tr>
<td>CBO</td>
<td>Church-based organisation</td>
</tr>
<tr>
<td>FBO</td>
<td>Faith-based organisation</td>
</tr>
<tr>
<td>PLWHA</td>
<td>Person living with HIV/AIDS</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually transmitted infection</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary counselling and testing</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Program on HIV/AIDS</td>
</tr>
<tr>
<td>CME</td>
<td>Continuing medical education</td>
</tr>
<tr>
<td>SAMJ</td>
<td>South African Medical Journal</td>
</tr>
<tr>
<td>MRC</td>
<td>Medical Research Council</td>
</tr>
<tr>
<td>CBP</td>
<td>Church-based project</td>
</tr>
<tr>
<td>FBP</td>
<td>Faith-based project</td>
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<tr>
<td>PEP</td>
<td>Post exposure prophylaxis</td>
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<tr>
<td>TAC</td>
<td>Treatment Action Campaign</td>
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ABSTRACT

This dissertation examines the participation of the church and Christians in the lives of women who are infected and affected by HIV/AIDS in South Africa. To this end two Christian facilities; Sparrow Village and St Francis Care Centre, were examined in order to gain insight into the ethical issues of knowledge of patients and caregivers, the prevention measures being taught and the care facilities available to women in the plight in which they find themselves. A partial survey was conducted into the current policies and contributions by the church in an attempt to assess new ways to combat the disease. Medical information was examined as to what the virus is and how it is transmitted and reasons why women are particularly vulnerable to the virus. The dissertation seeks to understand practical ministerial ways in which the church should participate in women’s lives while being sensitive to the cultural, social and political and economic elements involved.

Keywords: knowledge, prevention, care, ethics, catholic, faith based, spirituality, church, Christian, community, HIV/AIDS
CHAPTER 1: INTRODUCTION

This dissertation discusses the call for action from Christians and churches to deal with HIV/AIDS, specifically in relation to women. Richardson (2006) poses the ethical question as to why Christians and the church should be involved in the fight against this pandemic. Richardson says that the ultimate point of reference is our Lord Jesus Christ. Jesus broke away from social convention to mingle with, conduct discourse with and heal the stigmatised and the ill (Richardson 2006:49).

The ministry of Jesus Christ was based on a courageous, unique approach where a prophet, teacher and Messiah met physically with the diseased and grief stricken. His healing not only encompassed physical healing but he also ministered to people’s sense of self-worth, their deep desire to be forgiven, and to become whole and one with God.

The reasons why this dissertation is placed in the theological ethical framework are numerous: firstly, the very ethic of a calling or ‘diakonia’ needs to be analysed in terms of an individual and community call for an ethic of care and the assistance for HIV/AIDS sufferers (Richardson 2006:48). Nicolson (1996) states this call is a moral obligation of the greatest force. He states that churches or Christians who ignore or refuse to face the problem are not in harmony with the nature of the church (Nicolson 1996:86).

Once it is realised that Christian ethics is rooted in a community which remembers the crucified Christ, and those who make up the community are shaped by the discipleship to that Christ and their belonging in his community, it can be seen that such ethics must be different from other ethics (Richardson 2006:49).

A discussion of Christian responses to HIV/AIDS cannot be explained or discussed in an ethical vacuum. The following chapters will analyse the ethical complexities affecting sufferers, and the individuals and the communities which make moral decisions. This is particularly true for women in Africa, thus gender ethics and feminist ethics will be analysed with a view to discussing the patriarchy, violence and fear which is so detrimentally affecting women’s lives and decision-making.

1 Nordstokke defines *diakonia* as; "the care of fellow humans and the work to promote fellowship, especially in service which in a particular way is directed towards people in distress" [http://www.lutheranworld.org/News/LWI/EN/2284_EN.html](http://www.lutheranworld.org/News/LWI/EN/2284_EN.html) (accessed 22 Feb 2009).
capabilities. HIV/AIDS can also not be discussed without researching medical ethics and social ethics so that Christians and churches can understand the complexities and dynamics of the rampant spread of the disease as well as the reasons why people are dying despite medical advances.

The aim of this thesis is to discuss the practical and theoretical frameworks of the church’s response to women living with HIV/AIDS in sub-Saharan Africa, particularly South Africa. The ultimate purpose is to draw comparisons and conclusions from broad-based research of community-based projects with two specific case studies to serve as a guideline for future faith-based projects (FBPs) and church-based organisations (CBOs). Likewise, the motivation for this thesis is to improve current projects through an analysis of some of them, highlighting shared problems with a view to finding solutions. It is my intention to create an awareness of the current level of activity in the church in dealing with HIV/AIDS in a social, political and medical context within the field of theological ethics.

The value of the work will be to improve current models and discuss common themes, ethical concerns and mechanisms to help the church and FBOs address the pandemic of HIV/AIDS which is affecting men, women and children. My hope is that the discussion will be meaningful for churches and FBOs in testing policy and procedures concerning the three core ethical issues of the knowledge of HIV/AIDS, prevention strategies to counter its spread and infection and methods to care for those infected with HIV/AIDS and their affected families. For example, some churches or FBOs may be confident with their model relating to care but might have difficulty dealing with knowledge and prevention of the disease. This dissertation’s purpose is to outline issues from the medical, theological and social fields to assist FBOs and churches to address the core ethical issues with sensitivity, dignity and purpose.

The reasons for this thesis are extensive. Firstly, I wished to address certain suppositions and preconceived ideas about the church’s involvement in addressing HIV/AIDS in Africa. The general consensus amongst the populace may be that the church is not involved, or that their involvement is limited to care only but lacking in terms of knowledge and prevention strategies. The following chapters hope to analyse the current level of participation of the church and FBOs in dealing with the three ethical issues noted above, as well as the strengths and weaknesses of current projects. The dissertation is
written from a theological ethics standpoint. This is important as the spread of HIV/Aids cannot be understood without taking into consideration numerous ethical concerns, ranging from cultural and communal issues of violence and patriarchy to sexual morals and the decision-making status of women in Africa.

Hopefully, this contextual approach within a theological ethical framework will assist church congregations and FBOs to address the rapid infection rate of HIV/Aids in communities and the numerous concomitant social problems this presents to homes and communities.

The design of the dissertation sets out to prove that churches and FBOs are an efficient means of showing and facilitating the love, compassion, grace and humility of Jesus Christ. By living out Christian lives which exhibit the doctrines of Christian love and faithfulness, Christians can empower others to live life in the palm of God's hand. It is through the compassion and non-judgemental care we bring to the suffering that we can, indeed, mould and fashion moral formation, change lives and evoke emotional, spiritual and physical healing.

The authentic principles of Christian ethics, once introduced to Aids sufferers through actions of caring, and providing information, knowledge and assistance, are very different from political and social vehicles of 'denialism', stigma, anger and judgement which are also sometimes found in the church. Through the implementation of Christ-led projects and initiatives to teach communities about HIV/Aids, ways to prevent infection and how to care for themselves and others, Christians can testify to the love and sacrifice of Jesus Christ. Then the words of Matthew may become a reality for the downtrodden, vulnerable and sick.

Come to me, all you who are weary and burdened, and I will give you rest. Take my yoke upon you and learn from me, for I am gentle and humble in heart, and you will find rest for your souls. For my yoke is easy and my burden is light (Matthew 11:28–30).

1.1 THE SITUATION OF WOMEN IN AFRICA, PARTICULARLY SOUTH AFRICA

Researchers for the United Nations as well as other nongovernmental organisations (NGOs) have for many years tracked the progress and current status of women in Africa. Important factors in determining a woman's status in Africa include their decision-making capacity, their
ability to trade and be legally recognised as majors, particularly in terms of their contractual and testate capacities, their ability to educate themselves and seek employment of their choice, as well as the issue of glass ceilings within workplaces.

African women are guardians of their children's welfare and they have an explicit responsibility to provide for them materially. They are the household managers, providing food, nutrition, water, health, education and family planning to an extent greater than elsewhere in the developing world. Despite developments such as improved agricultural technology, the availability of contraception, and changes in women's socioeconomic status, which one might think would have made their lives easier, the UN believe their lives have actually become more stressful as they try to meet modern-day demands in a cultural setting based on male patriarchy and primogeniture.\(^2\) Their workload has increased with the changing economic and social situation in Africa.

Chapters 2 and 4 discuss some of the medical, social and cultural problems facing women in Africa, particularly in South Africa, where African women still face legal issues of perpetual minority and contractual incapacity. It is important to recognise the long history of legal discrimination women have faced in South Africa, particularly black women. Apartheid created a climate of unfairness and exclusion. The 1996 Constitution and the Bill of Rights aimed to deconstruct the inherent unfairness pervading South Africa's legal and social systems. Rights in the Constitution (South Africa 1996:6–24) pertaining to women's rights include:

- **Section 9** Freedom from unfair discrimination on the basis of sex and gender and the right to equality.
- **Section 12** Freedom and security of the person which includes the right to be free from all forms of violence, either from public or private sources and the right to bodily and psychological integrity which includes the right to make decisions concerning reproduction.
- **Section 15** Freedom of religion, belief and opinion which recognises that certain religious or customary practices may be recognised, but these must be consistent with the Constitution.
- **Section 16** Freedom of expression does not extend to advocacy of hatred that is based on gender.

\(^2\) Primogeniture is the common law right of a firstborn son to inherit an entire estate.
• Section 25 the right to property.
• Section 26 the right to adequate housing.
• Section 27 the right to access to health care services including reproductive health care, sufficient food and water, and social security.
• Section 29 the right to a basic education including adult basic education.
• Section 30 the right to a language and culture of choice, as long as it is consistent with the Bill of Rights.
• Section 31 the right of cultural, religious and linguistic communities to enjoy their culture, use their language and practise their religion, and to form, join and maintain associations, as long as they are consistent with the Bill of Rights.
• Section 34 the right of access to the courts.

The Commission on Gender Equality was established in April 1997 to monitor and evaluate policies and practices of the organs of the state, statutory bodies, public bodies, authorities, private bodies, businesses and institutions in order to promote gender equality. Equality is thus the cornerstone of the Constitution. Through my involvement with community-based projects in different provinces and the research conducted for this dissertation, the sad truth is that constitutional principles of fairness and gender equality are not a reality for most South African women. Most of the women I interviewed openly revealed lives of domestic abuse and sexual violence; the inability for them to choose when it came to sexual relationships and encounters. Many women expressed the fact that they had been victims of discrimination in their homes and communities and at their workplace. Feminist theology proposes a recovery of women’s lost voices and addressing the marginalisation of their experiences and reflections (Ryan 2006:49).

This dissertation hopes to draw on women’s personal experiences and reflections and integrate them into proposals on how the church and Christians can address HIV/AIDS.

Poverty marginalises women in Africa leading to many resorting to crime and prostitution in order to survive. According to Interpol, South Africa has the highest rate of rape in the world. The National Prosecuting Authority states that 50% of all cases before our courts are for the crime of rape. Smith reports that the Law Reform Commission estimates there are 1.7 million rapes a year in South Africa yet, on
average, only 54,000 cases per annum are actually reported owing to the lack of support and sympathy of medical personnel, the police force and the courts. ³

So, how can the values of the Constitution mean anything if women in Africa and South Africa live their lives in fear and shame of sexual and physical abuse as well as cultural beliefs and social norms which state they are minors, lacking the ability to contract without a dominant male signatory? Chapters 2 and 4 discuss cultural law and the conflict it has created for constitutional principles.

According to the UN, female education affects family health and nutrition, agricultural productivity, and fertility, yet there is a wide gender gap in education. ⁴

The chapters dealing with medical and social issues will address the education gap and the effect it has on women's ability to make correct and educated decisions affecting their sexuality and health. It is important to discuss and analyse the context in which women live in Africa when researching issues of HIV/Aids. The nature of HIV/Aids being a sexually transmitted disease means that ways and means of preventing infection and re-infection form part of a moral choice to abstain or participate in a sexual relationship. Thus the factors affecting a woman’s right to choose freely her sexual attitudes and morals, without fear of intimidation, victimisation and abuse, are of great importance when analysing the rapid spread of the disease.

1.2 WOMEN AND AIDS IN AFRICA, PARTICULARLY SOUTH AFRICA

In 2001 I began working with the International Labour Organisation (ILO) and the Tourism Enterprise Program (TEP) to research community-based projects to be included in tourism products as well as the Arts and Crafts Imbizo for the World Summit for Sustainable Development held in Johannesburg in 2002. The majority of the community-based projects I visited were projects aimed to create employment and to alleviate poverty amongst sufferers of HIV/Aids. One of the most striking features of every single project visited was that

they were set up, managed and overseen by women, and most of their community members were women. This was the first time I realised that women are indeed the face of Aids in Africa.

In an article commissioned by the United Nations, Michael Fleshman released the following statistics:

Three-quarters of all Africans between the ages of 15 and 24 who are HIV-positive are women. That astonishing figure, just released by UNAIDS, highlights the growing concern of international agencies, African governments and AIDS activists over the 'gendered' impact of AIDS in Africa. It also has spurred the beginnings of a campaign to help young African women counter the disease (Fleshman 2004:6).

The fact that women have become the face of Aids has caused the UN to issue a warning of immediate urgency. Director Kathleen Cravero of the UN’s Africa Renewal Program has stated that of those African women in the 15–24 age group, fully 75% were young women. Cravero claims we are looking at young women becoming an endangered species in Africa as a result of this epidemic. The researchers of the Africa Renewal Program found a clear link in six areas between gender discrimination and the disproportionate impact of HIV/Aids on women and girls. These areas include prevention programmes, education, violence, women's property and inheritance rights, home and
community-based care-giving, and access to care and treatment.\textsuperscript{5} These statistics indicate the ripple effects, such as an Aids orphan pandemic, as well as the decimation of family units and the corrosion of the workforce. Chapters 2, 3 and 4 will explore this topic in greater detail with a focus on women's ability to choose, their overall knowledge of the disease, their ability to prevent infection and their ability to care for themselves and their families in terms of access to information, treatment and support, as well as issues of fear and stigma.

1.3 WHY IS THIS TOPIC PRESENTED WITHIN THE FIELD OF ETHICS?

The overall theoretical paradigm within which this dissertation is constructed is that of theological ethics. The dissertation concerns itself with both moral decision making and an ethics of character. These are attentive to traditional and Christian moralities and also to valued 'ways of life' which often critique the prevailing secular morality of our time (McClendon 1990:3-4), which is exacerbating the HIV/Aids pandemic. The various aspects of this field of knowledge, especially as it pertains to the dissertation, are outlined below.

1.3.1 Ethics defined

According to Connors and McCormick (1998:175), "ethics is a critical reflection on the moral norms, values and behaviour of individuals and societies in order to assess their validity or what is considered to be good or right and bad or wrong". Thus ethics is the study of moral experience; it is the systematic and communal reflection on and analysis of moral experience.

This dissertation is presented within the field of ethics because the issues, arguments and conclusions are brought into the ethical spheres of good or bad decisions, good or bad behaviour towards one another through interpersonal relationships and the good or bad spiritual, mental, emotional and physical consequences of the decisions we make and the harm or good we do to others. It is impossible to analyse HIV/Aids in an ethical or moral vacuum (Pojman 2005:20).

As HIV/Aids is a sexually transmitted disease there are moral questions and judgements made initially by the infected person as well as the

surrounding community. The issues of social stigma, fear and superstition are bi-products of ethical questions where most individuals and communities feel that they do not have clear-cut answers. Ethicists must be sensitive and recognise cultural and historical elements which have helped shape current decision makers.

The numerous political, social, medical and religious factors facing women in their decision-making process lead to many grey areas in a moral landscape, where judgements about good and bad moral behaviour are harder to make and not so clearly defined. As a researcher whose broad-based collection of research was a narration of personal accounts from women within these centres, I was consistently challenged with the question as to wrong or right decision making within their personal contexts of violence, domestic abuse, poor education, inadequate access to counselling and treatment, as well as an array of poverty-related dilemmas facing each and every one of them.

Whenever a decision or choice is to be made concerning behaviour, the moral decision ought to be one which works toward the creation of trust, confidence and integrity in relationships. It should increase the capacity of individuals to cooperate and to enhance the sense of self-respect in the individual. Acts which create distrust, suspicion and misunderstanding, which build barriers and destroy integrity, are immoral (Thiroux 1995:5). Thiroux’s definition of good and bad moral decisions will help us to understand what ought to be and whether actions should be condoned or discouraged.

In the following chapters, arguments are presented as to the context in which women suffering from HIV/AIDS have made their choices. Moralis implies a relationship, an association and rapport with others which is important. Immediately it moves from a moral position which is self-centred and introverted to a position that depends on mutual trust, communication exchanges and communion. It also means that moral decisions are not a ‘stand-alone’ phenomenon; they work in a network of bonds and alliances. Such alliances depend on mutual duties, responsibilities and rights. How can a woman who has been infected by HIV/AIDS through a violent sexual encounter be judged as immoral or corrupt? Likewise, how can a woman, although she has the legal and social security of a marriage, be held responsible for engaging in sexual relations with her partner without protection if he threatens her with physical or sexual abuse? These questions, once we look at them
in each context, affect our perceptions, reflections and understanding of what ought to be, our evaluation of the moral situation and the decision made.

1.3.2 Christian ethics defined

**Christian ethics**

Christian ethics is distinctive in that it is constructed within a Christian framework. Christian belief is that humanity is fallen away from God’s perfect plan and has replaced intimacy and relationship with God with separation and self interest. Humanity has chosen to live lives that are at odds with biblical principles replacing love with hatred, joy and peace with anguish, war and violence.\(^6\)

Stassen and Gushee in their discussion of the Reign of God and Christian living argue that the kingdom of God is not about what God does while humans stand by passively; nor our effort to build the kingdom while God passively watches. The Kingdom of God is performative; action that is required by way of behaviour change, this ethical praxis is our way of participating in the kingdom (2003:21-23).

Christian ethics adheres to a normative ethic; that there are universal moral principles that apply to all people, universal moral truths regardless of the time or place in which they live or their cultural setting. This is unlike ethical relativism which goes beyond cultural relativism by insisting that there are no universal moral principles or truths at all (Pojman 2005:20).

Christian ethics recognises that people need to be saved from sin, despair and oppression. The tenets from which they draw their norms and values are the Bible, and these norms and values must be understood in a cultural setting within a framework of ethical theories. Kammer (1988:72-73) defines values as representing that which we love and that to which we aspire. Norms are defined as “rules and principles which provide guidelines for our behaviour and which help us operate in a world of conflicting interests and confusing loyalties”.

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By understanding the norms and values of Christian ethics, Christians may themselves undergo a process of sanctification and empowerment which can further help them in bringing the redeeming work of Jesus Christ to those enslaved by fear, oppression, sickness and despair. This commitment and transformation recalls the words of St Peter:

As obedient children, do not conform to the evil desires you had when you lived in ignorance. But just as he who called you is holy, so be holy in all you do; for it is written, “Be holy because I am holy” (1 Peter 1:14–15).

Thus Christians engage in horizontal and vertical relationships, both with God and their neighbour. To understand why a Christian starts to undergo this shift in ethical paradigms one must discuss deontological and teleological theories. Deontological proponents claim that consequences do not, and in fact should not, enter their judging whether actions or people are moral or immoral (Thiroux 1995:64). Acts and people are judged to be moral or immoral regardless of the consequences of the action, hence this theory is also called nonconsequentialist. If you believe in a God who has set up moral commands, the action of the person, if the act or the person obeys the moral law, is moral and right regardless of the consequence.

The teleological approach to ethical decision making is deeply concerned with the consequences and, according to Kammer (1988:74), teleologists measure morality by the ability of an action to accomplish a desired end. The two main schools of thought in teleological theory are ethical egoism and utilitarianism. According to Thiroux (1995:40), both schools believe human beings ought to behave in ways which will bring about good consequences; however, the ethical egoist says people should act in their own self-interest and utilitarians believe human beings should act for the maximum good and interests of all concerned.

These two approaches should not be viewed as isolated or contradictory, in fact, they should be seen to complement each other. The Christian ethicist’s role model is Jesus Christ who stretched the boundaries of ethical thought in His life, where He was frequently faced with ethical dilemmas of disobeying the rule itself for a higher purpose. An example of this is in Mark’s Gospel where Jesus heals on the Sabbath. Jesus disobeyed the Sabbath laws to heal a man’s hand in a synagogue. He defended his actions with the argument that the Sabbath exists for humanity, not vice versa, and so when human needs become
critical, it is acceptable to violate traditional Sabbath laws. He looked beyond legalism, the letter of the law, to the deeper issues, the spirit of the law. Jesus looked at the consequences of His actions, He looked beyond the law itself and saw the greater good in the healing, as he stated to the Pharisees, “Is it lawful to do good on the Sabbath days, or to do evil? To save life or to kill?” (Mark 3:1–6).

Christians who are faced with the ethical questions of HIV/AIDS sufferers in relation to ethical issues of knowledge, prevention and the care of sufferers must be equipped to handle the grey areas which are not clear cut by analysing the scene within its cultural and environmental setting.

Christian ethics seeks to promote right actions and good outcomes. It seeks to identify ethical norms and values and how ethical decisions can best be made to achieve these good outcomes. Christian ethics looks for ways of understanding how we can find answers to moral problems raised by the ethical issues of human sexuality, sickness and suffering. It draws on biblical authority and it seeks to relate Christian faith to various experiences and contexts.

Therefore, Christian ethics allows a Christian to become a steward in the love, glory and peace of Jesus Christ. This stewardship entails a duty to both God and humanity which leads to ethical roles of knowing, being and doing. Christians should seek to show Christ’s love through their conduct and actions.

The community-based projects I have investigated for the purpose of this dissertation prove that Christians are effective in conveying the message of Jesus Christ to communities when their conduct is moral. By their concern for the wellbeing of HIV/AIDS sufferers, through acts of kindness and love for people facing stigma, fear and death, individual Christians and churches show God’s love in their actions, thus building character and virtue. Likewise, the Christian engaging with sufferers has an impact not only in terms of their actions but also in terms of their being. Virtue ethics points to what kind of a person we are, our motivations and character. Virtue and conduct-based ethics enable Christians to implement the fundamentals of love, humility and kindness. Virtue and conduct-based ethics allows Christians to become role models, challenging HIV/AIDS sufferers to recognise these Christ-like qualities and introducing them to the love and peace of Jesus Christ. Sufferers and communities can then make a conscious decision.
to either affirm or reject a life with Christ. People can then be engaged in an ethical decision-making process which leads to moral formation. There is no formula for moral decision making; it involves more than a mere hunch or intuition. Good moral decision making involves knowing the facts of the situation and carefully considering the moral principles that are relevant.

1.3.3 Medical ethical issues

Chapter 2 discusses medical ethical issues in greater detail. HIV/AIDS is primarily a sexually transmitted disease. HIV/AIDS induces us to question a person’s self-control, their sexual habits and relationships, their integrity and prudence. Moreover, the fact that HIV/AIDS is not a notifiable disease, in conjunction with social stigma, the strict laws and policies regulating the health sector and the practice of denialism on the part of the government, exacerbates problems characterised by the fact that there are extremely complex, sensitive issues which can be intrinsically ambiguous.

Medical ethics, also referred to as “bioethics”, refers to the morals and norms adhered to by medical professionals and personnel. The medical profession has long subscribed to a body of ethical standards primarily for the benefit of the patient. Physicians have a responsibility to their patients, first and foremost, as well as to society, to other health professionals, and to themselves. Norms of medical ethics are beneficence, non-maleficence, autonomy, truth-telling, confidentiality, the preservation of life and justice. Bioethics is concerned with the establishment and maintenance of vital and moral human relationships between the sick and the dying and the medical professionals. It is concerned with ‘treatment’ in the broadest sense (Thiroux 1995:374). In South Africa, medical ethics is directly affected and regulated by the Constitution of the Republic of South Africa (South Africa, 1996), the law of contract and the law of delict, as well as criminal law.

The medical ethical issues of HIV/Aids in sub-Saharan Africa are dramatically affected by gender discrimination, patriarchy, poverty, violence, political oppression and stigma. Political interference, as well as a lack of education, makes access to information which is concise, understandable and user friendly very difficult and will directly affect a

woman's decision-making capacity. Therefore, during the formal interviews, which are discussed in chapter 4 of this dissertation, women's broad medical knowledge was tested to see how educated they were about prevention of the disease, knowledge about treatment and testing, as well as whether they understood and were able to participate in care initiatives.

Chapter 2 investigates women's ability to choose and make informed decisions in a cultural setting of poverty, violence, poor education, sexual cultural practices and abuse. Christianity is simply incompatible with complacency because Christianity has been centred on action based on a virtuous life. Christians are called to care. Thus, medical ethical issues are explored in this dissertation to assess not only medical ethical issues of the availability of treatment, medical care, bioethical standards of privacy and medical care giving, but how they interrelate with social and political as well as theological ethical issues which affect a person's decision-making freedom.

1.3.4 Sexual ethical issues

Sexual ethics refers to the moral choices we make privately in sexual unions as well as the way sexual matters overtly affect the broader community, including the basic norms and values inherent in sexual behaviour and choices. Thiroux (1995:337) maintains that there is a distinction between the private sexual aspect and the public or societal aspect. The public aspects are governed by principles of justice, life and goodness. An example of the latter is the effect of the mass media, cultural expectations, pornography and television on our general values and norms which ultimately benefit or harm our relationships with one another. The intimate sexual aspect relates to moral choices founded on norms such as the Judeo-Christian beliefs about premarital sex, abortion, abstinence, safe sex, homosexuality, promiscuity, prostitution and procreation (:337).

Chapters 2 and 3 discuss sexual ethical issues raised by HIV/AIDS. They explore various cultural practices which make women even more susceptible to infection such as dry sex, as well as sexual relationships in a country affected by high rape statistics, domestic abuse and femicide. The chapters discuss assumptions and questions about a woman who are HIV/AIDS positive and explode the myth that women

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living with HIV/Aids are inherently promiscuous. The chapters delve deeper into issues of rape and the decimation of family units by HIV/Aids within a landscape modelled by poverty. These factors must be taken into consideration, as, firstly, they inhibit a woman from gaining the required knowledge about sexual practices which may place her at greater risk for infection; and secondly, these factors have an adverse affect on her decision-making capacity and thus her ability to prevent infection, as well as her confidence to seek treatment and care.

1.3.5 Feminist ethical issues

Feminist ethics has influenced the research methods used in this dissertation. Feminist ethics is defined as "an attempt to revise, reformulate, or rethink those aspects of traditional western ethics that depreciate or devalue women's moral experience".\(^9\) The experiences, pain and insights of women need to be taken into account when writing about or engaging in theological ethics. Women are excluded, for example, from ordained ministry in the Roman Catholic Church and in other churches the concerns of women may only be given lip service. Women experience exclusion, discrimination and violence which impacts negatively on the lives of women and their ability to minister to other women who are infected with HIV/Aids.\(^10\)

Ryan (2006:50) states that a woman's knowledge and experience is one of the central interpretive categories in feminist theory and thus also in feminist theology.

The dissertation has a strong focus on women's stories, personal experiences and knowledge. In chapter 3 the research methodology entails listening to women's individual stories at two care centres. There are five aspects to a woman's experience. These are her physical experience such as sexual intercourse, pregnancy and child birth. Then there is a woman's socialised experience, based largely on cultural beliefs and social norms and values. Thirdly, there is a woman's experience of female suffering through gender discrimination, racial and class oppression and poverty.\(^11\) Fourthly, there is a woman's

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\(^10\) Further reference to the Roman Catholic Church and ordination is made to Susan Rakoczy In Her Name (Pietermaritzburg: Cluster Publications, 2004) pp238-244.

historical experience and lastly a woman's individual experience, the latter makes a woman's story unique (Ryan 2006:50).

According to Jaggar (1992) traditional western ethics fails women in the following ways:

- It fails to focus on women's interests and rights.
- It dismisses the private realms of women and their daily sacrifices through care, nurturing and service.
- It suggests women are not as morally equipped and developed as men.
- It places more emphasis on male traits such as independence, autonomy, separation, mind, reason, culture, transcendence, war, and death, and places less emphasis on culturally feminine traits like interdependence, community, connection, body, emotion, nature, immanence, peace and life.
- It emphasises masculine moral reasoning over feminine reasoning which is based on relationships, unique traits and partiality. 12

The focus on women's experience seeks to liberate women from oppression and injustice and the sin of sexism. Thus, feminist ethics helps to address the patriarchal cultural values and norms causing fear, violence, oppression and intimidation within households and communities. This is particularly relevant in a discussion and investigation of HIV/Aids, as a climate of fear or duress will affect a woman's choice and decision-making capabilities. Susan Racoczy (2004:291) calls for action by the church to proclaim clearly and insistently that violence against women is wrong, sinful, evil and cannot be tolerated within the Christian community or society as a whole and she appeals against using culture as an excuse for sexual violence.

1.4 PRELIMINARY METHODOLOGICAL OUTLINE

As shown above, theological ethics forms the basic paradigm, or theoretical framework, within which this study is constructed. Specifically, medical, sexual and feminist ethics inform the questions posed and the interpretations advanced. Social ethics too provides the wider contextual understanding of the reasons why women contract HIV/Aids. Because of the importance of a basic, medical knowledge of

the HIV/AIDS virus, its transmission and the consequences of infection, the theoretical framework is further outlined before moving on to the empirical research of the two case studies. The methodology employed for this research is discussed fully in chapter 3 of the dissertation.

1.5 KEY ETHICAL ISSUES, KNOWLEDGE, PREVENTION AND CARE

The main ethical issues identified are the knowledge of HIV/AIDS, prevention mechanisms as well as care of self and others. Each of these three ethical issues is imperative in the sense that a woman without knowledge or information about HIV/AIDS is disabled in her capacity to make a choice. Even if she is educated and informed, but faces a situation of duress, she is less able to prevent infection. If a woman cannot access treatment and care there will be severe consequences for her, physically, emotionally and spiritually.

There are numerous other ancillary ethical issues to take into consideration as well; one cannot investigate the effect of HIV/AIDS on women in sub-Saharan Africa without acknowledging and discussing the problems in a context of dire poverty, politically unstable climates, war, gender discrimination, abuse and violence. These factors create a monstrous interrelated cycle and HIV/AIDS only deepens the chasm between misery and the hope of fulfilled, happy and spiritually stable lives. For example, the onslaught of infection of HIV/AIDS has led to family units being decimated and the emergence of millions of AIDS orphans. The prevalence of AIDS orphans is leading to concomitant problems such as increased juvenile crime, reduced literacy, children becoming vulnerable due to having no housing, sanitation or food and increasing levels of abuse and exploitation. This is causing an increased emotional and economic burden on the country.

According to the Medical Research Council (MRC), orphaned children are not only traumatised by the loss of parents (whose physical deterioration they may often have witnessed), they may also lack the necessary parental guidance through crucial life stages of identity formation and socialisation into adulthood. The MRC estimates that by 2015 we can expect an AIDS orphan explosion of 1.85 million in South Africa. 13

1.6 WOMEN AND THE CHURCH

Just as Thiroux (1995:13) describes private and broader sexual ethics, he also makes a distinction between social morality, which is one’s relationship to other human beings such as your spouse, children, parents, colleagues and strangers, and individual morality, which relates to one’s relationship with one’s self and the need for a sense of dignity, self-worth and respect. Thus social morality and individual morality are interconnected; the relationship you forge with strangers, the meek and suffering, directly impacts on their individual morality, their sense of self and worth. Likewise, this can impact on the life of a stranger through a good deed or act of compassion.

This is true for women in Africa who are particularly vulnerable. The United Nations records:

Across the globe women are not in the position to abstain. They are not in a position to demand faithfulness of their partners. In many cases they are in fact faithful, but are infected by unfaithful partners. A woman who is victim of violence or fear of violence is not going to be able to negotiate anything, let alone fidelity or condom use.14

During my informal discussions with women from community-based projects (CBPs) and faith-based projects (FBPs), I noted how women across provinces and age groups have the ability to form groups and how they have unique storytelling techniques.15 In a country such as South Africa, where informed consent, confidentiality and disclosure is of high importance, I was taken aback by participants’ willingness to share their stories, their eagerness to explain their situation, as well as their overwhelming fears for themselves and their families. In this way, narrative and participatory groups formed a baseline where they could firstly communicate in a way which facilitated a sense of dignity, camaraderie and self-worth and, secondly, endow them with a sense of purpose to have their lives and stories recorded. It reminded me of Wangari Maathai’s words:


15 Informal discussions were uninhibited talks during visits to both projects and also at the CBP’s where women talked freely about themselves and HIV/Aids. These were not conducted in a formal atmosphere. Formal interviews are discussed in chapter 4.
African women in general need to know that it is OK for them to be the way they are – to see the way they are as strength, and to be liberated from fear and from silence.\textsuperscript{16}

The church is in a unique position to act as an interface in scenarios such as the one described above where women, particularly African women, can come together without fear, threat or stigma and communicate with one another. This in its own way addresses the issue of knowledge as women discuss the technical aspects of HIV/AIDS, as well as ways in which they can prevent re-infection or how they can guide their families not to become infected. Women in this setting learn to become caregivers through the art of listening and sharing personal accounts; they begin to trust that they can reach out, counsel, hug, touch, sing and show compassion. In the female groups within FBPs women seem to forget the fear and numbness caused by abuse and stigma. They find an outlet to talk about their overwhelming sense of guilt and shame as well as their need to restore their honour and be acceptable in the eyes of God. More than just a tool for communication, the church, I have learned, is deeply trusted by African women; they feel safe, secure and confident to seek help from the church. The actual environment within an FBO is conducive to communication, transparency, counselling, sharing and volunteering.

As Christians we have an ethical duty towards those who are afflicted. The Bible speaks on many occasion of social justice where Christians act as advocates for the poor, the vulnerable, the ill and the down trodden. This moral tug should not be sourced from a feeling of guilt, duress or cold obligation; the source is a deep desire to be like Christ whose ministry spoke of turning poverty into a lack of want, illness into healing and suffering into comfort. Through this a virtuous Christian life becomes active not passive; it literally shows people the love, compassion, justice and mercy of Jesus Christ.

On World Aids Day in 2005 a pastoral letter to the Catholic Bishops of Florida on HIV/AIDS exhorted the Catholic Church to respond to persons living with Aids to be such that we discover Christ in them and they in turn can encounter Christ in us.\textsuperscript{17} This letter recalls the words of Christ

in John; “A new command I give you: Love one another. As I have loved you, so you must love one another” (John 13:34).

1.7 CONCLUSION

The paragraphs above have outlined this dissertation and why it fits within an ethical discussion. The importance of medical, sexual and feminist ethics for this dissertation as approaches that can throw light on the experiences of women in Africa, specifically related to the HIV/AIDS pandemic, have been noted.

This introductory chapter identified and defined key ethical elements which are, namely, the knowledge of HIV/AIDS, prevention of infection and care of sufferers. The church is suggested as being in a unique and viable position to not only practise virtue ethics but also action-based ethics. The duty of care and love is discussed with a view to understanding why, as Christians, we are called upon to love HIV/AIDS sufferers and show them compassion and understanding. It is through love that we as Christians effect moral formation and decision making. The church in this way is in a position to empower women infected with HIV/AIDS to regain their dignity and self-worth, to find justice and salvation in the love and hope of Jesus Christ, our Lord and Saviour. Perhaps the most powerful sermon on love is in 1 Corinthians, 13, where Paul examines how the opposites of love are jealousy, conceit, anger, pride, ill manners, selfishness, vanity, irritability, fickleness and bitterness (1 Cor 13:1–13).

Justice is imperative in Christian ethics. Justice allows dignity, liberty and freedom. In the Bible, the book of Amos exhorts: “let justice roll on like a river” (Amos 5:24). Justice is a constant, just as the moral law is a constant. God is Lord over all creation, He sustains the universe in a consistent and logical way, never changing His grand design and so He upholds the universe in a consistent, uniform way throughout time.

The message of Jesus Christ is based on faith, love and hope; these are important foundations for the stabilisation and progress of any culture. The way in which the church addresses the knowledge of HIV/AIDS, prevention and care methods will have a deeper effect on our culture and society as they will inevitably lead to questions about justice, faith, forgiveness and love. Christians have a responsibility to challenge evil and to transform the world and to fight for access to information and education about the disease, to fight for prevention strategies which are practical and meaningful and to insist on access to
treatment and care. Christians also have a responsibility to fight against poverty, stigma, abuse, violence, rape, substance abuse and oppression.

This dissertation, which analyses both the current state of FBPs and scenarios and plans for future FBPs, hopes to encourage a culture of leadership, where every sufferer and caregiver can become leaders in their own capacity in relation to decisions and choices impacting on themselves as well as others through communication, care and ministry. The greatest gift Jesus Christ gave us was His sacrifice. His ministry was one based on servanthood. Through modelling our actions on servanthood and stewardship, Christians empower others, therefore responsibility and authority is shared. The moral effect on individuals and society as a whole through Christian actions of compassion, love and care, lead not only to empowerment, but give credence to the words of Isaiah who said:

Is not this the kind of fasting I have chosen:
to loose the chains of injustice
and untie the cords of the yoke,
to set the oppressed free,
and break every yoke?
Is it not to share your food with the hungry
and to provide the poor wanderer with shelter
(Isaiah 58:6–10).

Cultures need to be constructively criticised in order to improve them, not to undermine them (Mugambi & Nasimiyu-Wasike 1992:26). The research undertaken here is presented in a way which is sensitive to the patients interviewed, the caregivers, and the cultural and social context in which they made their decisions.

In conclusion, it is important to note that at the outset the way and manner in which the research was initially conducted was through broad informal interviews with well over thirty projects from various provinces. This is why there is a continuous reference to the importance of narrative in African culture; storytelling became an integral part of integrating the main concerns as well as identifying the three core ethical issues. However, this ‘hands-on’ approach was refined through a critical analysis of various texts, sources and formal interviews to reach viable, quantifiable information and noteworthy conclusions.
The motivation behind this research has been to identify and encourage moral decision making and formation as well as to provide guidelines and assistance for current FBOs and churches who are faced daily with the severe implications of HIV/AIDS on their congregation, the broader community and society as a whole. The backdrop of the research and framework keeps in mind the words of Mother Theresa who said:

Jesus died on the Cross because that is what it took for Him to do good to us – to save us from our selfishness in sin. He gave up everything to do the Father's will – to show us that we too must be willing to give up everything to do God's will – to love one another as He loves each of us. If we are not willing to give whatever it takes to do good to one another, sin is still in us. That is why we too must give to each other until it hurts.18

CHAPTER 2: WHAT IS AIDS AND WHAT ARE THE ETHICAL
ISSUES RAISED BY AIDS?

This chapter, while in no way aspiring to a professional standard of medical knowledge, is nevertheless gleaned from professional pathology textbooks and is intended to clear up the confusion surrounding this disease rather than adding to it. It was written with the guidance and help of a medical doctor.

In this chapter the basic epidemiology and virology of the disease is discussed, looking at how the disease develops from an endemic to an epidemic to a pandemic. Thereafter, the factors influencing the spread and extent of epidemics are discussed, including the pathology of HIV/AIDS, and the infection and transmission modes of HIV/AIDS. These factors give the reader further insight into the cultural, political and gender dynamics that influence women's knowledge of the disease, their ability to act upon such knowledge and their overall decision-making freedom.

In section 2.4 the socioeconomic effects of HIV/AIDS are discussed in order to analyse the context in which HIV/AIDS infections occur and the ripple effect infection has on macro- and microeconomic environments. On issues of prevention and treatment the discussion integrates factors such as the dissident factor and the South African government's involvement in campaigns and policy to present an integrated approach within the South African context. This develops the overall discussion to a point where ethical issues affecting the knowledge, prevention and care of HIV/AIDS can be understood and debated within this social setting.

2.1 WHAT IS AIDS?

2.1.1 Basic epidemiology and virology

Although modern usage has applied some of these terms to nondisease entities, such as "an epidemic of litigation", for the purposes of this dissertation their original usage, as applied to diseases, will be retained. A disease is endemic when it regularly occurs in small pockets, and does not spread beyond certain geographic boundaries. Leprosy, for example, is endemic to West Africa. An epidemic occurs when a disease spreads rapidly through the whole population. Depending on the toxicity of the causative organism, the population is either decimated, as in smallpox epidemics, or becomes immune (herd
immunity). This is what typically happens with flu epidemics. When a disease infects large segments of the population and is not bound by geographical borders, it becomes a pandemic. The course of the pandemic depends on epidemiological factors, such as immunity, the length of the incubation period and mortality rate.

A virus can be defined as an infective agent of extremely small size that consists of nuclear material. It cannot, strictly speaking, be classified as a living organism because it does not meet the basic criterion of life: the ability to reproduce independently of other life forms. A virus can only reproduce in the cell nucleus of the host organism. The word is derived from a Latin word meaning "poison", or "slimy liquid". Viruses were discovered at the end of the nineteenth century, but were not seen until the discovery of the electron microscope 50 years later.

2.1.2 Antigen antibody response

The causative organism is described as having antigenic properties, which cause the host to produce antibodies. This process is called seroconversion, and leads to the detection of antibodies with specific tests. Before seroconversion the infected person may be infectious, even though no antibodies are detected. This is referred to as the window period. Another interval may occur before clinical signs and symptoms become evident: this is the incubation period. Thus, in measles for instance, the infected person can pass the virus on a few days after exposure, but only becomes ill after about two weeks. If the infection does not kill the patient, the patient becomes immune. Although antibodies are detectable for the rest of that person's life, he/she is no longer infected with the virus, and cannot pass it on. The exception to this is when an infected person builds a partial immunity which keeps the infection at bay, but is still infectious. Such a person becomes a carrier. Hepatitis B is a good example of such an infection.

2.1.3 Zoonosis

When an infection jumps the species barrier and infects humans, this process is known as zoonosis. Some of the most severe infections in our history have spread from animals to humans. Recent examples are Sudden Acute Respiratory Syndrome (SARS), avian flu, yellow fever,
dengue fever, and Aids (Hahn, Shaw, de Cock & Sharp 2000:576). The spread is usually blood borne (vectors include mosquitoes and ticks), through direct contact with blood, or food borne, for example, mad cow disease. The most dangerous infections then mutate to become spread by human to human contact.

### 2.1.4 Pathology of HIV/Aids

As already indicated, HIV/Aids has been extensively studied. The virus has been photographed, its genome mapped, and its fellow retroviruses identified. There is more known about this disease than most. The syndrome in all its manifestations features in virtually every issue of every medical journal issued currently. Knowledge of the virus and its transmission is of importance in curbing further infection. Without recognising and admitting the causes and the results of infection, behaviour will not change. As is shown later in this chapter, the fact that the causes and the results of infection have been disputed by prominent South African leaders has caused confusion in the populace. This has affected sexual behaviour patterns and contributed to the ongoing spread of the disease. Hence, the knowledge that we have of this disease should not be undermined by the anomaly of government opinion which suffocates dynamic and congruent methods of prevention and care.

### 2.1.5 Etiology and definition

Aids is defined as a secondary immunodeficiency syndrome resulting from HIV infection and leading to opportunistic infections, malignancies, neurological dysfunctions and other medical conditions (Merck Manual of Medical Information 1987:77). Two closely related viruses, HIV-1 and HIV-2, have been identified and cause Aids in different regions.

### 2.1.6 Haematology

The virus contains an enzyme, reverse transcriptase, which converts viral RNA into a pro-viral DNA copy that integrates into the host cell DNA. These copies are replicated with each cell division. In addition,

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19 Evidence of simian immunodeficiency virus (SIV) infection has been reported for 26 different species of African nonhuman primates. Two of these viruses, SIVcpz from chimpanzees and SIVsm from sooty mangabeys, are the cause of acquired immune deficiency syndrome (Aids) in humans. Together, they have been transmitted to humans on at least seven occasions. The causative factors are discussed below in this chapter.
multiple copies of the infected virus are produced, infecting more and more host cells. Cells affected include the host’s T helper cells and the CD4 cells, both of which are vital to an intact immune system, as well as pulmonary macrophages, dendritic cells of the brain and lymph nodes.

The most valuable prognostic predictor is the host’s CD4 count. This drops within months of infection by about 50%, from the normal range (1000–1300) to about 600 to 700. After this the decline is slower until the critical level of 200 is reached. This is usually when clinical Aids becomes evident. The normal antigen antibody response is also affected, so the response to vaccines is compromised.

2.1.7 Infectivity

HIV is not transmitted by casual contact. Transmission requires contact with blood or body fluids containing infected cells or plasma. This includes blood, semen, vaginal secretions, breast milk or saliva (Merck Manual 1987:78). Transmission by droplet infection (coughing) or saliva has not been documented. The usual modes of transmission are by blood transfusion, the sharing of needles, breast feeding, accidental injections (needle stick injuries) and sexual intercourse. Transmission occurs more readily in the presence of concomitant sexually transmitted diseases (STDs), such as herpes, syphilis and gonorrhoea. Vertical transmission from mother to child occurs during birth if there is a mixing of blood, and with breast feeding.

Certain types of sexual activity are more favourable to infection than others. It is currently accepted that the chances of infection through vaginal intercourse in the absence of concomitant STDs is about one in ten. This incidence rises rapidly in the presence of venereal ulcers, owing to such diseases as herpes genitalia, gonorrhoea, the primary chancre of syphilis and lymphogranuloma inguinale.

Anal sex, as a result of the nature of the anal mucosa, is almost impossible without the presence of blood. In the days when sodomy was a crime in the western world, the presence of semen, blood, faeces and pubic hair around the anus was taken as proof positive of anal intercourse. This type of sexual activity is very dangerous as far as the spread of HIV is concerned.

HIV infection is obviously more common after violent rape, because of the possibility of mixing blood. Assault and violence also fall into this
group. The current habit of criminals of biting their female victims' fingers to remove their rings is cause for concern. Child abuse, when penetrative, almost universally leads to injury and bleeding, and will certainly increase the risk of HIV transmission.

Oral sex is not a particularly risky practice (from the HIV point of view) as long as there are no open sores. It is quite common, though, for sex workers, both male and female, to have gonorrhoea of the nasopharynx, facilitating the spread of HIV.

2.1.8 Diagnosis

HIV infection is confirmed by serological tests. However, certain disease entities in a patient who is not on immunosuppressive treatment have been classified by the Centre for Disease Control as diagnostic of Aids. These include candidiasis of the pharynx and bronchial tree, extra pulmonary cryptocococcus infections, cryptosporidial diarrhoea for longer than a month, herpes simplex ulcers lasting longer than a month or infecting the lungs or pharynx, Kaposi's sarcoma in patients less than 60 years old and pneumocystis carinii pneumonia (pcp pneumonia). Toxoplastic encephalitis and parovirus encephalopathy are also Aids-defining conditions. A CD4 count of less than 200 is diagnostic of clinical Aids.²⁰

2.1.9 Clinical presentation

After infection, a period ensues with minimal or no clinical signs or symptoms (the incubation period). During this period the infected person has the virus present in his/her blood and is infectious, even while testing HIV negative. This is the window period. In a minority of cases the patient presents with a fever, rash and swollen lymph nodes at the time of seroconversion.²¹ From the time of seroconversion the infected person tests HIV positive and has antibodies to HIV.

The clinical manifestations of Aids are wasting, night sweats, lymphadenopathy, prolonged diarrhoea, dementia and opportunistic infections. A wide range of clinical signs and symptoms suggest the disease; serology and CD4 count confirm the diagnosis. Lymphomas,

²⁰ The issue of Aids dissidents is discussed in section 2.5.
²¹ The development of antibodies to a particular antigen occurs when people develop antibodies to HIV, they then "seroconvert" from antibody-negative to antibody-positive. It may take from as little as one week to several months or more after infection with HIV for antibodies to the virus to develop. After antibodies to HIV appear in the blood, a person should test positive on antibody tests [http://aids.about.com/library/glossary/bldef-sero.htm] (accessed 1 May 2006, 8 December 2008).
Kaposi’s sarcoma and intracerebral tumours are commonly found in Aids patients.

2.2 A HISTORY OF EPIDEMICS

Leprosy is the original Biblical plague, described as “pestilence” (Habakkuk 3:5). The disease is caused by an acid fast bacillus, it is not very infectious and depends for spread on crowded conditions and poverty.

Smallpox and the Black plague (Bubonic plague) swept through Europe in the Middle Ages, killing up to one in three people, devastating economies, and leaving their mark on history. Tuberculosis was the scourge of the eighteenth and nineteenth centuries, killing many millions of people in their prime. Chopin, Keats and Schubert joined countless thousands who died before their time from this disease. In the new millennium TB is making a big comeback in both the developed and the third world, as the bacillus becomes resistant to treatment.

2.2.1 Sexually transmitted disease: syphilis and gonorrhoea

Syphilis and gonorrhoea, commonly known as the pox and the drops, were introduced to Europe when the first explorers came back from Asia, and cut a swathe through the populations of the Old World. Because syphilis causes dementia in the infected, it probably changed history. Henry VIII, who was famously a syphilitic, changed over the years from an enlightened, caring monarch to a cruel and illogical despot. It was as a direct result of the syphilis pandemic that a new system of medical ethics was formulated in the early twentieth century. Syphilis led to the evolution of Victorian morality, which regarded sex as “dirty”. Syphilis swept through the known world at the time, and claimed many victims, including a number famous people such as Abraham Lincoln, Franz Schubert, Friedrich Nietzsche, Oscar Wilde and Karen Blixen (van Niekerk 2004:709).

2.2.2 Modern viral epidemics

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22 Recognising the gravity of the situation, the American Medical Association (AMA) adopted “Principles of Medical Ethics” in May 1903 to replace its "Code of Ethics" from 1847. This new set of principles did not expressly deal with venereal diseases but did set explicit guidelines for patient confidentiality. By June 1912, these principles had been revised again, with two sections added dealing with various aspects of communicable diseases. The revisions and additions show an immature practice attempting to professionalise in the face of tough ethical issues raised by syphilis (Jabbour 2000:76).
Viruses have only been known to medical science for about a hundred years. Their existence was postulated and they were classified and described for 70 years before the first one was seen with the aid of the newly discovered electron microscope. Today much is known about them, including the fact that they constitute a massive threat to the continued health of humanity. AIDS is only one viral disease in an increasingly ominous line-up.

2.2.3 The Spanish flu

Between 1919 and 1922 a viral flu swept Europe and America, and even visited South Africa. It killed more people than the Great War, was spread by nasal droplet infection, and had an extremely high mortality rate. It disappeared as mysteriously as it had arrived. The causative organism has never been found.

International epidemiologists, including the World Health Organisation and the Centre for Disease Control in Atlanta, Georgia, are constantly on the lookout for new epidemics.

The control of epidemics and preventable diseases is probably the greatest advance in the history of medicine, and partially accounts for the exponential growth of the world's population in the twentieth century. The recent Severe Acute Respiratory Syndrome (SARS) outbreak is a good example of how sound epidemiological principles, efficiently applied, prevented a global catastrophe.

These principles involve the identification of the causative organism, finding its source, isolating infected persons, and tracking down and quarantining their contacts. Close cooperation between the authorities and medical personnel is essential. Accurate diagnosis and record keeping, including notification, form the basis of effective control measures (Grant 1969:33).

2.2.4 A brief history of HIV/AIDS

HIV/AIDS appears to be a new disease. There is no convincing evidence that it existed, certainly not extensively, before the latter part of the twentieth century. Nevertheless, it may have been endemic to Central Africa for an unknown number of years before then.

2.2.4.1 America: The homosexual/drugs connection
In the early 1980s a number of homosexuals in California presented with a new disease: because their immune systems had become deficient they were susceptible to opportunistic infections. The clinical picture was recognised by medical scientists because chemotherapy for cancer and immuno-suppression in organ transplantation led to the same scenario. There was confusion as to the causative organism and it took several years before the lymphadenopathy associated virus (LAV) was isolated. This virus was soon renamed the human immunodeficiency virus (HIV). This is a retrovirus related to viruses which cause cancers and tumours. It is, according to Hahn et al (2000:607–614), of zoonotic origin: Central African chimpanzees.

Illustration of HIV.
Russell Kightley Media: Scientific illustration

2.2.4.2 Infection in Africa
The rapid spread of HIV/AIDS has been well documented. It is now the second biggest killer in Africa after malaria (Anderson 2004:278). The peak of the epidemic has not been reached yet, and frightening mortality statistics are available. Incidence in some African countries is calamitous, for example 39% of the population in Swaziland are HIV infected (Anderson, 2004:278). The main type of infection in Africa is of the HIV-1 virus; in America it is the HIV-2 sub-type. 24

A striking feature of HIV-1 is its severity. The first cases were discovered in Uganda and Tanzania in 1979–80 (Buve, Carael & Hayes 2001:5-14). Population studies in Central Africa show many circulating

23 A retrovirus is any virus belonging to the viral family Retroviridae. They are enveloped viruses possessing an (RNA) genome, and replicate via a (DNA) intermediate. Retroviruses rely on the enzyme reverse transcriptase to perform the reverse transcription of its genome from RNA into DNA, which can then be integrated into the host's genome with an integrase enzyme. See also 2.1.4.

24 HIV-1 is the main family of HIV and accounts for 95% of all infections worldwide. HIV-2 is a very different virus and is only generally seen in a few African countries. Although HIV-2 generally progresses more slowly than HIV-1, some HIV drugs (like nevirapine and efavirenz) will not work against HIV-2. [http://www.theafricaneye.co.uk/] (accessed 3 February 2007, 19 December 2008).
strains, indicating that the virus has been around for a long time (Janssens, Buve & Nkengasong 1997:705–712).

2.2.4.3 Statistics in Africa
In the mid-1980s, the HIV epidemic seemed to be worst in the Democratic Republic of Congo and Uganda, and, to a lesser extent, in neighbouring countries in East and Southern Africa (Quinn, Mann, Curran, Piot 1986:955–963). In the Democratic Republic of Congo, Cameroon and Gabon, HIV-1 prevalence has remained fairly stable for many years, and only recently has a worrying increase in prevalence in Cameroon suggested that the epidemic is entering a new phase. In 1999, HIV prevalence in adults in Cameroon was estimated at 7.7%; in 2000, a prevalence of 11% was noted in a nationwide survey of pregnant women (Macauley, Eyong, Shiro, Mbanya & Musi 2001:2011–2017).

This relatively slow and recent increase contrasts with the situation in many parts of East Africa and most of Southern Africa where the HIV epidemic has run an explosive course since the early 1990s. In many large cities in these regions, HIV prevalence in pregnant women has exceeded or still exceeds 25%. In Uganda, the prevalence of HIV infection has fallen since the early 1990s, which has been attributed to changes in sexual behaviour (Asumwe-Okiror, Opio, Musinguzi, Madraa, Tembo & Carael 1997:1157–63).

More recently, a similar, declining trend in HIV-1 prevalence has been noted in Zambia (Fylkesnes, Musondo, Sichone, Ndhlovu, Tembo & Monze 2001:907-16). However, in other parts of Southern Africa the epidemic continues to spread unabated. The UNAIDS Aids Epidemic Update issued in Geneva in 2000, stated that the worst affected country so far is Botswana, where an estimated 1 in 3 adults is infected (UNAIDS, December 2000). In West Africa, with the exception of Côte d’Ivoire, Burkina Faso, Nigeria, and Togo, HIV prevalence in pregnant women has so far remained under 5%.

The considerable variation in HIV prevalence between different regions in sub-Saharan Africa cannot always be accounted for by differences in the date of introduction of the virus. The rate of spread of HIV infection varies between populations across Africa. It seems that the spread of

HIV infection has been more rapid in Eastern and Southern Africa than in Western and Central Africa. In a population-based study, differences in sexual behaviour patterns alone could not explain differences in HIV-1 prevalence between areas (Buve et al 2001:14). The study was done in four cities: two (Cotonou in Benin and Yaoundé in Cameroon) with a fairly low prevalence of HIV of around 5% in the general population; and two (Kisumu in Kenya and Ndola in Zambia) with a prevalence of around 25%. Differences in sexual behaviour were outweighed by differences in the prevalence of factors that alter the probability of transmission during sexual intercourse. Factors which alter the probability of transmission and thus make one more vulnerable to infection include male circumcision and infections that cause genital ulcerations, that is, herpes simplex virus-2 (HSV-2) infection, syphilis, or both (Buve et al 2001:127-31).

Furthermore, differences in prevalence were not explained by variations in circulating subtypes of HIV-1 (Morison Buve & Zekeng 2001:109). The findings show how the spread of HIV-1 infection is determined by a complex interplay of sexual behaviour, including rate of partner change and sexual mixing patterns between different sexual activity classes, different age groups, or both, and the biological factors that affect the probability of HIV-1 transmission per sex act.

The study also drew attention to the high prevalence of HIV-1 and other sexually transmitted infections in young people, especially young women, in many parts of sub-Saharan Africa. For instance in Kisumu, Kenya, 23% of women aged 15–19 years were infected with HIV-1, compared with 3–5% of young men of the same age (Buve et al 01:14). Female adolescents in Tanzania, Zambia, Zimbabwe and South Africa have much higher rates of HIV-1 infection than male adolescents (Laga, Schwartlander, Pisani, Sow & Carael 2001:931-34). Possible explanations for this discrepancy include the higher biological vulnerability of young women to HIV-1 and other sexually transmitted infections than young men, and sexual relations between young women and older men who are more likely to be infected than younger men (Glynn, Carael & Auvert 2001:51-60). Indeed, sex with older men is a risk factor for HIV infection in young women in Zimbabwe (Glynn, et al 2001:41–50).

Various factors make it difficult to obtain accurate statistics on the incidence of HIV/Aids, especially in South Africa. Reluctance to be tested owing to the fear of stigmatisation and discrimination; a serious
shortage of health workers, financial constraints and ethical considerations such as confidentiality, all conspire to prevent adequate screening. Figures are based on estimates, usually using ante-natal screening statistics, changes in mortality figures and the incidence of opportunistic infections and tumours.

Bodies such as the World Health Organization and UNAIDS periodically produce estimates of figures. Thus UNAIDS estimates that 26.6 million people were infected in the whole of sub-Saharan Africa by 2001. These figures were brought into question by a commentator in 2003, where it was alleged that the Aids pandemic was greatly exaggerated by various interested parties with hidden agendas (Malan 2003:13–20). However, these claims were vigorously refuted by other authorities including the World Bank.26 A recent study undertaken on behalf of the Government of South Africa paints an even bleaker picture (Naidu 2004:1). According to the study between five and seven million Aids-related deaths will occur by 2010 in South Africa. The number of school enrolments has also drastically declined.

A national community-based study by the Medical Research Council in Durban was released in September 2004. Results were based on data drawn from the whole population aged two years and older, and not just on pregnant women at state clinics, as was done previously (Shishana, Rehle, Simbayi, Parker, Zuma, Bhana, Connolly & Jooste 2005:776–781). Over 7,000 households were selected for data, and more than nine thousand individuals were interviewed. HIV prevalence in the general population was estimated at about 20% more in females than males. Blacks had the highest prevalence (12.9%), compared with whites (6.2%), coloureds (6.1%) and Indians (1.6%). Informal settlements in urban areas had the highest prevalence (21.6%). This survey was judged to be the most reliable yet for data obtained in South Africa.

2.3 FACTORS INFLUENCING THE SPREAD AND EXTENT OF EPIDEMICS

Some potentially lethal viral infections are kept under control through circumstance. They may occur in sparsely populated and isolated areas (ebola), or a vaccine may be readily available (polio) or they may have mutated into a harmless strain (the flu, on most occasions). Bacterial epidemics which devastated societies in the past may be rendered harmless by antibiotics, such as the plague, syphilis and scarlet fever. But there are still factors favourable to the rapid spread of disease; some of these are mentioned below.

2.3.1 Poverty, crowded conditions and violence

Poverty has played a vital part in the epidemiology of the pandemic. During the past 20 years, nearly all countries in sub-Saharan Africa have faced slowing economic growth. Between 1980 and 1991, the average yearly growth of the per capita gross national product in sub-Saharan Africa was \(-1.2\%\).\(^{27}\) Structural adjustment programmes imposed cuts in nonproductive spending, including spending on social services. This policy further impoverished African populations with increases in unemployment resulting from the privatisation of public enterprises and loss of jobs in the public sector. The remaining public sector workers saw their purchasing power diminished. Additionally, the provision of social services decreased, including education and health services. Thus, during the 1990s, overall public expenditure on health represented only 1.7% of the gross African domestic product (Bonnel 2000:81).

Poverty is associated with increased vulnerability to HIV-1 and other sexually transmitted infections. In conditions of poverty, the risk of HIV-1 infection assumes low priority among people’s daily concerns. Young people who grow up in poor conditions have little access to schools and few prospects for their future. They lack recreational facilities and sex becomes a way to pass the time (Fetters, Mupela & Rutenberg 1998:18–24). Poverty can also drive women into exchanging sex for money, food or other commodities. Poor people in rural areas migrate to towns in search of work, leaving their family and entering an

environment where sexual risk-taking is more common than in their rural homes.

However, the association between poverty or wealth and the risk of HIV infection is not straightforward. Higher educational attainment can be associated with more risky sexual behaviour and increased risk of HIV infection in individuals, which was true especially in the earlier stages of the HIV epidemic. At the population level, there is no simple link between per capita gross national product and the prevalence of HIV infection (Fylkesnes et al 2001:907–16).

Botswana, Namibia and South Africa have the highest per capita gross national product in sub-Saharan Africa, but are the hardest hit by HIV. Epidemiological, social and economic variables could account for more than half the variation in HIV prevalence between 72 countries in Africa, Asia and Latin America. Per capita gross national product was one variable, but also important were inequality of income distribution and the gap between male and female literacy. These factors of gender inequality affect women’s ability to empower themselves, to make choices and to be confident in their capacities.

During the Middle Ages bubonic plague originated in the slums of Europe; the unsanitary, crowded living conditions prevailing at the time were ideal for rat infestations that carried the xenopsylla chepensis flea, the carrier of the germ Uersina Pestis, which spread the plague bacterium. The rat was sick and carried the vector. Today massive crowding and poor standards of basic sanitation contribute to the spread of SARS. The devastation of the First World War led to the rapid spread of the Spanish flu. War, population shifts, refugee camps and poverty all contribute to epidemics. The Industrial Revolution and consequent urbanisation resulted in slum conditions in Europe, with resultant disease. Rheumatic fever, rickets and emphysema were diseases of overcrowding and poverty. Poverty in Africa is linked to violence as the despair and depression of unemployment leads to acts of anger against the immediate family unit. The abuse of alcohol and other substances also diminishes one’s capacity to act rationally and consciously increasing the risk of becoming abusive or becoming a victim of abuse. Women and children, in particular, are acutely

vulnerable to physical and sexual assault in an environment where men feel emasculated, bored and frustrated. The positive link between poverty and violence as a factor for the spread of HIV/AIDS is verified in chapter 4 as statistics reveal the large number of women at hospices who are reportedly victims of violence.

2.3.2 Poor public health measures

For adequate public health measures there has to be a measure of political stability. In times of war, especially civil war, public health officials are denied access to rural areas, and public health programmes such as vaccination efforts are hindered. Thus, there were more cases of rabies in the rural areas of Zimbabwe during the "bush war" of 1980 than in the preceding 50 years.

In Europe at the start of the twentieth century the relationship between nutrition and disease was not fully understood, resulting in scurvy, pellagra, beri beri and rickets. The relationship between disease and dirty water, inadequate sewerage disposal, unsanitary abattoirs and infected farm animals is now well understood. Unfortunately this does not mean that these conditions are now extinct. Effective public health measures, especially in terms of the transmission of reliable information about HIV/AIDS and the provision of antiretroviral (ARV) drugs could retard the spread of HIV/AIDS. Sadly these measures are often lacking or ineffective.

2.3.3 International travel, shifting populations, war and civil unrest

International travel makes the spread of disease easier. In the days of sea travel a disease could be more readily contained because it would show itself during the voyage. Today, with air travel, an infected person can move to a different continent during the incubation period of an infective disease (Leggat & Goldsmith 2002:25).

War and social unrest are potent causes of the spread of disease, including HIV/AIDS. Refugee camps, lack of infrastructure and scarcity of medical personnel all combine to facilitate diseases entering into new geographic areas. Africa, with its porous borders and corrupt border officials, is particularly vulnerable to this factor. The Southern States of the USA are vulnerable to a malaria outbreak: the anopheles mosquito is common in Florida. It is only the vigilance of border officials and health departments that prevent a catastrophe. Increased
travel in South Africa and the large number of refugees make the control of HIV/AIDS very difficult.

War and civil strife are conducive to the rapid spread of HIV. During conflicts, soldiers are living in a high-risk environment in which the risk of HIV/AIDS is balanced by stressful situations and dangers related to war. Civilians are often subjected to human rights abuses, including sexual violence, and are left in conditions of poverty that might lead them to use commercial sex to survive (Amowitz, Reis, Lyons, Vann, Mansaray, Adyinka, Smith & Taylor 2002:513–521).

Additionally, war and civil strife are associated with massive displacement of people. In January 2002, more than 6 million people in sub-Saharan Africa fell under the mandate of the United Nations High Commissioner on Refugees (UNHCR). Displacement is associated with the interruption of social cohesion and relationships, and with promiscuity, inadequate shelter and commercial sex. People may also flee from areas with quite low HIV prevalence to an area with a higher prevalence. In Kigali (Rwanda) in 1995, the prevalence of HIV in pregnant women originating from rural areas was higher than expected (24%), which was attributed to rape and displacement during the genocide (Leroy, Ntawiniga, Nziyumvira, Kagubare & Salamon 1995:1488–89).

The decline of health, education and other social services implies a loss of opportunities for HIV prevention. People with little or no education have poor access to safe-sex information. For instance, condom use is associated with higher levels of education (Lagarde, Cariel & Glynn 2001:931–934). Reduced provision of quality health services also represents a loss of opportunities to control other sexually transmitted infections, offer reproductive health services and provide quality care for people infected with HIV. For instance, in the Mwanza region of Tanzania, fewer than 10% of symptomatic sexually transmitted infections occurring in the population were cured by health services. Health staff had been unable to update their skills and knowledge, and health centres were provided with insufficient and inappropriate antibiotics (Buve, Bishikwabo-Nsarhaza & Mutangadura 2002:127–31).

The rapid growth of urban areas in developing countries, resulting from increased urban birth rates and continued migration from rural regions,
has fuelled the rapid spread of HIV. In most parts of sub-Saharan Africa, HIV prevalence is higher in urban than rural populations, which is one reason why some highly urbanised countries have the highest rates of adult HIV-1 infection. Zambia, Botswana and South Africa are the most densely urbanised countries in sub-Saharan Africa and are the most affected by HIV.

Urbanisation and modernisation exchange traditional village moral norms for an urban modern ethos with fewer restrictions on sexual behaviour and marriage. Part of the high urban prevalence of HIV infection results from massive migration of young, unmarried adults from conservative rural environments to more sexually permissive cities (Brockerhoff & Biddlecom 1998:833–56). Furthermore, loss of culture and erosion of social networks are associated with social problems such as alcohol and drug abuse, which encourage high-risk behaviour. Migration to urban areas in search of employment separates spouses for extended periods. Urban men and women who are separated from their spouses are more likely to engage in high-risk sexual behaviour than cohabitants in urban areas (Caldwell, Caldwell & Quiggin 1989:185–234).

For many decades, rural migrants have typically been young men aged 15–30 years, especially in Africa (Todaro 1997:138–148). Male migrants may engage in high-risk behaviour with sex workers, thereby increasing their own and their partners’ vulnerability to HIV and other sexually-transmitted infections.

Women now increasingly migrate to cities, and frequently end up in low-status, low-wage production and service jobs, and may be forced into exchanging sex for money or gifts as a survival strategy. Rapid urbanisation has been linked to growing urban poverty, because of unemployment (Adeyi, Hecht, Njobvu & Soucat 2001:8).

Results from a study in Nairobi showed that slum residents initiate sex at younger ages and have more sexual partners than other city residents (Zulu, Ezeh & Dodoo 2002:1993-98). Under the population pressure of rapid urbanisation, city infrastructures are overstretched.

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and health services deteriorate with concomitant loss of opportunity to prevent the spread of HIV.

Modernisation has brought higher mobility. Better communication and transportation now link urban and rural areas economically and socially. Inter-country and intra-country population mobility has been a critical factor in the spread of HIV in many regions (Mann & Tarantola 1996:21). Some key population groups that are highly mobile and at high risk of HIV-1 transmission are sex workers, truck drivers, transport workers, the military and mobile employees of large industries. Occupational travel is associated with high rates of partner change, transactional sex and unsafe sex.

2.3.4 Gender, socioeconomic status and age

Statistics show that in South Africa adult deaths overall have increased by about 44% between 1998 and 2003, but, specifically, by more than 150% in women aged 20–49 years (Bradshaw 2004:278). A recent study estimates that up to 50% of deaths in children younger than 5 in South Africa are HIV/AIDS related (Moodley 2004:202). A survey involving 44,000 employees in the mining and manufacturing sectors across three countries showed overall infection rates ranging from 15–35%. The study showed a marked increase in infection rate as the job levels became less skilled. The highest incidence was in contract workers (Anderson 2004:125).

The seroprevalence in South Africa is estimated to be 20% of the total population. It is claimed that 60% of South Africa’s prisoners are infected, due to the high incidence of male rape and homosexual intercourse in our prisons. Three hundred thousand of these prisoners are released and return to society every year.

In 2005 Statistics South Africa (Stats SA) released figures reflecting a 57% increase in deaths between 1997 and 2003. The greatest increase in deaths was in women and people aged 20–49. Although the study did not directly implicate AIDS, the head of Stats SA, Pali Lehohla, said that there was strong indirect evidence that “the HIV epidemic in South

30 Authorities who until recently denied that illicit sex could happen in prison have now begun a programme of education and prevention (Hanna 1996).
Africa is raising the mortality level of prime age adults". The article was reported in the Washington Post (Lehohla 2005:A23).

The study showed a large increase in deaths in the 30–34 age group attributed to pneumonia, tuberculosis and influenza, diagnoses often used on death certificates. The significance of this is that death certificates in South Africa were changed about six years ago. Whereas the previous certificates required a great deal of specificity, now diagnoses such as "natural causes" are acceptable. Bearing in mind how few people voluntarily have HIV tests, and that these are usually anonymous if part of a survey, it stands to reason that Aids as a cause of death is severely underreported in South Africa.

Cultural and socioeconomic features common to most societies in sub-Saharan Africa have played, and still play, a part in the spread of HIV-1 infection. These factors include gender inequality, impoverishment and the decline of social services, as well as rapid urbanisation and modernisation. In the CARE International Consultancy Report of August 2002, Shah explains that there is also the factor of many wars and conflicts in Africa. Since 1980, no fewer than 28 of 53 African states have been at war. Most cultures have rules requiring women to have very little sexual experience before marriage and to be monogamous thereafter, whereas for men premarital and extramarital sex are tolerated or even expected. Young men and boys are often encouraged by peers to demonstrate their masculinity through early sexual initiation and many sexual conquests (Zulu, Ezeh & Dodoo 2002:1993–1998).

Abuse of the practice of lobola, which is a dowry or bride wealth paid in terms of a customary union to a bride's family by her new husband, perpetuates the idea that a woman is her husband's property. This culturally prescribed lack of control on their sexual relationships has made women, particularly married women, highly vulnerable to HIV infection. Wives are not allowed to refuse sex from their husband, or to use a condom, even if the husband is infected with HIV. The subordinate position of women also has implications for safe-sex

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31 The report found that natural deaths were rising and the increase could be "fairly attributed" to HIV/Aids and the opportunistic diseases that followed. Natural deaths rose by 57% from 1997–2003, with 1,087 deaths in 2000 and 1,683 in 2003. (http://www.info.gov.za/view/DownloadFileAction?id=68560) (accessed 3 March 2007, 8 December 2008).

education. Men are supposed to know everything and cannot admit ignorance, whereas women are not supposed to be aware of issues related to sex (Buve et al 2001:12).

The gender power differential is compounded by age differences and the economic dependence of women on men. Women typically marry or have sex with older men (Glynn et al 2001:S51-S60). In a multi-centre study (Buve et al 2001:14); the median age difference between spouses, reported by women, was 6–7 years (Ferry, Careal & Buve 2001:41–50). Furthermore, young married women in Kisumu and Ndola had a higher risk of HIV infection if their husband was more than three years older than them (Glynn et al 2001:51-60).

Women still face restrictions such as discriminatory laws in South Africa, traditions and cultural values when they try to access education, knowledge, land, capital and employment. As a result, women are economically dependent on their male partners; which makes negotiation of safe sex difficult. This affects their capacity to act upon knowledge and hampers the effectiveness of prevention strategies. The ABC campaign (Abstinence, Be Faithful, Condomise) which the South African government launched, has little or no effect when women are unable to make choices. For unmarried women and women who are widowed or separated, sex in exchange for money can be a strategy for survival or acquisition of goods. In another multi-centre study (Buve et al 2001:14), 40% of women in Kisumu and Ndola who had sex with persons other than their spouse in the previous year, reported sex in exchange for money or gifts. The corresponding figures for Cotonou and Yaoundé were 6% and 14%, respectively. Most of these women were unmarried and could not be termed sex workers (Ferry et al 2001:41–50).

The vulnerability of women results from a combination of factors which include war, poverty and prostitution, violence in slum areas, inadequate health services, poor levels of education, inability to make choices regarding their sex lives, and cultural barriers of patriarchy, primogeniture and gender discrimination. These factors all work to cultivate a situation of fear, where women feel they have no choice when it comes to engaging in sexual relations, as well as the terms of such sexual relations, for example, the use of contraceptives and condoms. Women feel that to voice their choices and opinions is to oppose men both in their private and public lives. Opposition to men in society is met with physical and mental abuse by their respective
partners and leads to the women being ostracised by society as a whole. The culmination of this is starkly revealed above in the statistical data of the peaked increase in deaths of women aged between 20 and 49. Migration, urbanisation and commercial sex for survival are also discussed above as key factors leading to the spread of HIV/AIDS. The following section examines the effects of HIV/AIDS both socially and economically in terms of gross domestic product (GDP), life expectancy and demographics.

2.4 SOME SOCIOECONOMIC CONSEQUENCES OF HIV/AIDS

Socioeconomics studies the link between economic activity and social life. Socioeconomic development can be measured in terms of GDP, life expectancy and population structure. The following paragraphs explain how HIV/AIDS has affected socioeconomic development from the change of population structure, lower life expectancy, lower quality of life through poverty, lower education levels and ultimately a lowering of overall economic skills. The consequences of HIV/AIDS can therefore be measured in tangible economic terms, a lowering of output and a shortage of skills and ultimately an increase in poverty.

2.4.1 Macroeconomic consequences of demographics, life expectancy and GDP

2.4.1.1 Demographics
Recent studies, including the figures released by Statistics SA, show that the HIV/AIDS pandemic has had a dramatic effect on South African demographics. Population growth, which in the 1980s was about 2% and indicated a population doubling time of twenty-five years, is now negative. School enrolments are down, and the numbers of orphans are increasing rapidly. Children are ending up caring for their siblings, or depending on pensioners for support. Life expectancy is markedly down. Economically active people are dying, causing a serious skills shortage and exacerbating the problem of poverty.

2.4.1.2 Life expectancy
The HIV epidemics in sub-Saharan Africa are causing profound changes in the population structure in more severely affected countries, that is, societies are becoming less functional mainly as a consequence of high mortality in adults and children younger than five years. In community-based studies in Tanzania and Uganda, the adult mortality attributable to HIV infection was 35–47% in Tanzania and 69–74% in Uganda (Boerma, Nunn & Whitworth 1998:S3–14).
In South Africa, where the HIV epidemic is of more recent onset, the Medical Research Council (MRC) estimates that in the year 2000, 20% of all deaths in adults was due to HIV/AIDS (Dorrington, Bourne, Bradshaw, Laubscher, Timaeusi 2001:8). In rural Botswana, Zimbabwe and South Africa, life expectancy has been estimated to have fallen from 60 years in 1990, to about 30 years by 2010 (Bonnel 2000:3). AIDS-related illness and death leads to deepening poverty. Furthermore, one of the first actions taken by households to cope with the crisis is to take children out of school, thus jeopardising their future.

2.4.1.3 Gross domestic product (GDP)

GDP is a measure of a country’s economic prosperity and performance (Chetty, Greyling, Heyns, Loots, Schoeman 1998:129). According to research conducted by the Bureau for Economic Research, simulation results of various scenarios show that AIDS will have a negative impact on the future GDP of South Africa. The Bureau for Economic Research’s results suggests that the South African economy will be 8.8% smaller by the year 2020 than it would have been without HIV and AIDS. According to this report in the absence of antiretroviral therapy (ART), the rate of GDP growth could fall from a projected average of 4.4% over the period 2000–2020 to 4.0% per year due to the HIV/AIDS epidemic (Horton 2001:1–3).

What is interesting about the Bureau for Economic Research’s results is that the per capita GDP is projected to be about 8.0% higher (in real terms) by 2020. Per capita GDP is the average domestic production for each member of the population (Chetty et al 1998:128). This projection shows how the per capita GDP is linked to life expectancy. The overall negative impact of HIV/AIDS-related deaths on the economy might be outweighed by the perceived benefit of a higher per capita GDP as the population shrinks.

However, the macroeconomic effect of AIDS is difficult to assess. It depends on how the epidemic affects savings and investment rates and whether AIDS affects better educated employees more than others (Loewenstein & Whiteside 1997:166–196). Some studies predict a negligible macroeconomic effect of HIV/AIDS in countries with a high unemployment rate, whereas others predict significant effects on growth rates, because of the loss of skilled or semi-skilled workers.
In Malawi, for example, the annual loss in per capita GDP as a result of AIDS is estimated to reach 0.7% by 2010 (Loewenstein & Whiteside 1997:199). A more useful indicator of the effect of AIDS might be the human development index, which is used to measure achievements in basic human development. The composite index includes life expectancy at birth, education and adjusted per capita income. For example, Zambia had a lower index in 1997 than in 1975, largely as a result of the effect of HIV/AIDS on life expectancy.33

2.4.2 Consequences of HIV and sexual abuse of children

The link between HIV and the sexual abuse of children is discussed below as women and children are inherently the most vulnerable members of society. Children represent the future generation as their moral, sexual and spiritual beings are being fashioned to cope with future relationships. This disease and the link with abuse not only affect their health but also their sexuality and their sense of self. As soon-to-be contributors to the GDP and overall economic climate of our country, they are also future economic units and their health, education and welfare is of high importance to ensure a healthy and sustainable future economy.

The incidence of HIV transmission in child sexual abuse is not known due to the fact that it is very difficult to research. In a study of 200 children conducted by the University of Cape Town, infection rates were difficult to assess as once an assault has been reported, children do not follow up treatment (Schaaf 2004:782). Therefore, researchers and counsellors should become aware that it is highly unlikely an abused child will be available for further testing at a later stage to check for infection. The prevalence of HIV infection in sexually abused children is said to be as high as 33%. It is pointed out later in this dissertation that sexual abuse is the most common co-morbid factor in children admitted to the hospices studied. Schaaf (2004:783) feels that poverty, gender inequality and disruption of families are significant contributing causes. There is also the myth that sex with a child or a virgin will cure STDs. As shown in chapter 4, an investigation of two projects, Sparrow Village in Maraisburg and St Francis Care Centre in Boksburg, provided

evidence of the high rate of child abuse of the children in the HIV hospices and care clinics.

2.5 TREATMENT AND PREVENTION OF HIV/AIDS

Like many diseases HIV cannot be cured at this stage of medical knowledge. It can, however, be treated. Results with ARV treatment depend on many factors: the stage of the disease, the particular strain of the virus, and the lifestyle of the infected person. Patient compliance is particularly important. Aids-infected people should be taught how to take their medicines regularly and monitor their own condition as effectively as possible. Therefore knowledge of the treatments and procedures is an integral component not only of effective prevention mechanisms but also of care.

According to current medical literature, treatment with ARVs is very successful. Patients that, a few years ago, would be expected to die within a year can now expect to go into remission for up to fifteen years. Successful treatment depends largely on good team work between a patient who is informed, compliant and responsible, and a well-trained and motivated team of health professionals. The cornerstone of effective treatment is good follow up with regular blood tests. The patient must also adopt a more ethically responsible lifestyle to prevent re-infection or the production of resistant strains of the virus. This means that the patient must be counselled sufficiently to understand that, as part of the care procedure, a modification of sexual behaviour is necessary. The knowledge a patient gains from this vital part of counselling and care will equip them to make moral choices which will prevent them from re-infecting themselves as well as infecting others.

Great strides have been made in ARV treatment in the last few years, both in efficacy and bringing down the cost. Although these agents are fairly toxic, and have many potential side effects, there is no doubt that they dramatically prolong life. Recent studies have shown that, in a sample of patients with a CD4 count of 100–200, who would normally be expected to die within a year, more than 85% were still alive three years after ARV treatment was started. Similar figures for a sample where the CD4 count was less than a hundred were even more encouraging. Where life expectancy would normally be less than a year, 65% were still alive three years later. A healthier lifestyle complementing ARV treatment has been stressed in studies. For example, good eating habits, a moderate use of alcohol and nicotine,
rest and exercise all contribute to a favourable outcome (Meintjies 2005:230).

The guidelines for ARV treatment have been modified constantly during the last ten years. Originally treatment was started soon, and with high doses of drugs (HAART: highly active anti retroviral treatment). However, it was felt that this regimen would lead to unnecessary drug side effects and increased drug resistance. Currently, ARV treatment is initiated when the CD4 count falls below 200, and is never monotherapy; in other words, more than one ARV drug is used.

Lately there seems to be a swing back to initiating treatment sooner: when the CD4 count is between 200 and 350 (Wood 2005:8). According to Professor Wood of the University of Cape Town, the life expectancy of untreated HIV is 6.3 years, that of a person with a CD4 count of less than 200 after ARV treatment is initiated, 17 years, and of a person where ARVT is initiated at a count of 350 is twenty-five years after diagnosis.

Continuing with risky sexual behaviour while on ARV compromises the effectiveness of treatment, leading to new infections and the proliferation of resistant strains of the virus. In chapter 5 some deductions are drawn on how the teachings and practices of the church can help to change habits and attitudes regarding lifestyle choices to avoid infection and the caring facilities that are required for those already infected. Let us now examine a few case studies which indicate the importance of knowledge, treatment and behavioural change.

2.5.1 Some case studies:

A medical practitioner I interviewed, who had been treating Aids for about ten years, outlined a few familiar scenarios to me which examine the outcomes of personal knowledge as well as issues of prevention and care.

The gardener:
A few years ago he saw a young man, a gardener, who was brought by his employer. After counselling the patient consented to an HIV test, plus a CD4 count. He had clinical Aids. The position was explained to him, and arrangements were made for him to attend the Hillbrow clinic.

34 Dr HW Martin, 4 August, 2006.
His employer was willing to shoulder the costs. After a few weeks the patient announced that he had consulted a traditional healer (cost: R1,500), and was now healed. Shortly after, he absconded, and was not seen again. This case is a frequent scenario in South Africa, with the majority of the population of South Africa visiting traditional healers instead of orthodox medical practitioners because they feel culturally that they trust and recognise the methods employed by these traditional practitioners. Thus, despite the fact that the gardener was counselled and had full medical and scientific knowledge of the disease, his personal responsibility of care fell short as, due to cultural habits, he was unwilling to subject himself to a consistent programme of scientific treatment.

The driver:
The second case involved a driver at an engineering works. He was losing weight and feeling sick. He approached his employer and requested help. He was counselled and tested. His CD4 count was 75. He was at death's door. After a post test counselling session, during which the importance of compliance was explained to him, he was put onto ARV treatment. He improved rapidly, gained weight and, three years later, is relatively fit and well. This case is a bold statement about how knowledge of the disease can lead to effective personal methods for the prevention of further re-infection and care. The case highlights the personal milestone of a decision-making process. The individual chose to make a decision after all the counselling, facts and information had been presented to him in counselling sessions.

The printer:
The third case involved a printer who was also brought by his employer. He was also tested after counselling and had a CD4 count of less than a hundred. His wife and son had died after illness during the previous two years. After the commencement of treatment he immediately became better. However, he soon married again. He did not bring his wife for testing, and then announced that he was attending a clinic, and no longer needed to take his medicine. Within a year he was dead. The case of the printer is a common one, where individuals are compliant and receptive to treatment whilst they are at death's door. However, the moment their health has been regained their decision-making processes veer off towards apathy, denial and omission. The printer's knowledge of the disease and the ramifications of re-infection were not applied to his desire to re-marry or the need to continue his medication. His
personal knowledge did not lead to choices which would prevent a deterioration of his health through a programme of care.

The young girl:
The final case involved a young girl, aged 15. She had attended a model "C" school until Grade 7, when she suddenly ran off with a male friend and disappeared for 6 months. When she reappeared, her mother brought her for an examination. She had advanced genital herpes. She was well informed regarding safe sex and the risks of HIV infection. She refused testing, instead opting to attend a state hospital. Here she was treated for a genital infection, but was not tested for HIV, despite the fact that her sister and niece had died of Aids. She is currently pregnant by another boyfriend and unmarried and still has not willingly undergone an HIV/Aids test. This case presents an ominous trend amongst South African youth. The girl in the case study was educated and knowledgeable about HIV/Aids. She had been affected by HIV/Aids fatalities in the sense that family members had passed away. Despite the knowledge she had of how HIV/Aids is transmitted and the necessity of safe sexual relations, her behaviour and its physical outcomes reflected poor moral choices in terms of prevention and care.

2.5.1.1 The medical, sociological and moral effects of the cases
The combined ethical medical and social implications of these four case studies underline the main issues involved in the Aids pandemic. Firstly, there is a reluctance to be tested, mainly because of the stigma involved and traditional views regarding healing. The gardener was convinced that he was cursed, that his traditional healer could lift this curse and remove the sickness. In this case a degree of ignorance combined with cultural beliefs was fatal. There is also the issue of a positive test disturbing existing relationships. In the teenager's case, she was afraid of losing her boyfriend, even if this could mean losing her life. She was not ignorant of the issues involved. The practical and moral choices they made led to their early demise.

The successful case, the driver, revealed the importance of patient compliance. A compliant, mature attitude from the patient combined with good medical backup and experience, can relegate Aids from the status of a killer disease to a serious chronic sickness, which can be effectively managed.

The printer illustrates a vital factor in the effectiveness of Aids treatment: life-style changes are as important after diagnosis to treat
the disease, as before diagnosis to prevent infection. The printer's case also highlights an issue of consistent compliance. The moment the printer felt the positive effects of treatment he neglected to take his medicine and follow up on his treatment effectively.

The importance of compliance is stressed by authorities. The Harvard Consensus Statement on Antiretroviral Therapy for AIDS states that "patients will fail to take antiretroviral drugs consistently in countries of lower income" (Orrell 2001:483-4). The reasons for noncompliance are complex, and include complicated schedules, the side effects of treatment and changed personal circumstances.

Although treatment with antiretroviral drugs is very promising, these drugs have a highly toxic profile. Lipodystrophy (a derangement of blood lipids) can lead to an increased risk of coronary artery disease. Rashes can be very severe, even fatal. Pancreatitis and blood dyscrasias, that is, diseases of the blood such as aplastic anaemia, are also recognised complications of ARV treatment.

Monotherapy is strongly contraindicated because of the development of resistance. Treatment is always initiated with a combination of three drugs, which must be taken as prescribed. ARV treatment calls for applied knowledge or discipline from the patients, dedication and competence from the care givers, and regular follow up visits.

Drug resistance is a huge problem in both the treatment of Aids and tuberculosis. There is the very real possibility that ARV treatment may be ineffectual in a few years because of the proliferation of resistant strains. The same problem is faced in the treatment and prevention of malaria, where it appears that we are running out of options.

The four cases outlined link the synergy between the medical sciences and ethical paradigms within a society. Medical professionals can make a positive impact in terms of knowledge, counselling and treatment. However, modification of sexual behaviour is a personal moral choice and ultimately affects the effectiveness of prevention and treatment. The dilemma of influencing a society's moral behaviour is a controversial one. The case studies show the sensitivity and complexities the medical profession face on a day-to-day basis with individuals who, despite counselling and therapy, choose not to make sound moral decisions. The multiple effects of these personal decisions
affect not only their own physical health but also their families, employers and, in the case of the young girl, even the unborn.

2.5.2 Prevention of transmission and re-infection

Those most at risk of accidental infection, such as medical personnel, ambulance attendants, hospice workers and police, should be equipped with protective gear and trained in its use. For doctors, nurses and medical students at risk from needle stick injuries, post exposure prophylaxis (PEP) should be readily available. PEP should also be available for rape victims.

Ideally, sexual contacts of infected persons should be similarly informed regarding the practice of safe sex. Infected persons need to be counselled and educated as to the risks of re-infecting themselves and infecting others. It is only by boldly explaining the causes of infection and the risks of re-infection that those infected can better protect themselves and safeguard others from also becoming infected.

By empowering the population with the knowledge of what causes the disease, ways to prevent infection, how to prevent re-infection and where to receive care and treatment, we will be better equipped to face the socioeconomic challenges and changes as outlined above. The quality of information received is crucial and should preferably be disseminated in a language that is understandable, using concepts and explanations which are easy to grasp with an opportunity to ask questions or seek advice. Methods which prove to be effective are counselling and education by care workers as seen in Sparrow Village, Maraisburg and St Francis Care Centre, Boksburg, education programmes at schools, high schools and universities and technikons, and open discussions within the church setting. Media strategies prove to be problematic and ambiguous, as with the much-criticised LoveLife campaign.

Methods of prevention need to be explained thoroughly, from abstinence, to using condoms, to being faithful in a relationship. Likewise care and treatment facilities need to be available and known to infected persons and non-infected persons so that the broader public are aware of terms such as ARVs and PEP.

People partaking in risky sexual practices, such as having multiple sexual partners, need to take precautions. Also high standards for
testing donated blood are mandatory. Blood transfusion services have developed a protocol to reduce the risk of passing on infected blood to a minimum. Some of these precautions have led to furious debates where the perception is that some people are being discriminated against.

Mother to child prevention during pregnancy has been a subject of debate. Single dose Nevirapine, while reducing infection by over 80%, can lead to the detection of resistant strains of the virus in more than half of the women so treated (Shishana, Rehle, Simbayi, Parker, Zuma, Bhana, Connolly & Jooste 2005:739–781). This effect can be reduced by more sophisticated combination therapy which is only slightly more expensive.

2.5.3 The treatment of opportunistic infections

The various opportunistic infections found in people living with Aids are often life threatening. A person with a low CD4 count should be given Trimethoprim Sulphamethoxazole for life, to prevent some of the more serious opportunistic infections. Tuberculosis, pneumonia, diarrhoea and the like should be treated for the specific organism.

2.5.4 Palliative treatment

Terminally ill patients need palliative treatment to make them comfortable and ease the agony of dying. Treatment for diarrhoea, vomiting, mouth ulcers and throat infections are important. Hospice work is of great importance here. Co-morbid diseases like tuberculosis need treatment. The mode of death is usually overwhelming opportunistic infection.

2.6 THE IMPACT OF THE GOVERNMENT AND THE ANC ON HIV/AIDS

In 1987, despite few infections, the apartheid government recognised that HIV/Aids had the potential to become a problem. The Aids Foundation stated that, at the time of the first antenatal survey in 1990, only 0.7% of pregnant women were infected. Also in 1990 according to the Aids Foundation, Chris Hani, speaking from exile, warned that: "Existing statistics indicate that we are still at the beginning of the
AIDS epidemic in our country. Unattended, however, this will result in untold damage and suffering by the end of the century".35

In 1992 a National AIDS Convention of South Africa (NACOSA) was established and the new ANC government accepted its strategy for fighting AIDS in 1994. From this time, the way in which the HIV/AIDS crisis was dealt with has been ineffective and controversial.

The reason why the current government and the African National Congress (ANC) needs to be discussed in greater detail in this study is to equip and enable the church and faith-based projects to gain a better understanding of how and why the majority of people in South Africa trust and depend on the government. The current public opinion and reaction to government's policy and implemented programmes addressing HIV/AIDS, and all the concomitant factors affecting HIV/AIDS sufferers, have not happened overnight.

What is important to keep in mind is that the ANC has a long history of referring to and working with the church; the party also collaborates with cultural and traditional leaders. The church regularly gathers with ANC members to discuss concerns and render advice to officials. As a local pastor said: "Church leaders can be an active voice from God and offer unbiased advice and guidance to help the new leadership to be united and take decisions that will benefit their community and the people of the province as a whole".36

A brief examination of the initiatives the government of South Africa has set in place and their sustainability is cause for alarm. There are very few that have survived and brought meaningful change to the lives of women. Lovelife, the ABC campaign and various other media initiatives have had little impact on the lives of women. Some programmes are criticised by the media for, in fact, inciting the youth to participate in sexual activities. Posters, banners and advertisements with explicit photographs of sexually titillating material were used by Lovelife with small reminders at the bottom that illicit sexual activities led to contraction of the virus. No cognisance was taken of the fact that many people are illiterate and only saw the sexually explicit

photographs and the images were decoded to signify that risky sexual practices were acceptable, which were contraindicated to the fight to stop people from engaging in risky sexual exploits.

In 1997 the Inter-Ministerial Committee on HIV/AIDS (IMC), chaired by then Deputy President Thabo Mbeki, outlined a South African strategy for coping with the pandemic. Various areas of concern were outlined and measures proposed. The launch in January 2000 of the South African National AIDS Council to replace the IMC (chaired by the then Deputy President Jacob Zuma) followed. The main aim of this plan was to reduce the spread of infection by encouraging behaviour modification; abstention, monogamy, the use of condoms, and avoidance of intravenous drug use, and precautions for medical personnel. It was vital to raise public awareness of the nature of the infection, the modes of transmission and the measures needed to minimise person to person transmission.

These goals were to be realised by according the epidemic a high public profile (e.g. being mentioned often by the President and public figures, by encouraging an information campaign using billboards, the media, posters and the like, and arranging special events, dinners and galas). Business people would be mobilised through conferences and the trade unions. Condoms would be widely distributed. High risk people were to be identified and targeted. These included travellers, soldiers, truck drivers, sex workers and medical personnel. Mine workers were particularly at risk because of the hostel system and the availability of sex workers. Attention was also focused on mother to child transmission, which occurred during the birth process and breastfeeding.

In tandem with this educational strategy, a need was identified to train caregivers and counsellors, and to make cheap and effective testing facilities available. Legislation was passed to bring about the abolition of discrimination, especially in the workplace, including pre-employment testing, and the prohibition of dismissal on the grounds of infection with HIV.

Traditional leaders were to be trained in the basics of the infection and seconded to raising public awareness. Women's organisations were to explain to their members the particular vulnerability women have for the virus, and to raise awareness as to their rights. The youth would be approached via school and nonschool programmes. The need for
community-based health care systems was identified. Home care as well as hospice-based care required the services of volunteers, who needed to be trained. Social and economic support would extend to the care of orphans, and families who had lost their breadwinners. The National Aids Committee of South Africa launched the LADUMA project, which was a photo comic, funded by the Department of Health, Western Cape, the Levi Strauss Foundation, the Australian Agency for International Development, and the European Union. This comic aimed at informing the youth about HIV through their love for football. The comic featured a township boy, a brilliant soccer player, who gets infected through casual sex.

Dr Xundu of the Health Ministry said that the anti Aids drive involved the efforts of 12,000 doctors, 9,400 nurses and 21,000 voluntary or minimum stipend home-based caregivers, working in 340 hospitals linked to 4,302 primary health care centres. Seventy-three percent of these centres offered counselling and voluntary testing. By the end of April 2005, 1.2 million people had been counselled, 70% of these tested and 50,000 had commenced ARV treatment (Bateman 2005b:458–460).

2.7 THE DISSIDENT FACTOR

Aids dissidence has been an important factor in the evolution of the pandemic, and has been serious enough to merit detailed examination by the medical authorities. It has also negatively affected the implementation of the strategies of prevention outlined in the previous section. Aids dissidence has been a factor to consider in how information is disseminated, interpreted and acted upon. Therefore the affect of Aids dissidence cannot be over-emphasised in public campaigns relating to knowledge, prevention and care. Some of the views have a pseudoscientific sheen to them, and therein lies the danger. The denial of the existence of the HIV virus is highly detrimental to the attempts of all concerned, including government, nongovernmental and faith-based organisations, to create an awareness of the dangers of unsafe sexual practices. When the dissidents are prominent leaders, they create confusion in the minds of many, particularly the youth. This has a negative impact on the general public’s knowledge of the disease and their ability to make viable ethical decisions. All the condoms that have been distributed to universities, schools and youth centres are of no effect if the President
and the Minister of Health of the country deny the existence of the virus or downplay it as just another illness. 37

Popular dissident arguments are that the HIV test is unreliable and that there is no Aids in Africa. Aids is nothing more than a new name for old diseases and HIV cannot be the cause of Aids because researchers are unable to explain precisely how HIV destroys the immune system. AZT and other ARV drugs, not HIV, cause Aids and some people have many symptoms associated with Aids but are not HIV positive. There have even been suggestions that vaccination projects by the West have caused the Aids epidemic.

A frequently mentioned theory in dissident opinion is that the HI virus does not really exist, or that, if it does exist, it does not cause Aids. These pronouncements usually end with an invitation to any interested party to supply evidence to the contrary. In view of such determination to deny conventional medical evidence, it seems futile to supply such evidence. Nevertheless, the virus has been photographed by means of an electron microscope by several respected authorities, and its genome mapped as shown below.

![Viral particles are seen at medium magnification in this electron micrograph. Note the central core and the outer envelope. The image was provided by Edward C Klatt, MD, Department of...](image)

37 Now, since September 2008, the ex President Thabo Mbeki and ex Minister of Health Manto Tshabalala Msimang.
Pathology, University of Utah. From AIDS Pathology.

Viral particle seen by Scanning electron microscopy (SEM) at a magnification of 26,400x of human T-lymphotropic virus attacking a T-lymphocyte. This image is from Dennis Kunkel’s excellent Microscopy Science and Photography Through a Microscope website.

Nevertheless, these dissident views are regularly aired in the letters columns of the South African press by self-proclaimed experts. An examination of these arguments and explanations of the medical facts involved can be found at http://www.niaid.nih.gov/default.htm, the website of the National Institute of Health at Bethesda, Maryland, USA.

Progress in rising to the challenges of the pandemic can be severely hampered by these views, especially if they are adopted by influential people. Mantras such as “a virus (infective organism) cannot cause a syndrome” display profound confusion: endless debate occurs in the newspapers’ letters page as to what a syndrome really is. A syndrome is defined as a group of signs and symptoms with a common cause. Often these manifestations appear unrelated, but further study reveals their common causality. The signs and symptoms of the Acquired Immune Deficiency Syndrome are many and varied, and include wasting, fevers, chronic diarrhoea, opportunistic infections, tumours and dementia. All of these have a common cause: the destruction of the immune system as evidenced by a low CD4 count. You cannot have Aids with a normal CD4 count, and a low CD4 count is virtually exclusively found in HIV-positive people. In a well-known study in the USA two groups of gay men were studied. They had everything in common (their diets, sexual habits, socioeconomic circumstances, and recreational drug use) except for one factor: one group was HIV positive, the other negative. The negative group had normal CD4 counts, the positive group depressed counts. This was the group that, with time, developed Aids (Schechter, Craib, Gelmon, Montaner & O’Shaughnessy 1993:957–958).

2.7.1 The South African government and Aids dissidents
An article in The Spectator (20 September 2000) quoted Mbeki as saying: "Does HIV cause Aids? Aids is an acquired immune deficiency syndrome. I don’t believe it is a sensible thing to ask if a virus causes a syndrome. A single virus cannot cause a syndrome. A virus causes a disease. Aids is a syndrome … including 29 different diseases. When you ask the question, does HIV cause Aids, the question is: does a virus cause a syndrome? It can’t" (Kenny 2004:1–3).

In April 2000, President Mbeki addressed a letter about HIV/AIDS in Africa to world leaders. The following is an extract:

We will not, ourselves, condemn our own people to death by giving up the search for specific and targeted responses to the specifically African incidence of HIV-AIDS.

I make these comments because our search for these specific and targeted responses is being stridently condemned by some in our country and the rest of the world as constituting a criminal abandonment of the fight against HIV-AIDS. Some elements of this orchestrated campaign of condemnation worry me very deeply.

It is suggested, for instance, that there are some scientists who are 'dangerous and discredited' with whom nobody, including ourselves, should communicate or interact. In an earlier period in human history, these would be heretics that would be burnt at the stake! Not long ago, in our own country, people were killed, tortured, imprisoned and prohibited from being quoted in private and in public because the established authority believed that their views were dangerous and discredited.

We are now being asked to do precisely the same thing that the racist apartheid tyranny we opposed did, because, it is said, there exists a scientific view that is supported by the majority, against which dissent is prohibited. The scientists we are supposed to put into scientific quarantine include Nobel Prize Winners, Members of Academies of Science and Emeritus Professors of various disciplines of medicine! Scientists, in the name of science, are demanding that we should cooperate with them to freeze scientific discourse on HIV-AIDS at the specific point this discourse had reached in the West in 1984.

People who otherwise would fight very hard to defend the critically important rights of freedom of thought and speech
occupy, with regard to the HIV/AIDS issue, the frontline in the campaign of intellectual intimidation and terrorism which argues that the only freedom we have is to agree with what they decree to be established scientific truths.

Some agitate for these extraordinary propositions with a religious fervour born by a degree of fanaticism, which is truly frightening. The day may not be far off when we will, once again, see books burnt and their authors immolated by fire by those who believe that they have a duty to conduct a holy crusade against the infidels.

It is most strange that all of us seem ready to serve the cause of the fanatics by deciding to stand and wait (Mbeki 2000).

These views on the part of the ex President and his ex Minister of Health have led to a severe rift between the United Nations and the South African government. Sharon Lafraniere reports in the New York Times that Stephen Lewis, the UN's special envoy on AIDS to Africa, has outlined this difference in a new book titled The race against time. Lewis writes that "every senior UN official, engaged directly or indirectly in the struggle against AIDS, to whom I have spoken about South Africa, is completely bewildered by the policies of President Mbeki" (Lafraniere 2005:14). Lewis's opinion drew a sharp response from the Health Ministry, in which he was accused of bias.

In a question and answer session in Parliament on 18 February 2005, which was attended by TAC members and the South African Health Minister, Manto Tshabalala-Msimang, once again expressed doubt as to the efficacy of ARVs, and suggested that traditional medicines and her dietary recommendations comprised a viable alternative line of therapy. This was a few days after Statistics South Africa had released its study showing a massive increase in deaths in South Africa. There have been controversial opinions voiced by the Minister that a diet of garlic, olive oil and the African Potato is as good, if not better, at combating HIV than ARVs, as illustrated in the following cartoon.
The Minister unapologetically reiterated her conviction that micro-

nutrients were a viable alternative to ARVs at the second national 

HIV/Aids conference in Durban in June 2005 (Bateman 2005a:464). She 

also rebuked the conference chair, Professor Lynn Morris, for asking 

whether the Department would be giving an update on the government’s 

national HIV/Aids plan. She told 3,900 scientists attending the opening 

session that an alternative approach to health and medicine was an 

attempt to restore the dignity of Africans through traditional medicine.

When criticised by the former World Bank Director, Dr Ramphele, the 

Minister said: “What is all this about proof and tests – nobody 

understands HIV and Aids.” Tshabalala-Msimang did her best to 

downplay the impact of HIV, calling for equal attention to be paid to all 

illnesses.38

The relevance of the statistics released by Stats SA was called into 

question by the interim president of the Medical Control Council, who 

stated that data from death certificates was explicit enough to draw 

conclusions from in South Africa (Mbewu 2005:78).

This viewpoint was criticised by Ehrlich and Myers (2005:2), who 

pointed out that ignorance as to the deceased’s HIV status and 

pressures to maintain confidentiality were factors preventing a medical 

practitioner from certifying HIV/Aids as an underlying cause of death.

In June 2005, at the second South African Aids Conference in Durban, 

Health Minister Tshabalala-Msimang was quoted as saying that broken

teeth and diabetes are just as important as HIV/AIDS (*The Star*, June 8: 2005). She repeated her views that vitamins and nutrients are a viable alternative to ART.

The ethical issues of HIV/AIDS are compounded by voices lauding the actions of both government and the Minister of Health, Manto Tshabalala-Msimang. Anthony Brink, in his book *The Problem with Nevirapine*, condemns the Treatment Action Campaign for their demands on the government, through the courts, to provide Nevirapine to pregnant women.39 His reasoning being that there was no clinical trial data on the efficacy and safety of the drug and in fact that the drug was dangerously toxic to babies.

The dissident factor is discussed here as it is an important factor within our political setting and only fuels the confusion, ambiguity and uncertainty of what the disease is; how one becomes infected and how one is treated. The denial at government level has hindered cooperative and mutual strategies to address knowledge of the disease, strategies of prevention and for infection and re-infection and varied means of treatment and care. With the social and medical arguments presented above as a backdrop, in the following section we discuss the ethical implications of AIDS with a particular focus on women.

2.7.2 The politics of denial and obstruction

Unfortunately, it takes more than a good plan to achieve a goal. In South Africa, government intervention in the pandemic has not been consistent, coordinated or particularly successful in the past. Denial and obfuscation have been well documented. There are observers who feel that AIDS is a purely medical matter, and should be left to Health Specialists (*Modi & Webber 2004:80–82*). There has also been criticism of the way government has handled aid funds from abroad (*Bateman 2002b:848*). The Health Minister was quoted as being furious because the Global AIDS fund had awarded R712 million to AIDS intervention projects in KwaZulu-Natal, without siphoning the money through her department (*Mbanjwa 2003:4*). She insisted on exercising what she saw as her right to distribute the funds as she saw fit.

It would appear that there is no shortage of funds; however, implementation of meaningful policy has been hampered by infighting and poor management skills (Bateman 2002b:848). There has been an ongoing fight between the Treatment Action Campaign (TAC) and the government, which led to litigation and a defeat for the Minister of Health in court. To add insult to injury, the TAC was awarded the 2003 Mandela Award for Health and Human Rights.

Some government officials have demonstrated a serious lack of insight as to the issues involved in the pandemic. In 2002, the Mpumalanga Health MEC, Sibongile Manana succeeded in dismissing the superintendent of the Rob Ferreira Hospital in Nelspruit. The dispute centred on the activities of a volunteer organisation which counselled rape victims and initiated post-exposure prophylaxis. The MEC went as far as denying access to baseline HIV tests for survivors. She expressed utter determination to evict the NGO involved, saying that she would be preventing the state hospitals being run by NGOs. She subsequently reported to Parliament that less than 20% of Mpumalanga’s Aids budget had been spent. She alleged that the Greater Rape Intervention Programme (GRIP), the NGO in question, was financed by a “third force”, bent on poisoning black people (Bateman 2002a:489–490).

The government still seeks to recruit the support of traditional healers, and it emphasises their importance in the community. The adequate and convenient provision of ARV drugs is being discussed, as are social mobilisation and communication programmes aimed at maximising community efforts to meet the challenge of the pandemic. This is an ambitious and detailed plan with a budget of about R4 billion. As the plan was still before Parliament at the time of writing, it had not yet been finalised.

The Aids Consortium, South Africa’s largest Aids body, has been all but crippled by bitter infighting over the management and allocation of funds (Deane 2004:7). Yet, despite the reports of mismanagement, corruption and a lack of transparency, a report in BUANews states that government plans to increase expenditure on HIV/Aids.40

It also appears that resources are wasted on the never-ending cycle of meetings and conferences to continually recycle issues that should have been settled years ago. The general cynicism felt by many involved in these conferences is summarised in the following anonymous poem:

**The Development Set**

Excuse me, friends, I must catch my jet—
I’m off to join the Development Set;
My bags are packed, and I’ve had all my shots,
I have traveller’s checks and pills for the trots.
The Development Set is bright and noble,
Our thoughts are deep and our vision global;
Although we move with the better classes,
Our thoughts are always with the masses.

In Sheraton Hotels in scattered nations
We damn multinational corporations;
Injustice seems easy to protest
In such seething hotbeds of social rest.
We discuss malnutrition over steaks
And plan hunger talks during coffee breaks.
Whether Asian floods or African drought,
We face each issue with an open mouth.

We bring in consultants whose circumlocution
Raises difficulties for every solution—
Thus guaranteeing continued good eating
By showing the need for another meeting.
Consultants, it’s said, believe it no crime
To borrow your watch to tell you the time.
Their expenses, however, are justified
When one thinks of the jobs they might later provide.
The language of the Development Set
Stretches the English alphabet;
We use swell words like "epigenetic,"
"Micro," "macro," and "logarithmic."

It pleasures us to be so esoteric—
It’s so intellectually atmospheric!
And though establishments may be unmoved,
Our vocabularies are much improved.
When the talk gets deep and you're feeling dumb
You can keep your shame to a minimum:
To show that you, too, are intelligent
Smugly ask, "Is it really development?"
Or say, "That's fine in practice, but don't you see:
It doesn't work out in theory!"
A few may find this incomprehensible,
But most will admire you as deep and sensible.
Development Set homes are extremely chic,
Full of carvings, curios, and draped with batik.
Eye-level photographs subtly assure
That your host is at home with the great and the poor.

Enough of these verses--on with the mission!
Our task is as broad as the human condition!
Just pray God the biblical promise is true:
The poor ye shall always have with you (Author Unknown).

On 22 September 2008 a new interim President was sworn in, Kgalema Motlanthe. The ANC also elected a new Health Minister, Barbara Hogan, a respected HIV/Aids activist. Hogan has already broken conventional ANC doctrine by declaring that the disease is unquestionably caused by HIV and must be treated with conventional medicine. Some analysts are positive Hogan will be successful in breaking away from a decade of denialism and confusion.41

Therefore, there is an exciting possibility of fresh beginnings and a desperate need for collaboration now, more than ever between churches and the government, to address knowledge of HIV/Aids, prevention of the disease and care of sufferers, particularly women who have been hardest hit.

2.8 THE ETHICAL IMPLICATIONS OF AIDS, ESPECIALLY FOR WOMEN

2.8.1 Medical ethics and disclosure

David Benatar maintains that the role of ethics is to enable people to think more clearly about moral issues. According to Benatar, there is a

demand for ethical expertise in medical fields. In medical ethics in general and in ethics related to HIV/AIDS in particular, we often encounter problems characterised by the fact that there are extremely complex issues which are intrinsically ambiguous. As Christians, our moral judgement of people infected by HIV/AIDS is tested once a context is taken into account or we engage with broader narrative.

As noted in chapter 1, medical, sexual and feminist ethics are important in the study of HIV/AIDS, especially as it affects women. These ethical fields are interrelated and co-dependent. John Stone, a Doctor of Bioethics, writes about the importance of collaboration between HIV/AIDS researchers, scientists and communities (Stone 2003:8). A process of debate should be encouraged with all three ethical fields to produce the kind of thoughtful judgement that is always more valuable than simplistic conclusions reached without the benefit of careful, sustained reflection and discourse (Benn & Boyd 1996:5).

Thiroux defines bioethics as “life ethics” or ethics in medicine which concerns itself with the establishment and maintenance of vital and moral human relationships. It is, according to Thiroux, concerned with “treatment” in the broadest sense (Thiroux 1995:374).

There are three views concerning the relationship of health care professionals and patients (Thiroux 1995:374-377).

1. The view of paternalism takes the view that health professionals should take a parental role; they are deemed privileged because of their expert knowledge. Thus patients should place themselves entirely in the medical professional’s hands.

2. There is a position called radical individualism which believes patients have absolute rights over their bodies. This position ties in with beliefs that patients know their own bodies and they should be the ultimate decision makers when it comes to their health and physical welfare. This view is a motivator for ethical issues of informed consent and confidentiality; patients should be informed in order to make their own choices about their health and confidentiality is of paramount importance to protect the individual and the individual’s choices.

3. The last position is called the reciprocal view which is a collaborative team approach. This position is more active and

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42 Benatar states that the demand for ethical expertise is leading to a “snake oil” view of ethics which is a quick fix and is substandard. He suggests that when we look at ethical dilemmas, we discuss topics of relevance to practitioners with practical solutions rather than esoteric matters in ethics (Benatar 2003:7).
participatory in decision making, with doctors and patients working together with shared information which is easily understandable and informative in order to come up with the best possible decisions for medical treatment and the patient, as well as the public at large.

Truth-telling and informed consent are based on principles of a patient's right to know, the sharing of appropriate information both by the patient and the medical professional (Thiroux 1995:378). The ethical issues above become particularly ambiguous and dangerous when it comes to treating HIV/AIDS patients and dealing with their families. The ethical dilemmas of confidentiality and informed consent are particularly confusing. For example, should a medical professional disclose a patient’s HIV/AIDS status to a spouse who may be at grave risk of infection? Should the medical professional disclose a patient’s HIV/AIDS status to a patient’s employer if the patient is, for example, working with children? According to Jens Mielke, when it comes to the direct harm of spouses or partners who are great risk of infection, the HIV/AIDS status of a patient should be disclosed. Mielke recognises that this presents a conflict of interest between a primary responsibility towards a patient and an identifiable individual who is at significant personal risk (Mielke 2003:35).

The UN, the WHO and the SAMA also provide guidelines for "disclosure without consent" when a patient refuses to tell their partner that they are HIV-infected and there is a real risk of infection to an identifiable sexual partner. However, according to JOURNAIDS, there is no "disclosure without consent" to HIV/AIDS patients' immediate family, as HIV/AIDS is not a notifiable disease.

The issues of disclosure and confidentiality of HIV/AIDS has largely been regulated by legislation, policy and case law. For example, according to labour law and legal cases, and the Employment Equity Act, employees may not be dismissed purely because they are HIV positive. There is only a restricted number of cases where employers can legally request a person's HIV status (Labour Relations Act, South Africa, 1995).

Case law, likewise, has set precedents where the courts have been tested with cases of discrimination and stigma. In an unreported judgement of Karen Perreira v Sr Helga Nursery School, a nursery school was sued because it deferred a decision to admit an HIV-
positive child stating that they were not ready to look after HIV-positive children. The court, however, did not find on the matter because, it was found, the school had merely suspended its decision to admit HIV/AIDS-infected children. The decision has received criticism from jurists stating that the decision further perpetuates stigma.43

Whilst HIV is not a listed ground in the equality clause, the Promotion of Equality and Prevention of Unfair Discrimination Act (2000) sanctions the courts' discretion in dealing with each case individually. This can be seen in the case, Constitutional Court in Hoffmann v SAA 2000 (1) BCLR 1211 (C). The court held that refusal by an employer to employ someone on the basis of their HIV status constitutes unfair discrimination in terms of the equality clause. A strong ethical statement came from Judge Ngcobo who said that “people living with HIV must be treated with compassion and understanding. We must show ubuntu towards them. They must not be condemned to economic death by the denial of equal opportunities in employment”. 44

Thus there is a body of policies, case law and legislation that has been tested and largely protects the rights of HIV/AIDS-infected people against unfair discrimination and stigma. However, there are ethical arguments about HIV/AIDS not being a notifiable disease to the broader community at large (Mielke 2003:34). Women in particular are vulnerable if partners do not disclose their HIV/AIDS status. Most African women living in rural areas are particularly vulnerable as they have very little information or education at their disposal.

It is trite to say that all health care workers and related institutions have a moral and legal duty to keep a patient’s status confidential. The locus classicus on the right to privacy is the Appeal Court's decision of Jansen Van Vuuren v Kruger 1993 (4) SA 842 (A), where Judge Harms held that where rights of this nature are threatened, people should be afforded protection by our courts.

2.8.2 Ethical issues of women and moral decision making

Connors and McCormick (1998:223) suggest that women often find themselves in a world shaped and contaminated by patriarchal, colonial

and racist structures, that they have developed a learned helplessness and a passive participation in their own victimisation. In my experience and dialogue with women, many African women have no ability to change their circumstances and are completely helpless to make choices or even to change their environment.

The world in which women live shapes their behaviour towards other people as well as their self-identity. The social context of sub-Saharan Africa which is largely patriarchal and violent will have an impact on women's decisions. Connors and McCormick (1998:223) suggest that there are six basic traits that characterise human persons capable of becoming a person of good character: a human person should be free, intelligent, responsible, unfolding, social and spiritual (223). Freedom means to be independent, not to be controlled by obligation or the will of another. Intelligence means one should have the capacity to understand; think and make adequate decisions, which is closely connected to a sense of inherent responsibility to oneself and others. Unfolding means an opening out; a gradual opening to understanding, in other words, that a person can be receptive to new ideas, concepts and insights. For a person to be social means having the independence and ability to network and interact with the community and their peers, to become socially involved and socially responsible. To be spiritual means for them to become God oriented as opposed to carnal.

Thus being spiritual implies becoming open to the work of God's Spirit in their lives. It means looking beyond the corporeal to the intangibles dealing with the spirit, God and the soul also as these relate to their material lives. Most of the women interviewed for this study and encountered during the research had neither the freedom to choose their sexual behaviour nor to be good people in terms of moral choice. Without this basic freedom, it is not possible to proceed with the other character-building exercises and this could be the cause of their vulnerability to the HI virus.

The incapacity of women in Africa to make firm decisions with regards to sexual encounters and sexual safety, as well as their lack of knowledge, has created a minefield with regard to education, treatment and prevention campaigns. According to the World Food Summit most
women only find out they are HIV positive when they visit an antenatal clinic.45

The lack of will to get tested prior to falling pregnant is a cause for concern; questions must be raised about disclosure and notifiability when it comes to women who are becoming infected with the disease with no knowledge whatsoever that their partners are infected.

In Uganda in the age group 15–19, seven times as many girls as boys are infected (Marcus 1993:22). As the pandemic spreads, men are seeking ever younger females with whom to have sex. Thus with the age of the female partner in a sexual encounter becoming increasingly younger there is an even greater risk that the female will not have the capacity to fully understand and appreciate the act engaged upon. This lack of knowledge as well as the lack of capacity disallows young females the exercising of their moral choices; a situation is created in which women are often helpless, voiceless victims. Their moral choices are taken out of their control and they are mute when it comes to fully protecting themselves or following prevention and care strategies.

Physiological factors also make it easier for females to become infected: the mucosa of the vagina is very permeable to viruses, especially in the presence of concomitant sexually transmitted diseases which cause ulcers. By the nature of female anatomy, these ulcers are often invisible. Women, by virtue of their subservient status in Africa, are often denied an education, and are not aware of the significance of vaginal sores or discharges. Furthermore, a basic lack of education is further enflamed by a lack of information through reliable sources such as the media and telecommunications such as the internet or television. This affects women's overall knowledge of HIV infection and prevention.

Many women are illiterate and cannot read posters and other literature about the disease, as well as having little access to and understanding of the media. Information is mostly distributed by friends and relatives. The church plays a valuable role here, but according to Marcus, can do more harm than good by moralising (Marcus 1993:22). The message of fidelity is thus thought to be futile because many African women who

are subordinated by their partners are in no position to demand such from their partner.

Although many African women are monogamous, the same cannot be said for their male partners. Male sexual promiscuity is not culturally rejected in Africa, and is often regarded as the norm. In modern Africa traditional sexual taboos have largely broken down. It is also unheard of for a woman to refuse a man sex: there are documented cases of girls who have left their husbands after assault and abuse being forced to return by their mothers. It has been documented that women in abusive relationships have a substantially higher risk of contracting HIV (up to 50%) (Reaney 2004:29).

Other cultural practices are important in accounting for the ease with which women contract the virus. Dry sex is well documented, where the woman dries up vaginal secretions by inserting herbs intravaginally. This leads to trauma to the mucosa and facilitates absorption of the virus (Kistner 2003:48–53). There is also the culture of “washing the woman”, where a widow is passed on to another male member of the family.

Physical and sexual abuse of women by their partners is rife in South Africa. A study in Durban showed that 38% of women attending the antenatal clinic at a state hospital had been physically abused. Six hundred women from a low income community were included in the study (Mbokota & Moodley 2003:455). The conclusion was that these acts of violence and abuse were seldom isolated events, and tended to escalate in frequency and severity over time. Surprisingly, the mother-in-law was the abuser in a quarter of the cases.

Another setback for South African women is the legal position on testing of HIV/Aids when a sexual assault takes place. A victim of rape or sexual assault will be able to request that the sexual offender be tested for HIV, according to the Compulsory HIV testing of Alleged Sexual Offenders Bill (2003).

Only the victim and the offender have access to the results. The victim is not allowed to disclose the offender's HIV status and the HIV test is not admissible as evidence in criminal or civil proceedings. Rapists are notoriously repeat offenders; so once again, the fact that a perpetrator's HIV/Aids status cannot be disclosed is a cause for
concern as other women are at risk of infection from a sexual predator.46

Male reluctance to use condoms is well documented, and relates to the belief that a real man always ejaculates inside a woman. A survey in Uganda in 1987 showed that only one man in 10 had ever used a condom. By 1992, after condom use had been emphasised as an anti Aids measure, only an insignificant rise in condom use was recorded (Anderson 1993:393–394).

Worldwide, the majority of women infected with HIV were infected by their husbands. A common finding in questioning women on what measures they themselves think they could take to limit their exposure to Aids was their helplessness to take definitive precautions. Universally, they felt that it was imperative to modify their husbands' behaviour. It becomes clear that preventing the infection of women depends largely on getting through to men that their lifestyles need to change. Ethically, these women are restrained, unable to make effective decisions despite any personal knowledge of the disease, to prevent infection or to take adequate measures to care for themselves if infected by means of treatment for fear of stigma and judgement. This feeling of helplessness and powerlessness is a sign of their inability to act. Referring to Connors and McCormick's basic traits of becoming a person of good character, these women are held captive by a lack of freedom, their inability to unfold and their arrested social and spiritual development.

When it comes to ethics of prevention, methods of condom usage, abstinence and faithfulness are all affected by women's feelings of lack of empowerment, a feeling of being culturally and socially mute and unable to make decisions affecting their sexuality. A study carried out at the University of Botswana showed that students, although familiar with the causes and effects of Aids, were reluctant to use condoms. They cited cultural factors (older men having sex with young women) and lack of female empowerment as prime factors in condom rejection. They also recommended that lecturers and faculty members who have sex with students should be dismissed (Kelly 2001:16).

The message of abstinence is also not very successful. In some sub-Saharan countries schoolgirls exchange sexual favours with older men for school fees and other favours. Little value is placed on virginity and a climate of promiscuity seems to be growing. The tendency is to blame circumstances rather than to have a sense of accountability for actions. As Kaye and Wenham (1978:173) state “to accept accountability for one’s choices is part of what it means to be truly human, and any proposal to ignore or change this, or to destroy people’s awareness of it, is not humanizing; just the opposite. It is the most radical and grotesque dehumanisation that can be imagined”.

Attempts to promote abstinence in school children have been largely unsuccessful, perhaps because of prevailing attitudes of virility and fertility in the broader community. Around 25% of 15–24-year-old girls in KwaZulu-Natal said they had been “tricked” or “persuaded” into their first sexual experience.47

The ABC campaign has been well publicised, the ABC standing for abstinence, be faithful and condomise. The success of this campaign is open to debate. Wits University showed that many young girls, although well aware of the campaign and well informed on the epidemic, chose unsafe sexual behaviour rather than risking losing their men. Workplace-based peer education programmes have been in place for about ten years and recently came under review (Flisher 2005:245–248). The results were extremely disappointing, and called into question the effectiveness of similar programmes in high schools (Flisher 2005:245) Although these initiatives have been in place for a number of years the prevalence of HIV in the 15–19 year age group is still rising (Dept Health, Western Cape).48

Peer education theoretically influences adolescent behaviour by modifying social norms.49 “Opinion leaders” (peers who are popular in the group) are enlisted to help change perception of norms. The sentiment amongst women in particular, their insecurity of being involved with a man or losing him, becoming sexually active at a young age to try to keep the man in her life satisfied, whilst fitting in with cultural and social norms, is a direct factor impeding prevention

campaigns and affecting choice making. A moral reformation needs to be strategised which takes into account this lack of freedom, cultural and social barriers, government’s role and youth peer pressure. Such a reformation is the only viable solution to effectively addressing how a nation of individuals interprets and acts upon knowledge of a disease such as HIV/Aids, how they employ prevention methods by means of abstinence and faithful relationships and how they care for themselves and their communities.

CS Lewis identifies the human species as puzzling when comparing it to the mythical hrossa in Out of the silent planet, who are naturally monogamous with no perversions. He wonders at the deplorable instincts of man that makes him fall into such a frenzy that he desires two mates (Lewis 1938:75). Monogamous relationships don’t just happen because they are ordered by way of an ABC campaign. The communities and relationships of young people are influential in their moral development and shape their choices. Character is shaped by the stories and actions of their community, their family, their school and their peer group (Connors & McCormick 1998:194). This is a sad issue when one takes into account that many children in South Africa live in an environment of violence, abuse and deprivation, making their moral and ethical reasoning flawed and basing their choices on desperation or, as discussed above, they are not empowered to make their own decisions.

2.9 CONCLUSION

The point of the above discussion is that medical and sexual knowledge are central to the control of the HIV/Aids pandemic, but so also is a functional society and the ability to exercise choice. The future looks bleak in Southern Africa if society cannot be taught basic morality. From a theological perspective God has set limits and ideals which correspond to the way in which we are made. To play the game of sex any other way and to compromise is to court disaster in the long run.

The chapter outlines the epidemiology of the Aids pandemic, which includes the reasons for its dramatic spread. The fact that Aids is, for the most part, a sexually transmitted disease, makes it, in Dr Peter Piot’s words, an “extraordinary” disease (Piot 2003:378). Because it is mainly a disease of lifestyle, it can only be effectively prevented by encouraging lifestyle changes. Care centres on treatment and care of people infected with an incurable infection – there is no easy answer. So what is the future of this pandemic? According to Banerjee and
Welsby (2005:20–22) over 50 million are infected worldwide, and five million are newly infected. Over 90% of these people are in developing countries. An effective vaccine is still years away. These authors feel that the epidemic is still at an early stage, and the medium- and long-term outlook is unpredictable. They stress the fact that failure to modify behaviour will lead to massive drug resistance, and render the current crop of ARVs useless.

Chapter 2 has explained in detail the medical definition, causes and symptoms of HIV/AIDS. It discussed governmental, social and ethical factors affecting general *knowledge* of the disease, *prevention* and spread of the disease, treatment and *care* concepts and systems. The chapter explained the focus on social, medical and theological sciences as an interrelated study, as well as study and research methods for the ethical issues of *knowledge*, *prevention* and *care*. By adopting an integrated, interdisciplinary approach, where social, medical and theological analysis are combined, the discussion can investigate the ethical issues related to accurate *knowledge* about HIV/AIDS and strategies of *prevention* and *care*. In chapter 3 I will outline the methodology used to conduct the research for this dissertation from embryo stage to the final working model.
CHAPTER 3: RESEARCH FRAMEWORK AND METHODOLOGY

3.1 THE SCOPE OF THE RESEARCH

The research in this study focuses on women in sub-Saharan Africa who are infected or affected by HIV/AIDS. The dissertation reflects on medical, sexual, social and theological concerns relating to women in the church, with a particular focus on the ethical issues of knowledge of the disease, the prevention of infection and caring for those who are infected. In this chapter the key matters of knowledge of HIV/AIDS, the prevention of the disease and care of self and others are discussed with reference to the chosen research methodology.

Prior to outlining the empirical methodology and process adopted for this study, I will set out the limits of this dissertation within my chosen research fields, my own positionality within the research and why I have chosen to focus particularly on women.

3.1.1 Research fields

As mentioned above, theological ethics is interdisciplinary in nature and therefore theoretical sources examined for this dissertation have been drawn from a range of disciplines including, medical, sexual, feminist, social and theological studies. When ethics loses contact with social sciences, it becomes more remote, abstract and irrelevant and when it loses links to theology it can become formal legalism and normless expediency. "From Christian theology, it derives the faith-premises that validate its moral norms. From the sciences that study human behavior, it derives the understanding of the complex factors in the psychology of human nature and the cultural circumstances surrounding the problems of choice and decision" (Beach 1988:9). The dissertation is located within the theological ethics discipline and concerns itself with the church's responsibility to women affected by HIV/AIDS in sub-Saharan Africa.

This dissertation engages with the ethical debate in three ways: it reflects on the degree of knowledge of the Aids virus of women in Southern Africa, their ability to prevent infection and it engages with the ethical debate of care. The aim of the dissertation is to develop a Christian model of collaboration between the fields of medical science, social sciences and theology. The model should not only be a theoretical analysis which examines the strengths and weaknesses of
current faith-based projects (FBPs), but rather its purpose is to create guidelines that churches can implement in the future.

3.1.2 Positionality

I have to address how my own background and my position have impacted on the scope and content of this dissertation. I am a white, middle-aged woman who has experienced both the apartheid era and post-apartheid South Africa.

It was during the 2001 World Summit that I was asked, in an employment capacity, to research community-based projects (CBOs) addressing the HIV/AIDS crisis. During this period I realised that it was often the faith-based organisations (FBOs) that managed to move beyond the embryo stage and proposed a viable, sustainable model to communities affected by HIV/AIDS.

Another realisation was to see how the projects examined were managed and largely attended by women. As a woman myself, involved in assisting the women with marketing their projects, I was invited into their confidence and they began to share their stories with me. I soon came to a conclusion that the world that I had experienced both in Canada where I completed some theological studies and apartheid South Africa gave me a limited and protected view of the problem. I had a new insight into the scale and magnitude of a deadly disease which not only struck me as a moral issue but also led me to question our changing social and cultural setting. This led to the following research questions: “Do women know how the disease is spread? If so, why can’t they prevent infection and why is there an obligation on the part of the church to care for those affected?” My reflections later led me to research the extent and causes of AIDS in Africa and to focus my empirical work on two case studies to present a viable model for other churches to follow.

3.1.3 Women with AIDS

As stated in the previous chapter, not only are the statistics for women with AIDS higher than those of men, but those who care for the infected are mainly women. They are most often left with the burden for caring for children and grandchildren left by those who have died from the disease.
To arrive at a choice of three ethical issues, I asked a number of questions. To begin with “what were the ethical issues that led to the rapid transmission of HIV Aids which rendered women in Southern Africa vulnerable to infection?” A significant part of the answer was that women frequently have no choices with regard to their sexual activity; also they are often very young when confronted with their first sexual experience.

Another question was “how could the church instil in women the wisdom to make the correct lifestyle choices wherever they were able to do so?” And “what should the church’s intervention be regarding teaching ways of preventing further transmissions?” Finally, “who will take care of the women that are already infected?” These questions eventually led to the formation of the three ethical issues chosen for examination in this dissertation. The church cannot but be concerned for women because of their high numbers in the church and their relevance to the ministry. Throughout history the church, at its best, has been engaged in the creation of knowledge, the moral formation of people who can make good life decisions, and care for the abused and the sick. With the current Aids pandemic, its wisdom and love are needed more than ever.

In Rev Corine McClintock’s opening speech at Sparrow Village in Maraisburg on 14 February 2002, she stated that the plan for Sparrow Village was to implement a strategy where women sufferers developed leadership skills in order to become caregivers. This transformation from sufferer to caregiver brings women into a new role of discovering and using hidden strengths and wisdom, moving away from being merely a burden, and becoming a teacher and a caregiver.

My hope is that this dissertation will expound on this principle and develop a model that churches can follow. Women need to acquire knowledge to be able to make life choices and to be empowered to better care for themselves and others. All of this is part of the process of becoming a fully human moral being that can contribute to the creation of a more moral, healthy and functional society.

3.2 METHODOLOGY

Mouton (1996:3) states that one of the distinctive features of being human is that we live many different kinds of lives and constantly assume different roles. Most have a professional life, an academic life, a religious, moral, family, political and economic life. Despite what
Mouton calls our “every day stock of knowledge”, it is important whilst exploring this theme that other sources are consulted to challenge my opinions and allow a critical reflection of my own experience.

The theoretical aspects of this research have been drawn substantially from the literature on medical science as can be seen in chapter 2. Throughout the dissertation theological ethics and an ethical reflection on the social contexts in which people live receive particular attention. The empirical research was based on two case studies conducted at two FBOs; Sparrow Village in Maraisburg and St Francis Care Centre in Boksburg, the results of which are described further in chapter 4. This discussion now turns to a consideration of the empirical methodology of this dissertation and its relationship with theological ethics.

3.2.1 Methodological paradigms

A methodological framework was developed to examine three distinct yet interrelated worlds, medical, social and theological, linking issues of knowledge, prevention and care. A model I found best suited to achieve my research goal was Mouton’s model of methodological dimensions, which implements epistemological and ontological assumptions using methodological paradigms of quantitative, qualitative and participatory methods. I used predominantly qualitative research with quantitative research featuring whilst I collected and analysed two specific case studies to draw quantifiable conclusions. Statistical models in tabular format are drawn in an attempt to explain what is observed.

The research methods employed were sampling, data collection and data analysis. As Mouton (1996:37) states, these methodological paradigms, quantitative, qualitative and participative paradigms, are not merely collections of research methods and techniques, but also include certain assumptions and values regarding their use under specific circumstances. The two assumptions used here are epistemological and ontological assumptions. Epistemology is the study or theory of the nature and grounds of knowledge especially with reference to its limits and validity. Mouton (1996: 31) emphasises that knowledge includes all kinds of knowledge, every day knowledge, moral knowledge and religious knowledge. Ontology literally means the study of being or reality (Mouton 1996:36).
Working on the basis of Mouton's model I made contact with several different South African churches to obtain a general picture of the church's involvement in the AIDS pandemic. Of these the Catholic Church had by far the greatest involvement with AIDS. In order for me to define a social reality and understand the FBOs involvement with the pandemic, my first step was to approach individual affiliate churches to gather as much general information as possible about general policies, projects and structured frameworks already in place. Initially the questions were broad and the net cast very wide. Various people from different churches provided me with information and resources relevant to my study. I then chose two specific case studies to constitute a small empirical research project.

Mouton (1996:31) states that scientists who are engaged in scientific research are bound in a moral contract to commit themselves to the search for truth. This epistemic imperative led me to choose two specific case studies for in-depth research into the ethical issues of knowledge, prevention and care with respect to women's exposure to AIDS.

The diagram below explains the movement from a broad-based church analysis of ontological assumptions to a narrower epistemological method, using the methodical paradigms of qualitative, quantitative and participative research.

*Diagram Mouton's methodological paradigms*

(Mouton 1996:37)

The above diagram shows the research process moving from epistemological assumptions of knowledge to ontological assumptions of the study of reality through two specific case studies, that is, St
Francis Care Centre and Sparrow Village. The process was conducted from a general and broad base to a specific and narrow research method involving the methodological paradigms of quantitative and qualitative research methods which are participatory to meet the research goal through sampling, data collection and data analysis.

3.3 QUALITATIVE AND QUANTITATIVE RESEARCH

It was my intention in this research to test theories relating to the ethical issues of knowledge, prevention and care affecting women sufferers and caregivers of HIV/AIDS in the church. The theory was qualified in a Southern African setting by contacting some churches and specifically researching women’s responses to HIV/AIDS at Sparrow Village and St Francis Care Centre. It was the research process with the two case studies that bridged the gap between the formal, theoretical literature and the practice of prevention and care.

Qualitative data analysis was not done in isolation but was interrelated with quantitative methods. Qualitative data analysis is described as the mass of words generated by interviews or observational data. It allows researchers to seek relationships between various themes that have been identified or relate behaviour or ideas to the biographical characteristics of respondents.50

Qualitative research was used extensively as an interpretative tool to gain insights into the social setting of the women affected and infected by HIV/AIDS who go to a church. Several personal interviews and my own participant observation over several years allowed me to construct theories and interpret the meaning of the social phenomena as they related to knowledge of the disease, prevention of infection and caring for the infected.

Structured questionnaires included specific questions leading to yes or no answers and open-ended questions. The specific questions aided the research process by allowing for a quick collection of statistics in order to categorise the results and interpret the overall questionnaires more effectively. The open-ended questions allowed the research process to take a more personal approach. They also allowed for a more complex and integrated understanding on women’s perceptions of the relevant

ethical and social issues to assess their capacity to prevent infection and re-infection. The questions allowed a more open and free-flowing discussion as to their knowledge of the pandemic and their willingness to care for others. By contributing to these open-ended questions, participants did not feel isolated and outside the research process. They felt very much a part of it.

3.3.1 The purpose of the two case studies

Social research examines the world of everyday life as an object of exploration and inquiry. It means that the world of science is applied to a social world (Mouton 1996:41). Thus an important aspect of conducting research was to engage in social research to gain a deeper understanding of the everyday life of the people I interviewed within a scientific context. My empirical research enabled me to both test my theoretical understanding and extend it. Choosing two case studies allowed me to narrow my research down from a general enquiry concerning the church’s involvement in HIV/AIDS to specific representative case studies to explore the issues of personal knowledge, preventing the contraction of the disease and caring for those infected. The two case studies shared common characteristics: they were both initiated and run as FBOs, they were female orientated being mainly administered and attended by women, and they offered a working model to combat the lack of knowledge, to prevent infection and to promote care giving. The two projects are discussed in chapter 4.

The general aim of researching the abovementioned projects was to evaluate two representative examples of the church’s role in dealing with the HIV/AIDS pandemic. Generally, the two organisations in the case studies, Sparrow Aids Village and St Francis Care Centre, employed a combination of medical, social and theological sciences. Both had a fully equipped hospice with medical facilities. Both projects experienced problems relating to lack of access to knowledge of ARV drugs and PEP, both dealt with ongoing social issues of poverty, violence and gender discrimination and both had a spiritual ministry. Specifically this study aimed to examine the following:

- The participants’ level of consciousness about what causes HIV/AIDS and their ability to prevent infection or re-infection given the fact that cultural and social norms negatively affect choice and decision making. It sought to identify their
knowledge of where to seek care and how to become caregivers themselves.

- To assess shifts in the women's levels of consciousness and awareness about the disease, their ability to control and take responsibility for prevention and their ideas about care.
- To examine whether this shift was directly linked to the intervention of the FBO they attended.

3.3.2 Ethical research principles

Prior to administering the research questionnaires, ethical research principles were developed to best maintain the dignity and privacy of the interviewee as well as to establish moral boundaries for how the research was collected. Owing to the nature of the disease, the intensely personal nature of the questionnaires, and the controlled environment of a hospice situation, the following principles were followed.

3.3.2.1 Developing a rapport

I did not want the tenor of the research to be that of a cold and distant subject analysing a researched object. Instead moving from a subject–object type of research method to a subject–subject method research process was encouraged. Hence, interviewees answered questionnaires with the assistance of caregivers who had established a firm relationship with the interviewee; were of the same gender and the same ethnic background, and spoke the same indigenous language. This rapport helped bridge the possible lacuna of sentiment that a judgemental 'moral' academic is asking the questions. The approach also went a long way to prevent the obfuscation of answering certain questions. This led to interviewees offering information voluntarily and moving beyond a mere research of objects. Participatory research methods were employed by developing a balance between knowledge gathering and collaborating with the women as equals.

The relationship of trust, the ease of language and the familiarity of the hospice environment prevented a dampening of confidence so that interviewees were motivated, they cooperated fully and they were not evasive. The interviews were conducted in English with a manager or caregiver present. The caregiver or managers who accompanied me during the interviews could assist patients should they have difficulty understanding or responding to a question in English. This also strengthened the reliability of the data gathered and made for a more
truthful representation of the interviewees' beliefs and practices. A highlight of this research project was Sister Tilly of St Francis Care Centre reporting that both the caregivers and interviewees felt the research process was enriching. Sister Tilly stated that the process allowed the Centre to formulate new educational projects. For example, Sister Tilly reported that many of the patients did not know about PEP or where to go after being sexually assaulted. Thus the Centre now counsels patients so that they are equipped with the knowledge of how to seek care and treatment should they, or any other woman they know, need such assistance.

3.3.2.2 Privacy and trust

Dworkin (1982:252) states that to breach trust for the sake of research through deception, disloyalty or manipulation is an assault and diminishes human welfare. Therefore, my research rejected the approach whereby people were treated as a mere means to an end, hence disrespects individuals' autonomy, decision making and equality (1982:247). The Aids pandemic has raised many privacy debates and the rights and duties of privacy and trust are some of the moral issues affecting truthful research. These rights are also enshrined in the Constitution of the Republic of South Africa, 1996 as well as in current legislation. Hence the rights to privacy and confidentiality bring into effect moral and legal duties.

These codes of good conduct minimise harm and prevent stigma and discrimination. However, as noted in section 2.8, numerous debates have raged amongst jurists and scientists as to the overall harm of confidentiality and privacy. The question has been raised as to whether the harm to one person's privacy compares with the harm to a broader public that HIV/Aids is not a notifiable disease. The overlapping right to privacy and information was discussed by Jens Mielke, a bioethics professor. Mielke states that some doctors resort to forceful persuasion whereby medical practitioners ask patients to share available medical information with patients' spouses and partners (Mielke 2003:32).

However, case law dictates that, particularly when it comes to publication, researchers and journalists have to tread carefully and avoid disclosing an HIV/AIDS-infected person's personal details. The principles of disclosure in printed form were discussed, for instance, in the case of Patricia De Lille and Charlene Smith. The plaintiffs sued de Lille, Charlene Smith the author, and New Africa Books (Pty) Ltd the publisher, in the High Court, arguing that the disclosure of their
identities was unlawful and made with fault on the part of the defendants. The three female plaintiffs argued that due to the disclosure they had suffered a loss of dignity, privacy and psychological integrity and wellbeing. The court found in favour of the defendants; the court found that it would place a burden on journalists - they had to obtain informed consent from people before publishing their names and HIV status. The matter was then referred to the Constitutional Court in the reported case Case CCT 69/05 NM and Others vs Charlene Smith and Others. The majority of media lawyers believe that the issues of this case were summarised by the words of Justice Sachs:

The moral of the story is that unless overwhelming public interest points the other way, publishers should refrain from circulating information identifying the HIV status of named individuals, unless they have the clearest possible proof of consent to publication having been given, or that the information is in the broad public domain.\footnote{http://www.journalism.co.za/insight/privacy-hiv-and-de-lille-lessons-from-the-concourt-9.html (accessed 13 December 2007, 8 December 2008). Ethics and journalism.}

Therefore questionnaires were anonymous with no names recorded and the interviewees were informed prior to undergoing the research about what the research entailed so that they could voluntarily consent to be questioned. In these surroundings, a rapport was established of mutual trust which deepened the experience for both caregiver and interviewee.

3.4 METHODS

As noted above, initially my research method was a generalising research strategy where FBOs were studied as representative examples of a larger population of similar objects or phenomena (Mouton 1996:133). Owing to my profession as a tour operator specialising in cultural tours to Africa, I was able to visit hospices in Uganda, Kenya, Tanzania, Mozambique and South Africa. Informal discussions were conducted with women who were interviewed during the process of setting up cultural tours instituted by our tour organisation. Several churches were then contacted to identify a broad range of ethical issues, strategies and policies relevant to women and Aids in Africa and to help conceptualise the key matters to be studied.
The *generalising research strategy* was undertaken to examine the actions of the church in general toward women affected and/or infected by the HIV/AIDS pandemic. The *generalising research strategy* gave me a bird’s eye view of the linkages and interrelatedness of how medical science, the social sciences and theology interacted to form the current levels of knowledge about AIDS, women’s ability to prevent infection and their views about care. Information for the general strategy was gathered using electronic mail, general face-to-face discussions, questionnaires and telephone calls. The churches that were contacted were the Methodist Church, the Catholic Church, the Faith Movement Church and the Dutch Reformed Church.

During the first year of general research, numerous FBOs were contacted to discuss policy and frameworks in place for knowledge aimed educational programmes, prevention strategies and care initiatives organised and implemented by the church within their communities.

The assistance from the Roman Catholic Church and their responses to questioning was dramatic and one of the reasons why they were chosen for this research project in terms of St Francis Care Centre. Calls, faxes and electronic mails to Father Anthony Ambrose and Sr Allison Munro in the AIDS office of the Southern African Catholic Bishop’s Conference were met with a deluge of useful information. This is discussed in chapter 4 of this dissertation.

Father Ambrose detailed the Catholic Church’s projects for areas such as home-based care, volunteering, medical assistance, prayer groups, psychological counselling, education, youth initiatives, social grant projects as well as literacy and employment projects.

When asked what the aim was for the Catholic Church with their centres across South Africa, Father Ambrose’s one written reply stated the following:

> The formation of a support group is vital. People should know the Church as a place of hope, whereby hope can be provided, a forum for people living with HIV and AIDS to talk about their status without fear and discrimination. Support groups should be encouraged.
The generalising research strategy preceded a contextual research strategy which called for case studies to be selected and studied. The two case studies chosen were St Francis Care Centre, a Roman Catholic Church project, which is a CBP, and Sparrow Village, which is an FBP. They were chosen for several reasons: Sparrow Village and St Francis Care Centre are female orientated and each project caters for HIV/AIDS patients in terms of counselling, care, medical assistance, social assistance in terms of job creation, education and skills enhancement. The two centres are in reasonably close proximity to my office and my home. The research required several visits to the hospices to become familiar with the subject being studied. This was important because a relationship of trust needed to be created between myself, patients and care workers and questions needed to be asked and answered over a period of time to ensure the answers were given in a setting which was continuous and natural. The projects chosen were amenable to this research and allowed me to interact with the women at the facility who were ill and also with the caregivers. St Francis Care Centre and Sparrow Village were extremely open and helpful during the entire research process.

The manager of Sparrow Village, Corine McClintock, and the manager of St Francis Care Centre, Tilly Brouwer, participated in informal interviews. For the formal questionnaires, the interviewees approached at St Francis Care Centre and Sparrow Village were a cross section of caregivers and patients.

The structured questionnaires were all completed on the premises of Sparrow Village and St Francis Care Centre. The familiarity of the surroundings and the ability to seek help from personnel who spoke their language and who were also women allowed for a rich exchange despite the sensitive nature of the research. The interviews were conducted with the approval of the administrative heads; Rev Corine McClintock at Sparrow Village and Sr Tilly Brouwer at St Francis Care Centre, who were aware at all times of the interactions with their staff and the women at the centres and gave their blessing to the research.

Thus the aim of the empirical research using structured questionnaires was to establish patterns and recurring themes regarding the women's and caregivers' knowledge of the HIV virus, their awareness of prevention strategies and their ability to seek caring facilities when infected. The study attempts to understand why women are not in a position to say "no" to unwanted sexual encounters, despite a basic
understanding of how they could be infected, why they are not able to avoid re-infection and why they are the prime caregivers to others who are sick, but struggle to find help for themselves when they are infected.

The calls to Sparrow Village were always fruitful, which led to this hospice being the second case study chosen to represent the FBP’s response to HIV/Aids. Corine McClintock provided me with access to the wards, and access to the women who were in the wards and the hospice. I was able to interact on a one-to-one basis on several occasions with the patients, the care givers and Corine McClintock. Information on the structure of the Village, financial issues and all aspects of the running of the Village were readily available and transparent.

3.4.1 Process

The generalising research strategy phase took place over a period of one year. The contextual research strategy, which called for an empirical research process, was conducted over three years which included the process of writing up the dissertation.

3.4.1.1 Data collection

From the outset empirical data was collected with an epistemological dimension in mind; namely to arrive at results which are valid and truthful (Mouton 1996:63). The goal of attaining truthfulness of data is explained above in section 4.2.2 on Ethical research principles. It is important to avoid or minimise evasion caused by cultural and language barriers, fear of stigma and judgement. Privacy and consent are important issues which can lead to answers that are less than truthful. The issue of validity is discussed below. With the research principles in hand, data was collected in the form of structured questionnaires conducted with both the women with Aids and the caregivers.

(a) Questionnaires

A total of 14 questionnaires were given to women with Aids and a total of 16 questionnaires were given to caregivers at Sparrow Aids Village and St Francis Care Centre. The questionnaires followed factual yes/no type questions, open-ended opinion type questions and a combination of fact and opinion. The questionnaires are attached as Appendices 1 and 2.
(b) Questions asked of the women with Aids

The factual yes/no type questions and open-ended questions asked of women with Aids were designed to assess their basic knowledge of HIV/Aids and its transmission and whether the women knew how to prevent infection of the disease and re-infection. Finally, the women were questioned about their experiences of the caring facilities.

Factual type questions asked included:
- Personal information – age, marital status, religious affiliation, children, education

Opinion and feedback type questions asked:
- Personal knowledge of the disease
- Personal knowledge of prevention of contracting the disease
- The support and care received from family, friends and the church
- Community and family reaction
- Suggestions for the church

The groups of questions asked of the women with Aids were designed to give insight into the personal background of the women. Questions were asked on general awareness of the virus and ways of preventing its transmission. Questions were also asked about the levels of involvement by their community and friends to assess the stigma factor. The women were also questioned about the caring facilities available to them, as well as their perceptions of the church as a resource for assistance.

(c) Questions asked of caregivers

The factual yes/no type questions and opinion type questions asked of the caregivers helped me to gain insight into the facilities provided with particular focus on the core ethical issues chosen for research, namely, knowledge of HIV/Aids ways of preventing infection or re-infection and ways to care for sufferers. A recurring theme of the questioning was to gain insight into the needs of women to enable the church to render physical and spiritual help in their situation.

Factual type questions asked included:
- Personal information – age, nursing qualifications
Opinion and feedback type questions asked:

- Personal knowledge of the disease
- Personal opinions about the women they were caring for, their general perceptions about their patients
- Reasons why the women were there
- The financial backers of the project
- Their sense of moral obligation and calling toward those that needed care

Questions were grouped to establish personal information regarding the caregiver. They were questioned about their awareness of the HI virus and its transmission. They were also asked questions about their opinions of the women in their care to establish whether there was any stigmatisation of the women by the caregivers and also to adduce their knowledge of social factors underlying their situation such as violence and poverty.

The caregivers were also asked to give their opinion on the causes of infection and factors which could be changed to help stop the spread of the pandemic. Information on the financial backers was designed to gauge whether the caregivers understood the magnitude of the financial implications and also to assess general awareness of how the money was raised for running such a care centre. The question about a calling or duty to care was important to determine the root motivation towards care giving and to assess whether a sense of moral obligation was predominant or whether their motivation was primarily that of the need to obtain a financial reward or a salary.

3.4.1.2 Establishing validity

The outcome of the analysis which flows logically from the empirical data collected to conclusions drawn is only relevant if the whole hypothesis has actually been valid. This is also known as the epistemological criteria and is the sum of all the parts from conceptualisation of a research project to the operationalisation and interpretation or analysis.

The element of truthfulness was discussed above in terms of validity. The tension of truthfulness comes into play in social research as people tend to fare poorly as reliable “objects” of study. Reliability of information from people as objects of study is not guaranteed and developing a rapport with interviewees takes time and dedication.
Questions needed to be as specific and simple as possible to avoid any pitfalls in terms of misrepresentation and confusion. This led me to reformulate the questionnaires to ensure palatability for the interviewee whilst still maintaining an academic tenor.

Dworkin (1982:252) talks about the experimental deception and Mouton (1996:158) about the covert deception methods to which some researchers resort. I was sensitive to the criticism of certain methods of collecting information and so it was important to build trust and a mutual relationship over the last three years of gathering information and empirical data. I wanted the entire body of research to reflect theoretical and measurement validity, as well as to be representative and reliable. Confidentiality is a precondition for the attainment of validity in research; questions were answered anonymously by both the women with Aids and the caregivers, with no names supplied here (Mouton 1996:112).

As noted above, caregivers assisted the women with Aids to answer questions they had trouble interpreting, as the caregivers had already established mutual bonds of trust and faith with them and spoke their indigenous language fluently. Many caregivers were also HIV positive and therefore the culture of stigma and judgement was largely removed from the questioning process. Bias, duress, threat and breaches of privacy were avoided and informed consent, mutual trust and objectivity encouraged. At both centres I felt, and it was reported, that the women with HIV/Aids and the caregivers enjoyed the process of being interviewed and found it enriching and beneficial. It gave them a voice and enabled them to make a contribution to understanding the disease, which is critical to the issues of both prevention and care.

Analysing and interpreting data is a process whereby the researcher can identify patterns and themes and draw certain conclusions; it can also disqualify certain preconceived assumptions. The coding of results to establish themes and patterns was assisted by the structure used in the questionnaires. General opinions and interviews were coded using notes, informal questionnaires and electronic mail. Themes and patterns revealed difficulties in terms of medical knowledge and access to treatment, social norms and practices of abuse and cultural law. The research also detected paradigms of care within faith-based hospices namely: Sparrow Aids Village and the church-based St Francis Care Centre.
Themes and patterns identified individual and collective knowledge of the disease, whether preventative measures are working and how interviewees have responded to being cared for and their personal calling towards caring.

3.5 CONCLUSION

This chapter examined the methodological timeline from conceptualisation to operationalisation of this research. It explored the ethical constraints and limitations of the study and the progress from a general church assessment to a specific case-study approach using Sparrow Village and St Francis Care Centre.

The growth from informal discussions to formal questionnaires explored three ethical issues: the current level of knowledge to assess gaps and difficulties in access to information, ways to prevent infection and re-infection, as well as personal freedom to choose, and the nature of care giving.

In chapter 4 the research results are discussed in greater detail with an aim to call for social action, whilst presenting a workable model based on successful FBPs. The research showed how the women interviewed share common experiences and how social factors such as violence and patriarchy affect women’s ability to choose their sexual partners and prevent infection. My hope is that the research, as it has been an open and successful interaction with these brave women, will serve as a dialogue for current and future FBPs.

In the next chapter, I shall discuss details of the findings of the formal questionnaires. We will listen to women’s stories so that we can visualise them in their plight. We will ask women to tell us the stories of their pain and sorrow and hope that “the stories increase the capacity of our hearts and that these stories will give us a chance to walk around inside someone else’s skin” (Connors & McCormick 1998:82). The stories of the women at each centre, namely St Francis Care Centre and Sparrow HIV/AIDS Village, have been collected to “help us overcome our ongoing tendency towards self deception, they are stories that will help us to recognize the commitments humanity demands of us, and stories that will help us fulfil those commitments” (Connors & McCormick 1998:83).
CHAPTER 4: THE CHURCH AND AIDS – SPARROW VILLAGE AND ST FRANCIS CARE CENTRE

4.1 INTRODUCTION

In the previous chapter, the research methodology employed was outlined as well as the process undertaken to arrive at the choice of the two projects: Sparrow Village in Maraisburg and St Francis Care Centre in Boksburg. In this chapter I shall further discuss the two projects chosen for the study and analyse the interviews conducted with women living with AIDS and the care givers of these women. In chapter 1 ethics was defined as well as morality. This chapter analyses these two projects in the context of sexual ethics, medical ethics, feminist ethics and social ethics. The participants, both caregivers and the patients, were asked questions relating to these ethical areas in order to evaluate whether a good, healthy, positive and caring society is being reflected. The study discusses whether the patients and caregivers interviewed are virtuous people and the ethical dilemmas that HIV/AIDS presents to women in Africa.

The severe impact of HIV/AIDS, not only on the sufferers but their families, friends and communities, is one of the reasons why the disease needs to be discussed ethically. As Dr Eugene Rubingh, a former missionary to Nigeria states, HIV/AIDS goes to the heart of human suffering. Rubingh quotes Psalm 6, “O Lord, heal me, for my bones are in agony. My soul is in anguish, How long, O Lord, how long?” (Ps 6:2–3). Theological reflections on the disease call for researchers and the church to look at the innocent victims of the disease as well as those who became infected by the disease through a sinful or reckless lifestyle. Rubingh’s discussion persuades Christians to look at the full extent of human suffering on both the sufferer who is infected with the disease through sin and those who had little to no choice in the way in which they became infected (Rubingh 2002:43).

It is only by looking at the concept of suffering, the desperate need for spiritual forgiveness and redemption, as well as physical and psychological care, that we can begin to fully understand and exhibit God’s hope, grace, mercy and unconditional love. Rubingh’s reflections on theological ethics as it pertains to HIV/AIDS depends very strongly on the belief that God is just and that human beings require God’s intervention to be forgiven their sin and to live a life of hope and peace. Without God’s forgiveness, mercy and love, human beings cannot experience the hope of salvation. Without Christians showing
sufferers, whether they are infected through moral or immoral behaviour, God's immense love and compassion through their own acts of kindness and humility, sufferers become further alienated from God, a God of hope and restoration.

There is much written about God's love that is shallow and merely nice talk about a nice God. Let us understand that God's love joins with his justice to send his Son, and his Son in turn shows the essence of love in his obedience to the Father. This is the meaning of the account of Jesus Christ. In his suffering and death, Jesus as God's own Son accepted all the eternal punishment God laid on his shoulders. God accepted his death as a full payment for that sin – here is the essence of salvation (Rubingh 2002:46).

Through the two case studies I was in a better position to make deductions about the church's role in the development and communication of knowledge of HIV/AIDS, prevention of the disease and care of those with the disease. Moreover, I was able to question caregivers and patients on moral behaviour and assumptions, moral and ethical judgements as well as knowledge of medical ethical issues of informed consent, testing and access to treatment. Questions also addressed the social ethical issues of violence, rape and assault in order to determine a woman's overall choice-making capacity.

The chapter will analyse the strengths and weaknesses of both projects. The reason for this analysis is so that churches and FBOs running projects can compare their own projects to these two projects, alternatively if CBOs and FBOs are looking to initiate their own projects they can use this analysis as a guiding tool for common problems. The chapter therefore discusses how the two chosen projects approach the knowledge of HIV/AIDS, the prevention of infection and re-infection as well as care. It also investigates the national and local contexts of these women and acknowledges the interdependence of social science, medical science and theological ethics.

4.2 THE CATHOLIC CHURCH RESPONSE

The Catholic Church's response to HIV/AIDS was evaluated during the general collection of information through interviews and emails with the South African Catholic Bishops Conference (SACBC). This general information formed a backdrop against which St Francis Care Centre was chosen to be analysed to represent the FBO run by the Catholic
Church. The Catholic Church is the one organisation that stood as a beacon for the old adage, “how things ought to be done”. In terms of policy, strategy and concrete solutions, the Catholic Church is doing more than the private sector, public sector or any other FBO. It has a multidisciplinary profile and works together with both the medical and social sectors. Its responses to my questioning exceeded my expectations tenfold and its methods, mechanisms and means of addressing the issues of knowledge, prevention and care can be used as a model for other churches wishing to manage Aids care facilities. The Catholic Church engages the Aids pandemic on all levels, spiritually, economically, socially and even politically. Their policy presents an in-depth endeavour to address knowledge of the disease through education and youth projects, the prevention of HIV/AIDS infection as well as re-infection and care strategies both in a home care sphere as well as in hospice facilities.

4.2.1 Introduction to Catholic run initiatives

My first contact with the Catholic Church, in an endeavour to understand their policies, was with Sister Alison Munro, the Co-ordinator of the Aids office of the SACBC. My initial questioning was met with a huge amount of literature and information about ‘who they were’, ‘how they functioned’ and guidelines regarding the Aids virus transmission and the caring facilities run by the Catholic Church. I subsequently communicated with Father Anthony Ambrose who was equally forthcoming and who also guided me to the St Francis Care Centre for further research.

According to Stuart C Bate (previously Professor of Religious Education and Pastoral Ministry St Augustine College of South Africa), there are eighty different Aids pastoral care projects which operate under the auspices of the Roman Catholic Church (Bate 2003:3). Bate states that the response of the church to the Aids pandemic was hampered and influenced by sociopolitical realities, ethical dilemmas and reluctance on the part of the church and community to recognise the crisis. In October 1999 the SACBC established an Aids desk to coordinate and oversee various pastoral projects; this has served to investigate proposals for new initiatives and oversee general policy implementation.

The projects mentioned focus on education for HIV prevention and pastoral care. Impressively, almost every diocese has at least one HIV
Aids project. The most common activities within the projects are home-based care (HBC), orphan care, counselling and youth education. Beyond this, the Roman Catholic Church is also the only organisation encountered that goes beyond the brief of pastoral care in a medical or theological sense and offers practical services, for example, paralegal guidance to help people access benefits and social grants. They also run community art projects to keep youth occupied and off the streets; they have projects aimed at abuse prevention and form lobby and advocacy groups for sufferers.

4.2.2 Holistic Catholic run initiatives

As stated previously, the Catholics have adopted an inter-disciplinary and cooperative approach, networking dynamically with medical and social services. The community is involved with the planning and execution of each project and community involvement and linkages support this integrated or holistic approach.

According to Stuart Bate, every project has the dual aim of pastoral care and the promotion of awareness through education, especially youth awareness. Bate calls for further resources to be diverted towards preventative care, that is, promoting youth awareness around sexuality and behaviour. Knowledge and prevention are thus tackled by means of training, skills awareness programmes and interaction with stakeholders and communities such as schools, local churches, colleges, forums and clubs. When it comes to schools, projects work closely with the Catholic Institute of Education and with educators to identify social issues affecting the schools and current thoughts and opinions on sexual behaviour.

The Catholic Church implements an advocacy framework and a project addressing issues of care called the Circle of Care which I shall explain below. They have two projects dealing specifically with knowledge and prevention called Treatment Literacy and Education for Life. The latter is a youth project whereby community volunteers and church members teach and train youths about life skills development. Thirty-four projects have educational and training facilities supporting the abstinence, be faithful, correct moral choices and disease control (ABCD) campaign.

The Catholic Church is well aware of the poverty and violence which compound the transmission of Aids. One of its responses was the
formation of the Rural Development Support Programme (RDSP), which is an associate body of the SACBC. The RDSP supports CBOs and various development initiatives in an attempt to alleviate poverty in rural areas. Their policy is to work with rural leadership in an effort to initiate creative, viable development models that are specifically designed for those in need. Six years ago the organisation WomenDemanding Dignity (WDD) was launched in one of the many attempts by the Catholic Church to combat violence against women.

This organisation provides transit care for women and works together with men and women, recognising the need to involve men in positive change. As part of Fr Stan Brennan’s social upliftment vision, he set up a place of safety for abused women at St Anthony’s Care Centre in Reiger Park, Boksburg.

4.2.2.1 Community-based care giving

In terms of the Catholic Church’s response to community-based care, Bate (2003:3) states that one of the major problems for any CBO is community involvement. He stresses that participation is the life blood of any successful and sustainable project. Communities that harbour suspicion or a belief that the church was not involved in the care of a community had a short lifecycle. Bate specifically stresses the importance for the church not to be seen as part of an overall stigma, the church should not be perceived by the community as “them”.

When we discuss the two chosen projects below we analyse Bate’s call for the church to be accessible spiritually and socially. We investigate whether the two projects, St Francis Care Centre and Sparrow Village, allow care givers and patients the freedom to approach the projects and become involved without fear of prejudice.

The Roman Catholic response to care giving serves a dual purpose. Caregivers are trained in home-based care by accredited trainers. The volunteers are mainly women who are unemployed and they hope that by assisting the project they may receive cash or payment in kind. The Catholic programme allows these volunteers to become skilled caregivers and they receive remuneration.

Parallel to this, caregivers are raised and nurtured from communities so they understand patient fears and contexts. Patients feel that local caregivers are more approachable for spiritual, mental, emotional and physical needs. Proposals for such projects usually stem from various
parishes and dioceses. The legitimacy of any home-based care project is based on a number of factors, which highlight the interdisciplinary, cooperative approach adopted by the Catholic Church. These criteria include community involvement, contacts with the community, whether these contacts maintain viable links through networking or forums with the community, volunteers, access to adequate counselling, the church's capacity, adequate coordination, access to medical facilities and nurses.

The pillars of any home-based care initiative are a professional nurse to supervise caregivers, the acceptance by all of their policy and ethics, and good record keeping. These three pillars should work together with the criteria discussed above in order to be cooperative and interdisciplinary.

4.2.4 Concluding remarks: summary

Certain conclusions about these Roman Catholic run initiatives can be drawn. From the general research phase discussed in chapter 3, it was clear that the consistent strengths of the Roman Catholic projects include community support in treating the disease and dealing with the socioeconomic issues. People strengths such as the quality caregivers, individual counsellors, the implementation of care and education, management skills and training development are highlighted in the project discussed below, St Francis Care Centre. Weaknesses include lack of funds, difficulty of transport, village/tribal divisions, lack of male involvement, the cultural beliefs of the youths regarding caring for their elderly, government-related obstacles and bureaucracy, stigma and silence. The project, the St Francis Care Centre, is discussed below to provide a case study of how the Roman Catholic Church responds to knowledge of HIV/AIDS, ways to prevent infection as well as re-infection and care of oneself and others.

4.3 ST FRANCIS CARE CENTRE

The St Francis Care Centre is linked to the hospice and clinic work. It is but one facet in many initiatives in the fight against Aids undertaken by the Catholic Church.

4.3.1 History

St Francis Care Centre was founded in 1992 by Fr Stan Brennan, a Franciscan priest. His prime motivation was his compassionate caring
for the plight of people who were ostracised and neglected and left to
die alone in rural areas, which he experienced when he visited
hospitals and homes in the 1980s. He wanted to provide a haven for the
terminally ill where they would be nursed in a professional and
comfortable environment whilst their physical, spiritual, emotional and
social needs were catered for with care and dedication. He also
prioritised providing training and the empowerment of people in the
fight against HIV/AIDS.

St Francis hospice for the terminally sick is one of the outreach
programmes of the Sisters of Mercy, St Anthony Centre, Reiger Park,
Boksburg. Allied initiatives are the Rainbow Cottage for Aids orphans, a
day care centre for the aged and a centre for abused women.

There is now also a clinic for antiretroviral patients. Nominally
nondenominational, the outreaches are offered under the auspices of
the Catholic Church. The major funders of this project include the
Department of Health, the Department of Social Development, the
National Lottery Distribution Fund, PEPFAR (the President's Emergency
Plan for AIDS Relief), the Solon Foundation, Cadbury's and Unilever
South Africa as well as Colgate Palmolive, ITEC and the ABSA
Foundation.

Father Stan Brennan originally arrived in South Africa in 1957. He
stayed at Christian Brothers College in Boksburg, acting as chaplain to
the school and the brothers.
St Anthony Centre started with three students, and continued till 1968 when it was closed by Bishop of Johannesburg, Rt Rev. Bishop Hugh Boyle, D.D. It is now an old age home. The Dominican fathers were in charge of St Dominic's Parish, Boksburg, and St Albert's Parish, Stirtonville. In 1964/5 the black residents had to move from Stirtonville to a new township called Vosloorus and the coloured people all over the East Rand were moved into Stirtonville, which was now called Reiger Park.

A casual meeting between Father Stan and Father McGee took place at the post office in the 1980s. They discussed the removal of the people and the terrible hardships that had been inflicted on them. At this meeting Father Stan expressed keen interest in looking after the coloured people. With help from the teachers in the local community and a number of concerned citizens, St Anthony's Club was established. This club, assisted by Father Stan, has worked consistently over the years to develop amenities in response to the needs of the various communities. St Anthony's Centre quickly developed embracing not only education and training but also providing for the needs of the broader community through its outreach programmes. The centre is now a haven for elderly citizens, a drug and alcoholic rehabilitation centre for victims of substance abuse, a hospice for the terminally ill, especially Aids patients, and a place of safety for abused women and children.

4.3.2 Structure
St Francis Care Centre falls under the umbrella of St Anthony’s Centre. The Board of St Francis Care Centre works through the Director, Stan Brennan, and comprises the priest-in-charge and ten elected members. Associate members can be drawn from representatives of any institution, government department, firm or organisation who wishes to cooperate with the organisation. It meets monthly and attends to the running of the organisation, as well as financial matters. A manager oversees the day-to-day administration of the hospice, and reports to the Board.

In order to assist him, the manager has a secretary, an accountant and a fundraising section. There are also social workers and welfare officers who liaise with the Department of Health. There is an art clinic, and permanent housekeepers. The hospice section is run by a matron, who has nine professional nurses and a medical doctor to help her. There are also care helpers, a laundry, and kitchen and security staff. There is a nursery school with a teacher and helpers.

4.3.3 Patient profile

According to statistics reported in the annual general meeting of St Francis Care Centre held on 28 June 2004, from July 2003 to June 2004 there were 375 adults and 20 children admitted to the hospice. In that period 120 were discharged after treatment and 259 died. HIV tests are performed on all the children, and they are seen by a paediatrician. If indicated, they are put onto ARV treatment and, if possible, patients are taught to administer these themselves. Hospitals used include Oliver Tambo and the Johannesburg General.

4.4 FAITH-BASED ORGANISATION RESPONSES

For the purposes of this dissertation it is important to make a distinction between church-based projects (CBPs) and faith-based projects (FBPs).

A CBP can be defined as an organisation, programme, or project sponsored or hosted by a religious congregation of a specific church such as a Catholic Church or Methodist Church. An FBP can be defined as an organisation that has a faith-inspired interest in providing services to the needy. Thus FBOs may not be sponsored or affiliated to any particular faith or specific church and yet the project is de facto faith-based with an aim of including the Christian faith in the foundation
and management of the project. Byamugisha, Steinitz & Zondi define faith as follows:

Faith is the mainspring of the soul. Through faith, our aims, desires, plans and purposes are translated into physical, social, economic, political, artistic and spiritual achievements. Over the centuries, positive religious faith has stimulated individual and collective actions for the improvement of people, collectively and individually, in many different spheres of life. 52

Thus the importance of FBOs cannot be underestimated. Byamugisha et al explain how FBOs have been vitally important in the way communities cope with poverty and disease. The importance of FBOs is that each project is in a unique position to impact on individuals, families and whole communities.

4.4.1 Introduction to faith-based initiatives

The majority of projects I encountered whilst researching CBPs with the Tourism Enterprise Program were FBPs. According to Byamugisha et al many church leaders in Africa regard HIV infection simply as the consequence of individual sin. However, secular leaders at global and national levels, and among international agencies, have come to appreciate the unique potential that churches and other FBOs have for preventing the spread of HIV and helping communities cope with the impact of the HIV epidemic. Thus, it is this unique synergy between government, funders and faith-based leaders that FBOs have become increasingly important and have multiplied in South Africa.

Each FBO is unique. This is both an advantage and a disadvantage as each project must formulate their own policies, plans and structures. Thus FBOs cannot rely on a specific church for funding or contributions in terms of directives and frameworks. However, they are also perceived to be more flexible in how they obtain their funding and how they can manage a project’s strategies and policies.

Previously the main focus of FBOs has been on care and treatment. Dr Kevin De Cock, Director of WHO’s Department of HIV/AIDS states that FBOs are a vital component to civil society, providing a substantial

portion of care in developing countries, often reaching vulnerable populations living under adverse conditions.\textsuperscript{53}

The ethical issues of \textit{knowledge} and \textit{prevention} however seem to have been largely neglected by FBOs with very few developing dynamic responses to knowledge of the disease and ways to prevent infection or re-infection. Perhaps this is due to capacity constraints or a difficulty in forming educational programmes for youths based on abstinence and faithfulness since they rely more heavily on government and private donor funding. For example, should the FBO be applying for funding from the USA for a \textit{knowledge} campaign, the ultimate approval for the funding will depend on the FBO enforcing an ‘abstinence only’ sex campaign. To comply with this condition is difficult for many FBOs in Africa where they encounter a situation where women cannot say no to sexual relations because of the threat of violence and rape.\textsuperscript{54}

According to the Centre for Health and Gender Equity, nearly 60\% of funding for \textit{prevention} of sexual transmission, the single greatest factor in HIV transmission, goes towards abstinence programmes where there is little to no consultation on cultural and social factors such as gender discrimination, war and poverty.\textsuperscript{55}

FBP\textsc{s} are becoming increasingly important in fulfilling a role in home-based care. According to Magezi, when patients are discharged to go home after receiving treatment, poor families get very little support from government and social systems. Magezi stresses the importance of local home-based care pointing out that local home-based care systems in sub-Saharan Africa are responsible for 95–98\% of all care (Magezi & Louw 2006:70).

The project Sparrow Village, which is situated in Maraisburg, Roodepoort, was chosen in order to analyse and research an FBP.

\section*{4.5 SPARROW VILLAGE}

\subsection*{4.5.1 Introduction}

The second of the case studies included in the research is that of Sparrow Village. Situated just outside Roodepoort, in Maraisburg, virtually in the barren veld, stands a cluster of dome-shaped dwellings. The centre is an FBO with no affiliation to one particular church. The complex is surrounded by a wire fence. Each dome has a number of rooms, and is independent of the others. These people all have one factor in common: they are terminally ill with Aids, and often its deadly co-hunter, tuberculosis.

In the middle of the complex is a much larger structure, also dome shaped. This is the hospice, where the terminally ill are cared for in their last days. This structure is filled to bursting. A long corridor has rooms leading off it, each with up to a dozen patients. There is an ominous quiet here, with the occasional sound of retching, or a stifled moan. There is a smell of diarrhoea. Although some of the rooms are filled with children, there is no sound of little voices or infants at play. These children are too sick to play. In fact, they are too sick to sit, or stand, or sometimes to swallow. This is the grim reality of Aids. Every time I go there, I wish some of the "Presidential advisers" and assorted crackpots that deny the existence of Aids would come to see for themselves. But they never do.

This is a bizarre place. It looks at first like something from "Teletubbies", but is, in fact, Sparrow Village, brainchild of Corine McClintock. This remarkable woman is ordained by Rhema Church, but founded and built Sparrow virtually on her own, with scant help from her own church. In fact, she receives most of her support, especially financial, from secular groups and firms.

This is where I first met Godwin, a three-year-old boy with full-blown Aids. I visited him on Sundays. He shared a hut with about ten other children. There are certain rules when visiting Aids kids: don’t take them toys which will exhaust them, such as footballs, because they are
always tired. Don't take them sweets that will aggravate their chronic diarrhoea. And be prepared to be hung onto; these kids are mostly orphans, and are starved for love. On arriving at Sparrow Village one is immediately surrounded by children. They sit on your lap, hold your hands and come close for hugs. Another rule: don’t get too close to these kids. They may not be there when you go next week. Godwin died a few months ago.

4.5.2 Tackling knowledge and prevention and care of HIV/AIDS

According to an enquiry answered in 2005 as part of the general research conducted for this dissertation, Sparrow Village’s main purpose is to provide a hospice for the dying and a training centre for the living. Therefore, their best known and best known function is to provide care for terminally ill patients. Unlike St Francis Care Centre, at Sparrow you see entire families residing at the Village as one unit. Campaigns and policy for prevention of HIV/AIDS and increasing community knowledge is not linked to a faith organisation and does not form part of a broader scheme of a particular church such as is the case at St Francis Care Centre. Sparrow Village does, however, promote classes and training and seminars to ensure that business, schools and the local community have the opportunity to learn the facts about HIV/AIDS. This is their core campaign for community awareness and prevention.

Corine has received international recognition for her work. She has also had to endure condemnation, the main criticism being that hospices are not the “African” way of dealing with sick and abandoned people, and that Sparrow Village is a circus. She has even been accused of running a “leper colony”. With ongoing help from banks, Rotary groups, individuals and businesses, the village is expanding. ARV treatment is provided at Coronation Hospital, but is hampered, according to a newsletter, by a lack of organisation at provincial level (Office Bearers Newsletter 2003/2004:3). Apart from hospice comfort for the terminally ill an emphasis is placed on teaching others to “live with Aids”. There is a craft village, and Corine’s motto is “get up and live”. Sparrow Village stands as testimony to what can be done by a woman with a mission.
4.5.2.1 Community-based care giving

In an informal interview with Corine McClintock in 2007, she stated that Sparrow Village's main ambition was to increase their capacity in terms of community-based care; the reasons being that the centre was primarily a hospice facility and that the ongoing crisis of HIV/AIDS required home-based care methods in order to equip communities and the broader society better.

Sparrow Village therefore offers home nursing care, and offers advice and counselling, care and love to the patients, as well as to their relatives and friends. Sparrow trains care-givers in home nursing to enable them to assist their own families and other families who are unable to cope with this disease and the ensuing Aids crisis. Sparrow hopes to affect a multiple level of caring not only at Sparrow Village Hospice but also within the townships and cities. Likewise, Sparrow provides teaching seminars on Aids awareness, hygiene and home care to schools, companies, businesses, factories and churches.

4.5.3 History of the Village

Sparrow Village is a planned community that allows terminally ill mothers and children to stay together until they die. It provides a refuge for destitute, terminally ill adults and children with Aids. The Village was established in 1992 by Rev. Corine McClintock and is a predominantly secular financed operation with very little church financial contribution. Corine studied at Rhema Bible School after many years of practising as a nurse, and once she graduated it was Rev Corine McClintock's dream to find a way to help neglected people. With
the encouragement of a friend, Yvonne Nell, Rev McClintock began to see the realisation of this dream in 1992.

Sparrow Village is the physical evidence of ten years of planning and work to produce a home/hospice atmosphere for destitute adults and children enduring the last stages of HIV/AIDS. Corine McClintock is a qualified nursing sister, which lends a practical, functional air to Sparrow Village where she gets involved on a personal level with all the patients’ medical records and current medical status. It is not unusual to walk the wards with Corine and suddenly out comes the injection needle or cough medication from her pocket as she services the sick in the wards.

4.5.4 Organisational structure and finance

Sparrow Village is a nonprofit organisation, with an executive committee of eight members and six founder members. The board meets monthly. Financial support is from various businesses and international donors. According to a fax received from Cynthia Corine’s assistant on 19 April 2005, Rhema church donates R1000 a month, R200 of which is from Jesus Alive Ministries. These amounts were confirmed by Corine McClintock in an interview in 2007. There have also been contributions from the Lotto Jackpot. The books are audited annually by an independent firm. The annual budget is in excess of a million rand, and includes items such as food, cleaning, water and electricity, fuel and oil, nappies and stationery. Salaries account for half a million rand a year. Ongoing needs are toys, mattresses, clothes, cleaning materials and “first world medicines” (antibiotics and oxygen).

4.5.5 Patient profile and medical facilities

According to the informal interviews conducted at Sparrow in 2005, there were 105 children and 72 adults resident at the hospice. All except six were HIV positive. About 450 patients are admitted annually. In 2003, 136 patients died; in 2004 the figure rose to 166. More than 90% of the children are orphans. Of these children 46 go to primary school, four to high school and three to a facility for the hearing impaired. There has been no resistance on the part of the schools to taking these children. There are two attending doctors and five registered nurses, as well as 30 trained caregivers, a psychologist and a social worker. The professionals work in cooperation with Coronation Hospital, Chris Hani Baragwanath, Leratong and Helen Joseph hospitals.
The patients who are tested on admission and are found to have a CD4 count of less than 200/100 are put onto ARVs if indicated. In 2005, 36 were on ARV therapy. In 2008, there are 85 women at Sparrow and 17 males who are all black plus one white male. There are 136 male children and 137 female children who are all black. The children are aged from 1 month to 18 years. Over 60 patients are on ARVs and 33 have died between January 2008 and September 2008. Less than 10% respond well enough to treatment to be discharged back into the community. Tuberculosis is extremely prevalent amongst the patients. The majority of patients are also victims of sexual abuse and common assault. Although every attempt is made to make contact with and counsel the patients' families, most of them are alone in this world and die in the hospice. Those that are well enough are taught crafts, play sports and are taken on outings. Volunteer workers are involved in these initiatives.

The facilities at Sparrow Village include a 200-bed paediatric and adult HIV/AIDS hospice. This hospice is always full. HIV-positive children and babies who are part of an affected family are cared for. People who are well enough are encouraged to participate in income-generating projects. Because of the nature of the facility, patients have the peace of mind of knowing that their children will be cared for in the event of their death. In addition to the hospice, home-based caregivers assist patients in their own homes, providing nursing and counselling for them and their families.

4.6 ANALYSIS OF THE FORMAL INTERVIEWS

As stated in the previous chapter, two case studies were undertaken to collect empirical data. In the following analysis of the formal interviews, I have distinguished between the caregivers and the women patients with AIDS who were interviewed at the two projects, namely Sparrow Village, and St Francis Care Centre. Structured questionnaires included specific questions with a yes or no answer and some open-ended questions. The questionnaires were designed to gain insight into the caregivers' and patients' knowledge of HIV/AIDS as well as their perceptions of care. The questions also analysed patients' and caregivers' opinions on prevention of infection mechanisms as well the prevention of the re-infection of HIV/AIDS.

The questionnaires were also formulated to test participants' understanding and opinions of the relevant social factors, medical
issues and theological beliefs. Each table gives the reader insight into the themes of the knowledge of HIV/AIDS as well as the prevention of the disease. The ethical issues of care of self and the community are discussed and analysed for both the caregivers and patients. The responses of the participants were calculated in terms of percentages.

4.6.1 The caregivers at St Francis Care Centre and Sparrow Village

The table below is a profile of the caregivers interviewed. It gives an overview of their average age, experience in nursing, the number of patients in their care as well as their main motivation for their ministry. The period of service for caregivers ranged from 3 to 11 years.

Table 4.1: Profile of caregivers

<table>
<thead>
<tr>
<th></th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age: youngest 28, oldest 72</td>
<td>38</td>
</tr>
<tr>
<td>Caregivers with nursing experience</td>
<td>30</td>
</tr>
<tr>
<td>Overlapping motivating factors:</td>
<td></td>
</tr>
<tr>
<td>Motivated by financial reward</td>
<td>10</td>
</tr>
<tr>
<td>Motivated by calling</td>
<td>90</td>
</tr>
<tr>
<td>Motivated by duty</td>
<td>10</td>
</tr>
</tbody>
</table>

Eight women were interviewed at Sparrow Village and eight at St Francis Care Centre, a total of 16. There was an average of 15 patients per caregiver.

A difficult assessment to make was whether the patients who had caregivers who had nursing experience were better off in terms of medical care compared to those patients whose caregivers had no nursing experience. Overall, both projects provided medical oversight by a designated medical doctor and medical hospitals which might explain the prevalence of caregivers who did not possess nursing experience. There is an opportunity for both projects to train current and future caregivers in nursing to equip them better for medical issues facing their patients. The average number of patients cared for by each caregiver was 15 patients. Thus at both projects caregivers were not overwhelmed by the number of patients. Only 10% of caregivers felt motivated by duty or a financial reward for their care giving. A majority of 90% stated they felt called by God to care for patients.

4.6.1.1 Caregivers’ responses to issues of knowledge
Table 4.2 below analyses the knowledge of caregivers regarding the prevention of HIV/AIDS and the care mechanisms and facilities. The questions are asked within the framework of the project and relate to the caregiver's ability to recall and understand each project's counselling and treatment facilities. Moreover, the questions also analyse the caregivers' general knowledge of how they can be infected with HIV/AIDS, as well as known methods for treating patients with the disease.

Table 4.2: Knowledge of the caregivers

| %          |  
|------------|---
| Can direct contact with patients infect you? | 10
| Knowledge of home-based care | 50
| Knowledge of counselling facilities | 100
| Knowledge of PEP and treatment | 100
| ARV is effective | 100
| Knowledge of co-morbid diseases | 70
| Knowledge of tuberculosis | 90
| Knowledge of sexually transmitted diseases | 90
| Knowledge of herpes | 100
| Knowledge of pneumonia | 100
| Knowledge of Kaposi's sarcoma | 60

Ten percent of the caregivers felt that direct contact through holding hands or touching the patient could infect them with HIV/AIDS which can show their overall knowledge of the disease. Surprisingly, all the caregivers interviewed knew of each project's counselling facilities as well as PEP and other means of care. However, only half of them knew about home-based care. With the proliferation of infection of the disease across South Africa, home-based care has become a necessity. An opportunity for both projects would be for all of their caregivers to know about home-based care and be able to counsel visiting patients about the issue.

Attention should be paid to the fact that 100% of caregivers felt that orthodox means of treatment such as ARVs were effective. These caregivers could perform a vital function in dispelling political confusion and cultural misunderstandings about orthodox medicine as a form of treatment. Caregivers are representative of the surrounding communities, and speak the same language as the patients; hence patients feel comfortable and open with their caregivers. It is this trust
and bond which could further aid each project’s ability to teach and educate visiting and permanent patients about the success of ARVs.

When the caregivers were asked if they knew exactly what a co-morbid disease was, 70% stated they understood what this term meant. However when asked in greater detail to describe the most common co-morbid factors in their patients, 90% mentioned tuberculosis and other sexually transmitted diseases. All the caregivers listed herpes and pneumonia and 60% listed cancer (Kaposi’s sarcoma).

The importance of the above findings is to obtain accurate information concerning the care givers and identify where improved training is necessary. Their overall awareness of counselling facilities, PEP and treatment, as well as ARVs, is excellent. Considering that only 30% of caregivers have nursing experience, the overall knowledge of co-morbid diseases is superb with caregivers able to list and describe co-morbid factors such as herpes, pneumonia and even Kaposi’s sarcoma.

Caregivers need to become more aware of home-based care and to further counsel patients and visiting patients about the advantages of such care. Caregivers could also become an integral part of disseminating information to communities about the benefits and health advantages of ARVs and other orthodox treatment methods. If more people in South Africa had this level of knowledge, Aids sufferers would be able to access better treatment.

4.6.1.2 Caregivers’ responses to issues of prevention:
The table below analyses caregivers’ perceptions and opinions about preventing HIV/AIDS infection and re-infection. Of the three ethical issues discussed prevention is arguably the most controversial and complicated.

A participant’s ability to prevent infection by HIV/AIDS stems largely from choice and decision-making capacities. If a participant cannot say “no” or feels under duress in any way, her decision-making capability is hindered. Therefore, the line of questioning needed to address not only the standard policy and mechanisms in place for knowledge of the disease and care of women with HIV/AIDS, but also needs to assess the contribution of cultural and social factors.

Table 4.3 shows how the prevention of the spreading of this disease is hampered by women’s lack of decision-making capabilities, as well as
the sexual and physical abuse of women and children within homes and the belief that women are perennial victims.

Table 4.3: Caregivers ideas on prevention

| %        |  
|------------------|------------------|------------------|------------------|------------------|------------------|------------------|------------------|
| Their patients had been subjected to violence and rape | 90   | Assualts of patients by partners/spouses | 80   | Sexual/physical abuse of children | 100  | Are women perennial victims? Yes. | 100  | Are they weak and immoral? Yes. | 30   |
| Are they unfortunate? | 80   | Are they vulnerable? | 80   | Lack of education is a factor in their vulnerability | 90   | Poverty is a factor | 10   |

As shown in chapter 2, factors which affect women's decision making include intimidation such as violence, rape and the threat of physical assault. Gender discrimination is also a factor as cultural beliefs include the perception of women as minors and they are seen as inferior to men. The social vulnerability of women affects their ability to choose when it comes to unprotected sexual encounters and promiscuity. The social mores dictating that women are inferior to men have also warped women's ability to seek swift justice when a sexual offence occurs; therefore silence is the common response of women who have experienced a sexual assault.

Ninety percent of those looking after women said that their patients had been subjected to violence and rape. These women had been subjected to regular assaults, especially by their own spouses/partners. The children had all been sexually assaulted and physically abused. The social problem of abuse, especially by male partners towards women and children, is an area of great concern for the church and society as a whole. The church has always been a beacon of hope for social justice and its members have often protected the weak and suffering. The fact that women are vulnerable in their own homes and are abused by their male partners severely damages their psychological, mental and spiritual selves. It is only by fortifying the family unit and cultivating a home environment where women and children feel safe that women will feel as though they have the freedom to make decisions.
The dilemma of social and cultural perceptions regarding women and children is highlighted in table 4.3. All the caregivers regarded women as perennial victims with 80% being of the opinion that women are unfortunate and vulnerable.

From the information collected it is evident that women are victims of abuse as well as duress and have little control over their decisions. At the same time the social stigma that women are seen to be immoral and weak is still prevalent culminating in confusion and silence on the question of whether the women had brought the infection on themselves. Caregivers’ perceptions of the immorality and weakness of the patients was interesting with 30% remarking that patients were indeed immoral and weak. Yet, if you contrast this against the statistics where 80% of the women were assaulted by their partners and 100% of the children were sexually or physically assaulted by the male partner in the house, this belief in the women’s immorality needs to be re-examined. Women cannot be blamed or be held morally culpable in such an abusive setting. Asked whether the women in their care had brought their infection on themselves, not one caregiver gave an answer. Only 10% of caregivers felt that poverty was a factor regarding prevention. This is interesting since, overwhelmingly, caregivers felt violence and sexual intimidation was a factor affecting prevention whereas only a minority felt poverty was a factor. The aggression experienced by women, particularly in their own homes, is a serious cause for concern and should be regarded by the church and FBOs as a social justice issue.

4.6.1.3 Caregivers’ responses to issues of care

Dr Francois Venter, director of the Southern African HIV Clinicians Society (SAHIVS), is quoted in IRIN Plus News as stating that in the field of Aids, care which combines the strengths of religion and science could bring greater rewards in the fight against the HIV/Aids pandemic.\(^\text{56}\)

Venter states that churches and FBOs are uniquely positioned to help realise the goal of universal access to HIV prevention, treatment, care and support in Africa as they are well known and respected amongst communities. Care is a broad term; in the table provided below

caregivers were asked to discuss what they thought fell within the ambit of care. We shall discuss these findings below.

Table 4.4: Caregivers perceptions about care

<table>
<thead>
<tr>
<th>Perception</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care is emotional support.</td>
<td>40</td>
</tr>
<tr>
<td>Care is hygiene and physical care of patients.</td>
<td>50</td>
</tr>
<tr>
<td>Care is spiritual support.</td>
<td>20</td>
</tr>
<tr>
<td>Care is seeing to nutrition and medication.</td>
<td>50</td>
</tr>
<tr>
<td>Care is “going the extra mile”.</td>
<td>30</td>
</tr>
<tr>
<td>Caregivers counselled after the death of a patient?</td>
<td>90</td>
</tr>
<tr>
<td>Family counselled after death of the deceased?</td>
<td>90</td>
</tr>
<tr>
<td>Home-based care conducted?</td>
<td>50</td>
</tr>
<tr>
<td>Additional mechanisms to ease burden of suffering</td>
<td>90</td>
</tr>
<tr>
<td>Counselling helps me cope.</td>
<td>80</td>
</tr>
<tr>
<td>Regular staff rotation is essential.</td>
<td>100</td>
</tr>
</tbody>
</table>

FBOs, such as Sparrow Village, are uniquely placed in that they offer a platform which is dynamically close to communities. Moreover, they can work in an interdisciplinary manner with social systems and medical science. Hence, care-based strategies implemented by FBOs can incorporate many approaches and present a multi-layered solution to care-based programmes.

Care is multi-faceted especially considering Venter’s statements above and the reality that churches and FBOs are performing, overseeing and managing not only spiritual care but also social and medical care. Patients entering Sparrow Village and St Francis Care Centre experience physical care in the sense of medical treatment and hospitalisation. They also receive spiritual guidance and emotional care through counselling. Sparrow Village is using the opportunity for patients to become caregivers training patients to take on care-giving roles within the centre. Both Sparrow Village and St Francis Care Centre have home-based care programmes. Thus care should reach further than merely personal care adhering to spiritual, physical, mental and emotional care. It should incorporate a broader aim of community care with a focus on child-headed households, Aids orphans and caring for those who can no longer care for themselves.

The dimensions of care cannot be separated from the knowledge and prevention of HIV/Aids. Indeed, to teach communities about how HIV/Aids is spread and how re-infection should be prevented is, in
itself, a form of care. Jeremy Liebowitz notes that care activities by FBOs include: 1) awareness/education; 2) counselling and supporting testing; 3) home care; 4) food or material support; 5) support for orphans; 6) providing treatment or medication of some kind; 7) income generating activities and 8) condom supply. The success of FBOs in the fight against the pandemic lies in faithfulness, love and acceptance (Liebowitz 2002:50–51).

It is this recipe that allows FBO programmes to be better received than the private or public sector endeavours. Patients and day visitors recognise that caregivers speak their own language, that some are themselves inflicted with the disease and that the religious setting lends itself to surroundings free from fear and intimidation.

Of the caregivers interviewed everyone felt that the environment in which they worked was humane. Care was received by the patients not only in a medical sense but also in forms such as counselling and spiritual guidance. When asked to define what care encompassed, 40% of caregivers felt that care entailed emotional support. Half of the caregivers (50%) felt that care is mainly hygiene and the physical care of patients which ties in with the statistic that 50% felt care encompassed nutrition and medication. Only 20% felt that spiritual support formed part of care and 30% felt care also means going the extra mile. The small percentage of women who felt spiritual support formed part of care must be contrasted against the statistic that the majority of women felt that prayer and spiritual communication was a means to ease the burden of suffering. This provides evidence for the women’s narrow view of what constituted ‘spiritual care’.

Caregivers recognised that counselling is available to both caregivers and the family of the deceased. Caregivers felt that 90% of the time there was counselling of some kind at the death of a patient and 90% of the time counselling was also available to the family of the deceased. Ninety percent of the caregivers felt that there were also additional mechanisms to ease the burden of suffering, such as through prayer and open communication, as well as opportunities for a patient to become a caregiver themselves.

The above findings correlate with the informal interviews with the managers at both centres who stated that retreats, counselling and staff rotation were essential to help staff cope with the stresses of their occupation.
We can deduce that care is a multi-faceted and complicated concept especially when it is implemented by a church or FBO. Care means not only the physical, emotional, mental, spiritual and medical care of a patient, but also the care of caregivers so that they are emotionally, physically and spiritually equipped to deal with the ongoing ethical and practical issues of sickness, death, education and prevention. Caregivers face a barrage of problems such as gender discrimination and violence, an overwhelming increase of the number of Aids widows and orphans, poverty and unemployment, and gender oppressive cultural beliefs.

The above findings are interesting in that they highlight the physical or medical notion of care. This traditional view of care should be looked at very closely by FBOs. Making patients comfortable in terms of medical treatment, hygiene, regular meals and basic needs is indeed integral to the definition of care. However, care should also be looked at in a broader sense, taking into consideration spiritual care, ongoing counselling and communication about the prevention of re-infection. There is an opportunity here for caregivers not only to become part of the medical care process but also part of a process of spiritual awakening and healing.

It is through training caregivers in home-based care that FBOs can increase the range and scope of their HIV/Aids treatment and care. Care encompasses strategies for prevention and knowledge to educate communities. FBOs could incorporate these issues into a home-based care programme.

Home-based care also has advantages in terms of community ownership and stewardship. Running an HIV/Aids centre is labour intensive and expensive, with both projects reporting ongoing tension with unions and labour board disputes. By training patients and community members in home-based care, projects can encourage community members to take ownership of these programmes. Employment issues will be less cumbersome if caregivers and communities feel as though they oversee the project and the ongoing success of education, prevention and care projects is more a community-driven responsibility than a mere employment contract. With only 50% of caregivers reporting knowledge of home-based care mechanisms, an effort should be made to increase this type of care giving.
The next section outlines and analyses responses from the patients who were interviewed. The patients were all women interviewed at St Francis Care Centre and Sparrow Village.

4.6.2 Profile of patients at St Francis Care Centre and Sparrow Village.

Table 4.5 below shows the demographics of the patients interviewed, the number of women in the sample and their average age. It then looks at their educational level and how many of the women are in committed relationships or marriages.

<table>
<thead>
<tr>
<th>Table 4.5: Demography of patients interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of women in sample</td>
</tr>
<tr>
<td>Average age of women</td>
</tr>
<tr>
<td>Number of children on average</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Educational level attained:</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Matric</td>
<td>40</td>
</tr>
<tr>
<td>Grade 10 and over</td>
<td>80</td>
</tr>
<tr>
<td>No education</td>
<td>20</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Percentage single</th>
<th>40</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage in a relationship</td>
<td>10</td>
</tr>
<tr>
<td>Percentage widowed.</td>
<td>50</td>
</tr>
<tr>
<td>From Gauteng</td>
<td>80</td>
</tr>
<tr>
<td>From KZN</td>
<td>10</td>
</tr>
<tr>
<td>From North West</td>
<td>10</td>
</tr>
</tbody>
</table>

The average age of the women interviewed was twenty-nine years. They had, on average, two children each. Forty percent had matric, 80% had been educated beyond Grade 9 (including the matriculants) and only two women had no formal education. Information regarding their level of education was fundamentally important in order to analyse the success of knowledge and education campaigns. With the majority having had a formal education, most patients were thus capable and able to analyse and interpret basic texts in their own language from media sources such as newspapers, billboards and pamphlets. Thus, the overall capacity to digest information and instructions was good. This finding raised the question of how these relatively well-educated women with relatively good education could have contracted the disease. This finding will again be discussed below when we discuss intriguing issues of knowledge and prevention.
In table 4.5, we can see that 80% of the patients came from Gauteng, 10% from KwaZulu-Natal and 10% from the North West Province. Only one patient was involved in a relationship, 40% were widowed and 50% were single. None of them were married. The findings confirm women’s vulnerability in society, where the majority of these women are in sexually active relationships but none are committed to a faithful marriage.

Eighty percent had children with the maximum number being four children per patient. The burden of single parenting is clear from the results which show that none of the women were in a committed, faithful marriage, but all had children. Women are reduced to selling their bodies to support and feed their young, or put up with abusive and demeaning relationships to ensure male participation in a fractured family unit.

Social behaviour is changing with a degeneration of family moral values and a disintegration of traditional extended families. This is a worrying trend and has increased the spread of HIV/Aids as sexual relations are taking place outside the safety and sanctity of an exclusive marital relationship. Prevention strategies employed by the church should take these changing social dynamics into account. Issues of the breakdown of family structures caused by promiscuity, the death of partners, gender discrimination, violence and abuse of substances must be noted in the attempts of the church to respond to the Aids pandemic.

The methodology in chapter 3 outlined the manner in which the formal questionnaires were conducted. It is important to reiterate that the patients’ identity remained confidential at all times and no names were divulged during the collection of the data. Their names were never taken and full consent to participation was given by them prior to answering the questionnaires. The patients were encouraged to ask questions and participate so that the exercise could be a learning process. The patients were interviewed at the hospice facilities of both Sparrow Village and St Francis Care Centre.

The outline of the interviews for the patients followed the same themes as the interviews for the caregivers. The aim of the study was to gain information about how the patients are responding to the information and knowledge campaigns within the FBO, how they are responding to prevention mechanisms as well as to the care facilities.
The questionnaires also touched on the broader social issues of stigma, fear, gender discrimination, poverty and violence, as well as their basic knowledge obtained through social channels about HIV/AIDS prevention and treatment. The spiritual role of the FBO was also questioned in order to try and identify how patients' spiritual lives and moral formation had adapted and evolved since becoming part of these FBOs.

The breakdown of family units is an important factor leading to the cause of infection and re-infection of HIV/AIDS. The breakdown of faithful, exclusive marriages can be linked to a number of causes including poverty, gender discrimination, physical abuse and the abuse of substances.

Women no longer feel safe and confident in their homes when a contract and the bonds of marriage are no longer in place; they are abused and carry the burden of single parenting.

4.6.2.1 Patients' knowledge and perceptions of HIV/AIDS

Knowledge and understanding allow a person to make choices and appropriate moral decisions. As stated above, the majority of the patients interviewed had a formal education and were literate. The poor results pertaining to the basic knowledge of HIV/AIDS is a cause for concern and can be accounted for by poor dissemination of information by government as discussed in chapter 2.

Table 4.6 looks at patient knowledge. The knowledge of each patient was analysed by asking questions pertaining to how a patient became infected with the disease, their awareness of treatments available and their knowledge of their legal rights about HIV/AIDS, which includes informed consent, disclosure, HIV/AIDS testing as well as labour rights against discrimination.

Table 4.6: Awareness of patients interviewed

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aware that they had AIDS</td>
<td>100</td>
</tr>
<tr>
<td>Aware of how HIV is transmitted</td>
<td>100</td>
</tr>
<tr>
<td>Percentage receiving treatment</td>
<td>80</td>
</tr>
<tr>
<td>Aware of the availability of ARVs as medicine for treatment</td>
<td>20</td>
</tr>
<tr>
<td>Aware of the availability of PEP</td>
<td>0</td>
</tr>
<tr>
<td>Aware of their rights regarding HIV/AIDS</td>
<td>50</td>
</tr>
</tbody>
</table>
In table 4.6 only 30% knew what informed consent was, thus the knowledge about informed consent is lacking. Informed consent is defined as consent to be tested for HIV/Aids and questioned. With the increase in knowledge about their rights and the legal protection afforded to them, patients could also grow in confidence and assurance that protection mechanisms have been put in place. The overarching care afforded to HIV/Aids sufferers can also help teach patients that they are not alone with the problem of infection and this could go a long way towards dismantling social stigma and fear.

Knowledge about treatment and rights was shockingly poor. Patients lacked knowledge concerning treatment. Only four of the women knew about ARVs. None of them had ever heard of PEP, which is interesting if you reflect on the responses of caregivers where the majority knew about PEP as well as ARVs. St. Francis has already responded to this finding. The manager, Tilley Bouwer, told me that caregivers were now implementing plans and strategies to talk to patients and day visitors about treatments, especially PEP, which is vitally important to know about when a woman has been sexually assaulted.

The inability of the women to grasp forms of treatment such as ARV is largely due to the misinformation disseminated by government and the fact that a single conclusive policy has thus far not been implemented by our government sanctioning the use of ARVs. The macro effect of government’s bungling of ARV information can be seen at these two projects, where only 20% of the patients were aware of the availability of ARV as a medical treatment.

Patients were also unacquainted with their rights regarding HIV/Aids. Only 50% had a basic grasp of their rights to privacy, consent and access to treatment and this was only after they had been counselled by the respective FBO they were attending. Patients need to gain an awareness of their rights so that they can participate fully in treatment and so that they can protect their rights in the workplace and during formal interviews.
All the patients stated that they had only received detailed information about infection and prevention once they had reached either Sparrow Village or St Francis.

The fact that women are only receiving the necessary information to prevent infection once they reach a hospice facility means it is too late for them to take decisions which could have prevented the infection in the first place. This basic lack of knowledge, coupled with the breakdown of family units caused by violence and gender discrimination as discussed above, makes for an environment in which it is almost impossible for women to take correct decisions regarding their bodies and overall health. The women could not name a single consistent source outside of the care centre which provided them with reliable information about HIV/AIDS, including newspapers, radio or television mediums.

The overall knowledge of prevention, re-infection, treatment and rights was bleak. If care is to be interrelated with knowledge, current and future FBOs need to help fill the information void in society so that communities can care for themselves and their families by employing moral choices and understanding their rights.

Every patient interviewed knew they had AIDS and every patient stated that AIDS was caused by sexual intercourse with an infected person. The centre was their first taste of counselling and information dissemination regarding the spread and contracting of the disease. This is an important lesson for FBOs, especially if they want to make a difference in terms of prevention and knowledge of HIV/AIDS. It is essential that information and counselling are available at the actual centres, but the lacuna outside these centres cannot be ignored. A suggestion has already been made above that social justice campaigns should recognise that poverty, gender discrimination and violence contribute to the spread of the disease. If the church could encourage fidelity and safety in homes, households would be more receptive to prevention mechanisms and information about abstinence, faithfulness and safe sex.

4.6.2.2 Patients’ understanding of the prevention of HIV/AIDS and their ability to act

The following table shows how patients found out they were HIV positive. The table’s purpose is to assess the willingness of voluntary
testing as well as methods by which women, in particular, are becoming aware of their HIV status.

Table 4.7: How did they find out they were HIV positive?

<table>
<thead>
<tr>
<th>Method</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antenatal clinic</td>
<td>40</td>
</tr>
<tr>
<td>Tested when their partners became sick</td>
<td>10</td>
</tr>
<tr>
<td>Tested at clinic</td>
<td>50</td>
</tr>
</tbody>
</table>

Forty percent of the women discovered their status only when they attended an antenatal clinic. Ten percent went for testing when their partners got sick and died. Fifty percent became progressively sick and attended a clinic where the diagnosis was made.

The above statistics show how testing is not a norm within communities. Women do not get tested after a sexual assault or casual sex; they predominantly get tested once they have fallen ill, when their partners become sick, or when they attend an antenatal clinic.

Poor knowledge and preventative actions within communities can be seen in the fact that testing occurs at a late stage. This is quite disturbing as the virus was thus spread during the window period and right up to the time that there was physical evidence of transmission. Education regarding prevention prior to infection is of extreme importance. Women should be counselled to visit clinics immediately after rape, casual sexual encounters or if they suspect their intimate partners of infidelity.

The resistance to being tested can be due to social stigma, fear and poverty. With transport and medical costs escalating, the poor state of national hospitals and women facing a situation in which they have little understanding about the nature of the disease or their rights, the thought of ongoing tests are just too onerous.

There are numerous health implications if people wait too long to be tested. Resistance to being tested can lead to a rapid deterioration in health and, if patients are tested too late, ARVs may be ineffective. The moral issues of late testing and denial are that whilst they may suspect they are infected women are still engaging in sexual intercourse. This behaviour is dangerous in terms of spreading the disease to partners and unborn infants who are the results of such sexual relations. Often
women have been infected by their male partners, but are unaware of the fact.

If a community's basic understanding and knowledge of a disease is poor they will most likely be unable to grasp prevention methods using physical devices such as condoms, or making personal choices on abstinence and faithfulness. The social factors leading to the destruction of family units and marital unions enflame a situation of poor decision making and hamper prevention strategies within homes and communities.

FBOs have an opportunity to fight delayed testing and the ongoing stigma linked to testing if home-based care groups can include prevention strategies which include regular testing. The strategy of group testing together with counselling and open communication could diminish the resistance to being tested. Early identification of the HIV virus can improve care and reduce infection.

4.6.2.3 Patients' opinions on trust and care

Care is a multi-dimensional concept, particularly for FBOs. Care at St Francis Care Centre and Sparrow Village includes counselling, medical treatment, hospice facilities, the maintenance of physical and emotional health, spiritual guidance, economic assistance and continued education. Care is founded on relationships of mutual trust.

Table 4.8 analyses the level of trust of the patient in their partner as well as in the church and society as a whole.

Table 4.8: In whom did you confide and how was the news received?

<table>
<thead>
<tr>
<th>Confided in</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>my partner/husband</td>
<td>90</td>
</tr>
<tr>
<td>my friends</td>
<td>80</td>
</tr>
<tr>
<td>my children</td>
<td>50</td>
</tr>
<tr>
<td>my pastor</td>
<td>50</td>
</tr>
<tr>
<td>my employer</td>
<td>30</td>
</tr>
<tr>
<td>News received judgementally by society</td>
<td>10</td>
</tr>
<tr>
<td>News resulted in being ostracised by society</td>
<td>10</td>
</tr>
<tr>
<td>News received without condemnation from society</td>
<td>90</td>
</tr>
<tr>
<td>Have you experienced violence from a partner?</td>
<td>50</td>
</tr>
<tr>
<td>News resulted in increased partner violence</td>
<td>50</td>
</tr>
</tbody>
</table>
The patients interviewed were all quick to respond to the question as to whom they confided in upon hearing their status. Ninety percent confided in their partners and 80% told their friends. Fifty percent confided in a pastor which proves the inherent trust these patients felt towards their spiritual leader. This is important for this study as it shows how much faith and confidence women are putting in their spiritual leader. Fifty percent chose to confide in their children and only 30% chose to confide in their employer.

When the patients were asked to write down why they chose those particular people to confide in, 50% said that they wanted support, 10% stated they needed love, 10% stated they believed they would not be rejected. The response received shows that 90% of the patients who chose to confide in someone felt accepted. One woman also wrote that many of her friends were able to support her because they were in a similar situation. From the response the women took more than one person into their confidence.

The support received from patients who had had the courage to confide in trusted individuals highlights the need patients have to talk about their status as well as to be accepted and loved once their problems have been shared in confidence. The very act of listening and sharing this concern and fear with HIV/AIDS sufferers is in itself an important form of care.

The women were asked if they had experienced violence at the hands of a partner. Thirty percent refused to answer these questions altogether. Of the 90% who had confided in their partner 50% stated they had felt an escalation in violence after they had disclosed their status to their respective partner. This contrasts with the fact that 90% of women felt that they had not been ostracised by broader society, friends and spiritual pastors once their status had been disclosed. Thus the fear of stigma is greater than the reality of rejection. The increase in violence by partners is a sign of the instability of the family unit and the lack of acceptance by the male partner. For the majority of women interviewed, the fact they are also not legally married shows how relations are quite unstable and easily stressed within the family unit. The fact that most unions are not legally recognised marriages but simply a physical partnership of people living together reinforces the argument that the classical family unit is under threat. The escalation of violence upon disclosure shows further the overall lack of empathy, care, restraint, understanding and respect from male partners.
All the women who belonged to a church had experienced intimate partner violence and an escalation of violence upon divulgence of status. The fear and intimidation of these patients upon disclosure came predominantly from within their own homes by male partners. Hence women are part of a two-pronged process which ultimately catalyses the dilemma of infection and re-infection. Firstly, they are afraid to make moral choices regarding sexual unions with male partners for fear of violence. Therefore, their ability to act upon knowledge gained and to prevent infection is diminished. Secondly, although many of them confided in male partners, the felt afraid to tell male partners about their status for fear of physical and emotional abuse. This raises the question of whether the male partner infected them. Was he tested? Did he tell her about his status and why is the woman being blamed?

With the vast majority of women coming from abusive homes and a society laden with stigma and fear, it is the mutual bonds of trust which allow patients to confide in caregivers and allow caregivers the opportunity to provide medical, psychological and spiritual assistance. This ongoing interest in the patient beyond the walls of the centre is a recipe for success amongst FBOs.

4.6.2.4 Spiritual care

Care is a multi-faceted concept. Table 4.9 below addresses ways in which female patients received spiritual care, whether this was at the facility itself or within their broader community. It also analyses the element of trust by asking who the women confided in and whether the church or cell group to which they belonged was taken into their confidence.

Table 4.9: Women, their church and HIV/AIDS

<table>
<thead>
<tr>
<th>Percentage of interviewees who attended a local church</th>
<th>50</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denomination of church attended by the 50% who did attend:</td>
<td></td>
</tr>
<tr>
<td>ZCC</td>
<td>20</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>10</td>
</tr>
<tr>
<td>Various Pentecostal</td>
<td>20</td>
</tr>
<tr>
<td>Percentage who confided in:</td>
<td></td>
</tr>
<tr>
<td>Women’s groups</td>
<td>30</td>
</tr>
<tr>
<td>Cell groups in a church</td>
<td>10</td>
</tr>
</tbody>
</table>
Do patients feel they have spiritual support from the centre?  
Receiving prayer and Bible reading  
Receiving guidance and advice  
Is there ministry regarding the gospel of Jesus Christ?  
Experience love and support from the Church in general  
in broader society  

<table>
<thead>
<tr>
<th>Question</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do patients feel they have spiritual support from the centre?</td>
<td>90</td>
</tr>
<tr>
<td>Receiving prayer and Bible reading</td>
<td>90</td>
</tr>
<tr>
<td>Receiving guidance and advice</td>
<td>90</td>
</tr>
<tr>
<td>Is there ministry regarding the gospel of Jesus Christ?</td>
<td>90</td>
</tr>
<tr>
<td>Experience love and support from the Church in general in broader society</td>
<td>70</td>
</tr>
</tbody>
</table>

On the issue of receiving spiritual support and care from the church in general, 70% of the patients felt that the church had made an impact on the community’s overall knowledge, prevention and care of HIV/Aids. Ninety percent felt that they had experienced love and support from the church through the two chosen centres, St Francis Care Centre or Sparrow Village. They felt accepted and loved in the two centres.

Spiritual guidance focused on forgiveness of sins, personal guilt and injustice. The focus on forgiveness of sins addresses each woman’s overwhelming need for acceptance and the fear that HIV/AIDS is an unacceptable and immoral disease. Personal guilt is also a complicated issue which needed spiritual guidance. The patients stated they had guilt about being infected, guilt about the possibility of infecting others and, of course, guilt of infecting or abandoning their offspring.

The element of personal guilt also affects stigma. Patients’ guilt and shame affected them psychologically, where they believed their status made them stigmatised. Therefore their fear of rejection and the reality of acceptance by the community are important to analyse because the majority of patients did not experience rejection once they had divulged their status. Yet, they still felt immense personal guilt and shame. This is why an important component of the questioning was whether the patients felt they were receiving prayer, guidance and spiritual support at the centre. Although both centres were Christian centres, the ethical and moral formation of patients is affected when they literally come into contact with God’s grace and mercy through the advice, guidance and prayers shown at the centre by caregivers, personnel and visitors.

Very few women went to a cell group or a women’s group within the actual centre quite simply because they already felt a part of a group which was predominantly female by being a part of the centre’s workings. Thus they already felt a part of a community that was inclusive, safe and caring.
Injustice is a factor which is difficult for some of the patients to talk about as seen in table 4.8, where 30% refused outright to talk about violence at the hands of their partners. Spiritual guidance helps them to discuss the matter free from fear and duress and they can more openly discuss issues such as assault, rape and abuse by partners. Counselling about injustice has numerous benefits which include mending shattered psyches, restoring a woman's faith in not only herself but also in society in general, as well as reconstructing her self-confidence in the assurance that domestic abuse is wrong.

Patients felt encouraged to attend church services at Sparrow Village and St Francis Care Centre but were not pressurised to do so. The other interesting point is that upon delving into the abuse suffered at the hands of intimate partners none blamed the church in general for a lack of action; overall they agreed that the church and the respective centres, either Sparrow Village or St. Francis Care Centre, have been a haven of care and acceptance.

4.7 AN ANALYSIS OF THE ETHICAL ISSUES RAISED BY THESE FINDINGS AND THEIR IMPLICATIONS FOR THE MINISTRY OF THE CHURCH

The above questionnaires administered to the caregivers and the patients allow us to gain insights into the strengths and weaknesses facing St Francis Care Centre and Sparrow Village and how these centres affect patients' and caregivers' ethical and moral formation. An interesting feature of the results from the two centres was the symmetry of results.

4.7.1 Analysis St Francis Care Centre and Sparrow Village

The deductions from these formal questionnaires can be applied to current FBOs as well as future projects run by the church. This discussion aims to analyse the strong points and weak points drawn from the questionnaires on issues of knowledge of HIV/AIDS, prevention strategies against infection and re-infection, as well as care methods. Moreover, it will also address the interdependency and interrelatedness of St Francis Care Centre and Sparrow Village on medical science, social policy and theology.

The caregivers had excellent knowledge of medical symptoms facing patients although only 30% were qualified in nursing. The overwhelming opinion amongst caregivers was that ARVs and orthodox medicine renders excellent results. Knowledge of the project, such as
management, funding and policy, was also excellent as well as knowledge about counselling. The caregivers also displayed an understanding and empathy for broader social and political issues facing their patients with issues such as poverty, violence and abuse.

Contrasted with the well-grounded and mature knowledge of the caregivers was the deficient knowledge of the patients. The singular lack of knowledge on the part of the patients and probably the wider population is a major obstacle facing FBOs. The majority of patients only received counselling, education and information about HIV/AIDS once they became part of the FBO, either St Francis Care centre or Sparrow Village.

As discussed in chapter 2, it is extremely difficult for people to make sound moral and ethical decisions if their knowledge is lacking or affected by duress or an element of fear. As Borgert states:

> Christians living in a fallen world are frequently faced with difficult choices that may result in imperfect outcomes either way. The HIV/AIDS pandemic in Africa is just such a case. In these situations, prudence must direct our actions so that the greater good is maximized for the most people (Borgert 2001:5–16).

Borgert suggests that one of the main answers to the HIV/AIDS pandemic is to invest in moral formation rather than a distribution of free medicine.

There are various interpretations and ideas regarding condom usage within the Catholic Church and they reflect different theological positions. One particularly controversial issue is the use of condoms within a marriage, for example, what happens to a non infected partner? According to one Catholic Church lobby group, choices surrounding sexual and reproductive ethics should be based on justice and reflect a commitment to a woman’s wellbeing and respect and affirm the moral capacity of a woman to make decisions about her life.57

Only 20% of the women interviewed reported knowing anything about ARVs and none knew anything about PEP. The lack of knowledge about PEP is particularly disturbing given the fact that the female patients reported aggravated instances of sexual assault, abuse and sexual intimidation. Patient knowledge of their rights was also poor with only half reporting they had a basic understanding of their right to consent with regards to counselling, testing and treatment. The deficiency in overall knowledge reported by patients is a pressing concern and needs to be looked at in terms of government and church policy.

Ideally, FBOs should work together with the church congregations to form part of the knowledge disseminating process. For larger churches in South Africa, such as the ZCC, Rhema Bible Church, the Catholic Church and Methodist Church, the social justice plan of spreading information about HIV/AIDS prevention and treatment could have a multiple effect and assist organisations such as St Francis Care Centre and Sparrow Village in bridging the knowledge divide.

The acute need for knowledge and a prevention policy which is consistent, thorough and palatable is of pressing importance. Of the factors facing FBOs on a daily basis, is that the knowledge of HIV/AIDS as well as the inability to prevent infection due to abuse and poor decision making are in desperate need of attention. Caregivers reported on the ongoing violence against and intimidation of patients. Eighty percent felt that women were vulnerable and unfortunate; therefore their overall capacity to make informed decisions is poor. Caregivers also noted that patients' lack of AIDS education is a root cause of their inability to prevent infection. Thus the caregivers were able to link knowledge and understanding of HIV/AIDS with patients' preventative capabilities. The sentiments of the caregivers correlated with the statistics produced by the patients. The majority reported being abused, with half reporting that violence had escalated since revealing their status to their partners.

An outcome of the research which should be addressed by FBOs and the church is the breakdown of family units. With none of the patients being married but 40% being in relationships where abuse is reported, the health of these relationships and the family structure is severely under threat. Ethically, the church needs to be discussing what is happening in families and partnerships and what ought to be happening.
Marriage is the first institution that God established between people. Both men and women were created in His image; equal partners with distinctively different roles (Genesis 1:27). One of the most complete answers to the question as to the acceptability of abuse by a male partner towards his female partner is found in Peter.

Husbands, in the same way be considerate as you live with your wives, and treat them with respect as the weaker partner and as heirs with you of the gracious gift of life, so that nothing will hinder your prayers (1 Peter 3:7).

Thus the Bible shows how husbands are to love their wives as they love their own bodies. It is therefore a matter of concern that unions in South Africa are coming under increasing pressure and religious marriages seem to be diminishing with informal partnerships becoming more prevalent. This not only makes a woman more insecure as to her role within a household, but it also has important legal implications in terms of laws of succession, alimony and the ease with which a woman can claim child support.

The church likewise needs to find ways in which to support family units and confront domestic abuse. Victims of domestic violence need to be protected, even moved temporarily to a safe place if necessary. If a wife is being abused by her husband, or a woman by a male partner, she needs to separate herself from him while he receives treatment for his violence. Couples should also be encouraged to find spiritually mature Christians who are willing to disciple them either individually or in a small group. This will also assist in cultivating a relationship based on accountability, where a male abuser can come face to face with male Christian leaders and mature male Christian congregants who find domestic violence unacceptable. Reporting the abuser to the police is only one step; it does not take the woman out of harm’s way nor does it change the unethical behaviour of an abusive male partner.

Knowledge and prevention strategies must evolve to address the multiple effects of abuse, indignity and gender inequality. Teachings by the church to address the societal degradation of family units and abuse of women and children could strengthen the work of FBOs and diminish the effects of abuse. Likewise the counselling of male partners within FBOs such as St. Francis Care Centre or Sparrow Village should be considered.
Since women are susceptible to physical or emotional injury in the deepest recesses of their bodies and being by their male partners, the ability for them to conduct their sexual lives in their own manner is restricted and corrupted by fear. This is compounded by the fact that 90% of caregivers feel that the lack of education is a direct link to women’s vulnerability. The lack of education reaching women could be the result of poor educational programmes, but could also be as a result of a women’s inability to make choices, hence to actually access the information and knowledge available. Thus knowledge requires a two-tier process; access to accurate, clear information and then the ability to actually apply the information to their lives.

Therefore the church and FBOs should look at prevention strategies that not only incorporate broader social counselling about mutual respect and gender freedom, but also employ knowledge-based campaigns to better equip women in understanding the nature of HIV/AIDS and how the disease is spread.

Caregivers questioned on care displayed a deep personal care for patients, a responsibility and sense of duty beyond financial benefit. Ninety percent stated they were motivated by calling. Some caregivers felt calling was a moral tug towards helping the vulnerable women and children within their own communities; others who had likewise been victims of abuse and violence felt they knew on a deep and spiritual level what female patients were experiencing; others stated calling was a spiritual calling directly from God into this line of work.

Many stated there were ongoing prayer sessions to help them cope and to help ease the suffering of terminally ill patients who were afraid of death. Interestingly, when asked to define care, only 20% stated that care involved spiritual support. Perhaps caregivers who work in a hands-on manner within medical facilities see care more in physical terms of medication, hygiene and nutrition because these are the immediate physical needs facing them on a daily basis. Caring for themselves upon the death of patients also involved retreats and spiritual getaways and counselling. St Francis Care Centre and Sparrow Village had mechanisms in place to care for patients in terms of assistance with social grants, income-generating projects and employment opportunities.

At both projects there is the potential to multiply home-based care. This will ask ethical questions of the broader community as they see
Christian care and love in action. Perhaps every visiting patient and their families could be educated and counselled in home-based care. Only 50% of caregivers interviewed reported having been involved in home-based care. Home-based care could also have a knock-on effect of disseminating information on how HIV/AIDS is spread and the importance of getting tested.

Mary Pipher, a well-known psychologist, is quoted by Sara Martin as saying that it is time we look beyond parents for the reasons for the breakdown of family units. The parental structure of the family is not what causes a family unit to break down; it is the outside societal and cultural forces that do (Pipher 1998:1–5). Pipher states: “Too often psychologists focus only on helping individual families, but they need to be making a difference in their communities too.” Pipher stresses the interdependence between the healthy structures of families and a broader societal culture. The church is particularly well positioned to assist in effecting a broader societal culture with the aim to help build and heal family relations, particularly the prevalence of gender discrimination experienced by South African families.

If the church and FBOs could become more involved in reforming the social behavioural norms of men towards women and children, it would greatly improve trust, dignity and respect within family units. The ripple effect of this type of social justice would be a prevention strategy to dampen the spread of HIV/AIDS as women become more independent in choice making.

Pipher’s statements above about how counselling should approach a broader community instead of individuals, could be incorporated by the church and projects such as Sparrow Village and St Francis Care Centre.

The category of patient confidence is interesting, as 50% reported they had confided their status to their pastor. This is an opportunity for churches to work together with FBOs. If a pastor could give counselling upon the news of a congregant’s status they could direct the congregant to an FBO centre for treatment such as PEP and care. The relationship of trust already in place between a congregant and his or her spiritual leader will make it easier to persuade those divulging their status to seek treatment and care within the framework of FBOs. Churches should have a database of FBOs to which they can refer congregants should they need treatment, counselling and care. This is
a major advantage of the Catholic Church in that each diocese supports a project and the congregation are well informed about the location and management of the project. If the pastor who has been taken into confidence could counsel both partners, the male and the female, it might diminish the violence suffered by women upon divulging their status.

Patients received care in the form of counselling and support once they had joined the two centres. Although they were receiving medical care, few however knew about ARVs and none knew about PEP. Therefore knowledge of treatment and care needs to be linked with the care process so that patients gain a better understanding about how they are being cared for. This could also assist the FBO in knowledge dissemination as patients could likewise tell visitors and their families about the kind of medical care they are receiving and what types of treatment are available. Interestingly, the caregivers themselves looked at care more in physical and medical terms. However, the patients felt overwhelmingly that the centres provided spiritual support and care for them with Bible readings, prayer and experiencing the love of Jesus Christ. St Francis Care Centre and Sparrow Village have potency in that the daily workings of medical treatment and social assistance which address knowledge of HIV/AIDS prevention of the spread of the disease fall within a deeper, broader backdrop of spiritual care. Not only did patients feel they had received spiritual and emotional care from St Francis Care Centre or Sparrow Village but, when asked to give their opinion on the church, 70% stated they had received love and support from their respective churches.

As FBOs are respected by communities, the government and the medical sector, they have a unique advantage in being able to communicate and cooperate with all these different sections effectively and efficiently. There is, therefore, an opportunity for current and future FBOs to implement ARV and hospice centres with the support of government and the medical sector.

There is clearly a need to formulate policy and strategies that address abuse, violence, and the annihilation of family units and the breakdowns of marital unions. There is also an opportunity to increase and improve home-based care. The fact that FBOs are indeed faith based means they should receive the support, guidance and encouragement of the church. This can be seen with St Francis Care Centre which is affiliated to the Catholic Church. They are therefore
part of a larger body which assists them in implementing plans and strategies, oversees the management and creates a network for communication of concerns.

Sparrow Village is starkly contrasted; they are not affiliated to a particular church and receive little if any support from Jesus Alive Ministries. They have to formulate their own policy and their own strategies and have no support in terms of communicating with other churches or projects. The affiliation of an FBO also goes further towards the financial lifespan of an FBO. If the FBO is part of a church which has a large congregation, the congregation itself is an immediate support system for finance, charity work, volunteers and educational support. Sparrow Village relies wholly on corporate donations and financial contributions from individuals; therefore their fundraising needs are more complicated and labour intensive than St Francis Care Centre.

Problems facing St Francis Care Centre and Sparrow Village are the policy of the government in terms of the rollouts of ARVs, access to treatment and the taxation of FBOs. Other difficulties mentioned included transport costs, electricity outages, drug resistance and crime affecting the centres.

An important threat is the threat of union and labour disputes which are referred to the Council of Conciliation, Mediation and Arbitration. Both project managers reported the stress of dealing with unions. As stated above, projects should move away from an employer and employee contract mentality. Trying to curtail the inflexible employer and employee concept based on power can only be achieved if the community takes ownership of the project in some way, as they are the ones directly benefiting from the knowledge, prevention and care practices of the FBO. Home-based care could assist in alleviating this tension as it hands power to communities though education and support so that they can reach people in need. By encouraging home-based care methods, projects could encourage communities to become leaders in the field of care giving and thus ownership of branch projects could be encouraged and other community members may also feel called to become caregivers.

4.8 CONCLUSION

The ethical issues relevant to this empirical research project have been noted throughout this chapter. It is now necessary to summarise the
findings of this research with respect to the ethical insights revealed in the data collected.

We have seen in chapter 2 and this chapter that AIDS is a disease that thrives in a dysfunctional society. Factors such as dangerous and selfish sexual habits, gender violence, superstition and ignorance have a significant impact on the epidemiology of the disease. These factors directly contribute to the inability to make personal choices and prevent infection of the disease. Mennonite thinker Harry Huebner reminds us that “when we engage in moral activity, we act on the basis of our perceptions and our beliefs. We act on the basis of who we are as social/moral beings and on the basis of the characters into which our communities/families have shaped us” (Huebner 1998:399). Communities are crucial to sustaining character and values. Ultimately, we derive our personal convictions from the community that transmits to us an understanding of virtue and goodness (Grenz 1998:403).

Stigma impacts on all three ethical areas of this study. It affects knowledge and prevention because the implications if a woman divulges her HIV status can be so harsh that she would rather hide her fears and remain ignorant of her status than face the condemnation of her social group. Often women are reluctant to seek treatment or care for fear of her partner finding out about her status. Of the patients interviewed, the majority left testing until they had become pregnant or fallen ill. It was at this stage then that 90% of the patients interviewed divulged their status to their partners; half then experienced an escalation in violence.

Thus stigma, which is largely based on the elements of fear and duress, can be summarised as affecting women in the following ways:

- a fear of testing
- a fear of disclosure to partners, the church, the community, employers
- a fear that they will receive no loving support from their homes where family units are already maladjusted and partnerships exist with no matrimonial bond
- a threat of violence from partners due to a lack of social justice
- a fear that disclosure will affect job and labour opportunities therefore driving them further into poverty
- a fear that communities will exclude, ostracise or isolate them once they have divulged their status
• a feeling of personal shame, guilt, self-accusation and blame that they are HIV positive as the disease is largely a sexually transmitted disease and their infants may also be at risk of being HIV positive

According to Crosson, there are deep seated moral and cultural understandings of sex and sexuality. Women will often choose to die without ever disclosing their status or seeking treatment rather than risk the stigmatisation associated with the disease:

Sub-Saharan Africa is dying, in part, because of a cultural taboo. Cultural and religious traditions make talking to people about the HIV/AIDS epidemic almost impossible because it is a topic so closely associated with sexual behavior. Yet an estimated 28 million people are living with HIV/AIDS in sub-Saharan Africa, and new cases are cropping up at an alarming rate”.

This extreme form of stigma is often mentioned as increasing the complexity of dealing with the HIV/AIDS pandemic. Stigma discourages potential patients from having themselves tested, or from revealing their HIV status. It also causes the community to shun the victims and their families. Communities also do not acknowledge that many of the people they are burying have died as a result of AIDS. However, it was interesting to see that at both Sparrow Village and St Francis Care Centre the female patients interviewed did not feel ostracised or shunned by the other patients and caregivers at the project. They felt they received spiritual, medical and emotional support from fellow patients and caregivers many of whom were likewise HIV positive and many of whom had experienced violence within the home.

As discussed in chapters 1 and 2, stigma is recognised as being complex, deep rooted and destructive. Nadine France points out that even professional Aids counsellors versed in the causes and consequences of the disease, often fail to disclose their HIV status to even their closest friends. Nadine France defines stigma as:

Shameful because of its relation to sexual intercourse and promiscuity, most often being associated with particular groups

such as sex workers. Other words used over and over again include rejection, fear – being afraid of people and people being afraid of you, shame, isolation, judgemental, gossip, rumours, feeling threatened, uncomfortable, socially unacceptable, negative, low self-esteem, paranoid, abandonment. Interview participants said that stigma is perpetuated by lack of knowledge and ignorance and often related HIV/AIDS-stigma with witchcraft (France 2001:2).

During the course of the interviews and talking generally to patients outside the formal questionnaires, patients cited stigma and isolation more than any other factor that they had to deal with. The caregivers at St Francis Care Centre and Sparrow Village were also affected and often did not mention their profession. They hid the nature of their jobs from their social group; one caregiver mentioned that she had a situation where someone told her she should not drink from her cups because she worked with HIV people and perhaps she could spread it to them if she drank from their cups and ate from their plates. They also told the caregiver they were afraid that she might cough on them and they would catch Aids in that way, thus the knowledge of the disease needs to be addressed in terms of infection.

It is a complex stigma because Aids hospices and facilities are not like other hospitals. There are very few family visitors, not many friends come to visit and there are very few family gatherings around the bedside of the dying. Mostly women die alone or with a few friends that they might have made in the hospice, together with the caregiver. The disease is therefore hidden, with male partners who have infected female patients not attending or visiting the clinic. Therefore the spread of the disease is not being prevented. Perhaps home-based care could increase community involvement, community care and openness if caregivers profess the need for such community care. Through home-based care initiatives which work, together with knowledge and prevention campaigns such as youth education and cell groups, communities may become less shackled by fear and stigma.

In the light of the above injustice and desperation, it becomes clearer why the church, particularly the Catholic Church, can be successful in the fight against Aids where government and nongovernmental organisations have often failed. It is the message of the unfailing love of God who is active in the world and who is Himself in community with people who confess that Jesus is the Christ.
In the next chapter I will discuss how the church ought to respond to the crises women face. How can the church influence current policy affecting knowledge of the disease, the prevention of infection and care of those infected as well as modify and formulate new strategies? From the formal questionnaires and informal interviews conducted at both centres it would seem that, outside the centres, women struggle to cope, often alone, sometimes dying, frequently frightened and without the basic knowledge of where to go or what to do. They also act without any information on how to prevent transmitting the virus to their children and without knowing who will care for them and their children. Theirs is a lonely and frightening journey.
CHAPTER 5: CONCLUSION

5.1 INTRODUCTION

This dissertation has discussed the need for action from Christians and churches to deal with HIV/AIDS, specifically focusing on women in South Africa. Throughout the dissertation, the call to respond to the suffering of others has been referred to as a duty, an obligation whereby Christians can show the love and compassion of our Lord, Jesus Christ. De Gruchy states that, as a theologian involved in social research, it was significant for him to see how the Christian virtues of faith, hope, love, compassion, care and trust can motivate people to care for others (de Gruchy 2006:6).

The necessary 'response' of the Church was identified as acquiring accurate knowledge of the disease, seeking to formulate prevention strategies and caring for the infected and affected. These were defined as core ethical issues because, without knowledge of the disease, there can be no prevention of infection or re-infection. Care was noted to be a fundamental Christian moral value. The reason why this dissertation was approached from within the field of Christian ethics is because the way in which the disease is spread and treated requires moral values, virtues and decision making. By affecting a person's moral values and virtues, that person can be motivated to change the way they and the members of their community make moral decisions. Therefore there is a need for moral leaders who can influence others.

The aim of this dissertation was to develop theoretical and moral frameworks and practical guidelines for Christians to deal effectively with the spread of HIV/AIDS and to care for the sufferers, particularly women. The motivation behind this project was to assess some current projects run by individual Christians, or a church, so as to motivate others to get involved. In this regard it is important to encourage Christians to examine communities within their sociopolitical and medical contexts in order for them to address the problem coherently and logically. The value of the dissertation was to assess common themes and important factors that need to be taken into account by Christians in their attempts to address the problem of HIV/AIDS.

5.2 METHODOLOGY

Chapter 1 introduced the title of the dissertation and explained its aims and value. One of the aims of the dissertation was to discover whether
CBPs and FBPs are an efficient means to spread the knowledge of what causes HIV/Aids, prevent infection in communities and provide care for sufferers. The situation of women in Africa, particularly in South Africa, was discussed and contrasts drawn between the wealth of legislation and policy protecting their individual rights and freedoms and the stark reality of domestic abuse, gender discrimination, violence and sexual oppression.

This chapter defined Christian ethics, and noted the necessary interplay between medical science and a number of social science and theological disciplines. Medical, sexual, social and feminist ethics were especially stressed. Without a clear understanding of the medical causes of HIV/Aids, and of moral responsibility in terms of infecting others, little progress can be made in combating this disease. For example, infected men who rape children in the hope that they will be cured are displaying both a profound ignorance of the causality of HIV and a brutal, callous disregard for the persons of others. In terms of sexual ethics, unless women can make informed, free sexual choices, there is no hope of preventing the spread of infection. If women and children are, for example, regularly raped and abused, it is useless to propagate abstinence and faithfulness unless the men in their families and communities also adhere to these values. The importance of social ethics is seen in the insights it delivers concerning the effects of poverty, violence, war and the breakdown of family life when one is dealing with a highly infectious disease. Finally, in a feminist ethic of care, each woman is looked at as an important individual with her own unique story and past. Each woman is valued as a person in her own right, who seeks to live a life that is not broken by fear, suffering and disease.

This theoretical framework was expanded upon in chapter 3, where the various elements of Christian ethics were linked to the empirical methodology used in this dissertation.

In chapter 3, the history of the research project was examined and it was explained how I came to be visiting projects run and managed by individual Christians and groups of churches. Thus, my own agenda and exposure to a range of projects run by women in various parts of Africa were noted. In this period of broad-based research, it was noted that the majority of successful and sustainable projects within communities were run by individual Christians or a church. This posed questions at the outset about the role of Christians in relation to the HIV/Aids crisis.
It was decided to focus this study on how women are infected and affected, as the majority of the participants of these successful FBPs were women.

The Mouton model of methodological paradigms was utilised for the methodological framework which examined medical, social and other issues in relation to the HIV/Aids pandemic, especially as it affects women. The research methods employed were sampling, data collection and data analysis. The movement from a broad-based church analysis to a more focused approach – choosing two specific case studies – was explained with the aid of a diagram of Mouton's model. The ethical research principle of developing a rapport with the interviewees, based on trust and confidentiality, was a guiding principle during the research.

Two basic clusters of research questions guided this research project:

1. If women and their rights are protected by the Constitution, general legislation and specific gender commissions, why are they not in a position to make moral decisions about their safety, sexuality, family and finances? Do they have the necessary knowledge about the disease that can enable them to prevent infection through abstinence and safe sex? Why does the HIV/Aids pandemic continue to spread? Why do women not make moral decisions that can protect them and their children?

2. To what extent are individual Christians and the church as a whole involved in the care of those infected or affected by HIV/Aids? Are they also concerned with communicating knowledge about HIV/Aids and how to prevent the infection of their own members and the communities in which their churches are located? As noted above, in addition to accumulating some general information, this study focused on two case studies, as it was impossible to collect information about the role of all the churches in South Africa.

In order to answer these questions, information was drawn in chapter 2 from many primary and secondary sources in order to provide a clear understanding of the medical data about HIV/Aids and the social context within which this disease has flourished in sub-Saharan Africa. In addition to this theoretical discussion, I embarked upon an empirical study in chapter 4, in order to test this information and to create new knowledge.
A total of 16 caregivers and 14 patients were interviewed at Sparrow Village and St Francis Care Centre. These two projects were chosen because they responded to all the initial research questions and both allowed me to collect quantitative and qualitative information relating to both a CBP and an FBP to analyse knowledge of HIV/Aids, prevention of the disease and care facilities. The questions were divided into nine sections and designed in such a way as to obtain information about their personal knowledge and experience of treatment, prevention of the disease, concepts of care, marital status, violence and gender discrimination and demographics of the group. There were also questions about the spiritual support and input of the facility.

5.3 A SUMMARY OF THE CHAPTERS AND THE CONCLUSIONS DRAWN

Chapter 1 detailed the rights of women under the Constitution of South Africa as well as the formal commissions established under the Constitution to give effect to a woman's rights, duties and freedoms. The aim of these laws and statutory bodies was to counteract both the long-term effects of apartheid, which excluded large portions of the populace, as well as cultural beliefs and norms, which detract from the freedom of women. The chapter identified hard-learned truths that, despite progressive legislation and policy, women are still victims of patriarchy, fear and abuse, especially within their own homes. For African women in particular, the sin of sexism affects most women's ability to make legal contracts, to enjoy economic freedoms, to inherit property and to make choices about their sexuality. Moreover, women are the providers for their children and more often than not the sole responsibility for providing for children rests on them.

Chapter 2 aimed to explain the medical nature of HIV/Aids, using professional pathology textbooks and medical science to discuss what AIDS is and how it is diagnosed and spread. This chapter also examined the socioeconomic consequences of the disease and the government's role in the spread and treatment of HIV/Aids. It further examined the overall vulnerability of women in Africa to becoming infected.

The chapter provided statistics of the spread of HIV/Aids in Africa and South Africa and discussed the factors that influence the spread of epidemics such as poverty, violence, poor public health, shifting populations and gender discrimination. The socioeconomic consequences of HIV/Aids were outlined. They include demographic changes, life expectancy risks, and a negative impact on the GDP of a
country. Thus the medical evidence on how the disease presents itself was followed up by an analysis of the economic impact of the disease.

Treatment and prevention issues were discussed and the importance of the elements of compliance by individuals and communities, testing, following medical regimes and practising safe sex identified. The chapter further analysed the political environment and showed how the government’s policies have contributed to the spread of HIV/Aids, despite its policy and legislative frameworks. The dissident factor was discussed as an important contributing factor in the government’s failure to address HIV/Aids effectively.

The medical understanding and treatment of the disease, the socioeconomic contexts in Africa and the government’s role provided a foundation for a discussion on the ethical implications of Aids, especially for women. Here again a number of issues were noted. The importance of women being properly informed and consenting to be tested, treated and interviewed was discussed along with the legislation that seeks to protect workers from unfair discrimination. It was pointed out that women and girls are inherently more susceptible to infection because of their physiology. African women are often unable to make moral decisions concerning their lives owing to the paternalism of society, the upsurge of domestic violence within communities and the gender discrimination which has created an environment of fear and intimidation for most women, especially in their own homes.

Cultural sexual beliefs and practices were seen to contribute significantly to spread of the disease; these practices include virgin rape, dry sex and multiple partners, for example, in polygamous unions or unfaithfulness to one’s partner. The prevalence of abuse and violence as well as a lack of will from males to use condoms were shown to be well documented. Other factors that also lead to the spread of this disease are poverty, a lack of education, war, violence and urbanisation. These realities make it extremely difficult for women to abstain or insist on the terms of sexual acts, for example, the use of condoms during intercourse. Thus, women are incapacitated as their knowledge of the disease is insufficient and their decision-making ability in terms of sexual acts is limited. The chapter revealed how women’s lives are culturally prescribed and they are severely affected by silent, deadly gender discrimination and patriarchy. A few medical cases revealed how cultural views, the fear of getting tested and the fear of rejection affected medical and moral decision making. Finally,
inadequate public health measures make it difficult for women to gain access to the required and necessary treatment, particularly after a sexual assault. The result of all these factors is the spread instead of the prevention of infection.

In chapter 2, the link between government and the church was discussed. It was concluded that the government and communities usually trust and respect churches and individual Christians to deliver social justice, assistance, care and hope. The chapter also showed that moralising by the church in knowledge and prevention campaigns may do more harm than good. Campaigns based purely on abstinence are usually highly unsuccessful amongst the youth. Therefore churches and Christians must consider this when formulating policies and strategies to combat the spread of the disease. Communities should not be met with a cold, judgemental attitude, but churches need to provide trustworthy information and exhibit faith and love in action which will help to change communal morality.

As noted above, the purpose of chapter 4 was to investigate two specific HIV/AIDS projects, using the integrated and scientific method of collecting data and information as outlined in chapter 3. In this way the theoretical data outlined in chapter 2 and the new data uncovered in chapter 4 could be tested, confirmed and integrated.

The holistic and integrated approach of the Catholic Church was discussed and it was noted that their HIV projects are run in a coordinated, interdependent and cooperative manner, with each project adhering to a common policy. This is contrasted with the FBOs which are independent and autonomous. St Francis Care Centre is an example of a CBP (Catholic) and Sparrow Village represents an FBP. The history, organisational structure, patient profile and medical facilities of these two centres were analysed.

The Catholic Church has a comprehensive, integrated and effective organisational framework in South Africa to address the lack of knowledge of HIV/AIDS through specific measures such as youth education campaigns, prevention strategies by encouraging training and education as well as care initiatives. There is a specific focus within the Catholic Church that encourages community involvement, interaction and the participation of communities in order to identify and cultivate moral community leaders. There is also an emphasis on home-based care.
FBOs were also discussed in chapter 4. FBOs are in a unique position because they are trusted by both the government and communities. FBOs are both more vulnerable and stronger than a CBP in the sense that they are more flexible in developing strategies, campaigns and policies. Therefore they have greater creativity and flexibility in fund raising. The drawback of the FBO is that policies may be less sophisticated and developed than those of the Catholic Church, specifically in terms their knowledge and prevention campaigns. Small FBOs are isolated from a wider church network of support. The two specific projects, Sparrow Village and St Francis Care Centre, were discussed prior to analysing the formal interviews. Both projects experience similar problems with transport, funds, ethnic conflicts, a lack of male involvement, cultural beliefs, government bureaucracy and stigma.

Questions were asked of both the care givers and the female patients, using a participative method facilitated by the use of a structured questionnaire. In these formal interviews the researcher sought to test information gathered from other studies (chapter 2) and also evaluate these two Christian responses to the HIV/Aids pandemic. The two clusters of research questions noted above were kept in mind in the design of the questionnaire, as were the insights gained in chapter 2. In particular I wished to obtain data concerning the three core ethical issues that had been identified, namely, the interviewees’ knowledge of HIV/Aids as a disease and how a person could be infected, the means of the prevention of infection and re-infection, and also their experiences of care and treatment at the two hospices.

The formal interviews were divided into the caregivers’ and the patients’ responses to the given questions. The questions enquired as to their knowledge of the disease, their freedom and ability to prevent infection and their willingness and ability to care for sufferers. The answers were combined to create statistical data in the form of percentages. These statistics were then discussed in conjunction with summarising tables to determine patterns and conclusions. The findings of the research were discussed along with their ethical implications for individual Christians and the church as a whole in South Africa. This research made it possible to gain a better understanding of HIV/Aids, its prevalence, prevention and the care of those who are infected and affected. This is necessary if Christians are to play an effective role in relation to this pandemic. The two care centres also benefited from the
study as it revealed both their strengths and weaknesses. Patients benefited from being valued and listened to and care givers could become more aware of their own motivations and the quality of the care they offered.

The formal interviews conducted with the female caregivers and patients were very revealing. The horrific statistics attained reinforced the information collected in chapter 2 concerning the cultural, social and medical issues which affect and hamper women’s decision-making abilities. Ninety percent of the patients were victims of violence and rape. Eighty percent of the assaults were perpetrated by the patients’ male partners. One hundred percent of the children at the care centres had been abused. Thus the aggression and enormity of abuse of these most vulnerable of members of society was clearly revealed in the formal interviews.

It was significant that all the caregivers stated that women were perennial victims with only 30% stating they felt women infected with the disease were immoral. When the patients were interviewed, a stark reality was that not a single woman was married. The decimation of family units is a cause for concern since families are the basic moral substructure of a society. When women divulged their HIV positive status, 50% stated that partner violence increased.

The formal interviews revealed interesting findings as half of women trusted and confided in a religious leader. The majority of women interviewed felt that the centre was a place of refuge, where they received physical, spiritual and emotional care. The majority of caregivers and patients were informed about home-based care, thus each centre was developing community leaders.

In all, these findings reveal the vulnerability of women to the HIV/Aids pandemic. This vulnerability was identified in several chapters.

As noted in chapter 1, the strong focus in this dissertation on women’s stories, personal experiences and growth revealed the feminist/womanist concerns embedded in this study. The vulnerability of women in Africa was discussed in this chapter, with the United Nations stating that, overwhelmingly, women are not in a position to abstain due to violence and fear. In chapter 2, factors influencing the spread of diseases included gender disparity and violence. The ABC campaigns were said to have little to no effect where girls and women have no
choice in engaging in sexual intercourse due to prostitution, fear and intimidation by male partners and the cultural mindset that women are perpetual minors. In chapters 2 and 4, violence against women in South Africa was discussed. When women face abuse from intimate partners and commute, live and socialise in a country with the highest rape statistics in the world, it is difficult to assume they are free to make their own moral decisions.

The role of the church and Christians is to not only provide treatment and care for sufferers of HIV/AIDS, but also to look deeper at the mitigating factors which cause the spread of the disease and lead to fear-filled, desperate and abused lives. By addressing this social evil of abuse and gender discrimination, the church and Christians can devise better prevention campaigns against infection. Women in communities can build the ‘good character’ described by Connors and McCormick in chapter 2; they can become free, intelligent, responsible, unfolding, social and spiritual.

In chapter 4, the Catholic Church’s response to HIV/AIDS was described as addressing violence against women through specific community campaigns. Current contributions by the church in general to engage in meaningful dialogue on the topic of gender discrimination and abuse are vastly inadequate. Chapter 4 described how the majority of women interviewed were abused, as were their children, by intimate partners. The chapter also discusses the decimation of family units and the marital union. The church and Christians need to start including programmes which are female driven and female focused to protect, encourage and equip women in society. Programmes also need to start involving males and young boys and encouraging them to protect, love and care for their female partners. A moral change amongst women can only take place when they feel free and unthreatened; Christians and the church should encourage this moral change and discourage factors which hamper such an evolution, including violence, rape, abuse and gender discrimination.

5.4 What can individual Christians and the churches do in relation to HIV/AIDS in South Africa especially in relation to women?

5.4.1 Why should Christians and churches respond to HIV/AIDS?

The formation of perceptions and moral values is affected by a person’s background, experiences, community, religion and culture. The ultimate source for Christian ethics must be God and the work and life of His
son, Jesus Christ. The Christian needs to live a moral life according to
the Bible and their conscience within society. Harkness, in discussing
Christian ethics states the focus needs to be on Christian principles
and actions. Christians are faced with numerous decisions about what
to do or what not to do, how to do right and how to avoid doing what a
Christian ought not to do. 59

The question throughout this discussion refers to the need for
Christians to respond to the HIV/AIDS virus. De Gruchy (2006:2)
maintains that Christians and the church are called to respond to the
pandemic with love, care and compassion. The virtues of love,
compassion and care are virtues listed by the apostle Paul. Other
virtues include humility, generosity, patience and fairness (Col 3:5-8).
Good habits are formed through repeated moral actions and a good
moral character is based on good habits. Thus, virtues need to be lived
and practised.

An ethic of care is thus a primary duty of a Christian founded on the
premise that Christians must love their neighbours as they love
themselves. This principle is derived explicitly from our Lord’s
command (Matthew 22:39). According to Viola Larson, a feminist ethic
of care is an important alternative to ethics based only on abstract
principles; a feminist ethic of care is based on concrete human
relationships. The feminist ethic of care reinforces the notion of an
active ethic of care and includes the concrete individual in the
evaluation and allows the person making the ethical decision the right
to consider their own worth and value and their own integrity as part of
the decision. It protects and values cultural uniqueness when ethical
decisions are made using concrete individuals rather than abstract
universals. 60

De Gruchy (2006:3) discusses the ethical struggle between received
and revered moral frameworks about sexual practices in Africa
particularly concerning campaigns on abstinence, faithfulness and
condoms (ABC). He states that debates about sexual morality and
traditional teachings on marriage, abstinence and monogamy should not
detract from the pattern of infection particularly in a cultural climate of

60 http://www.naminggrace.org/id52.htm (accessed 9 December 2008). From the article; A Feminist Ethic
of Care and Biblical Ethics.
exploitation, abuse and violence against women and children, radical patriarchy and a lack of gender equity which permeates cultures, communities and churches.

The National Catholic Aids Network maintains that by addressing HIV/AIDS and helping sufferers, we are following the example of Jesus Christ. Churches have long cared for the sick. The global spread of HIV/AIDS and the serious suffering that marks this disease challenged and renewed this ministry, especially in developing countries where health care resources are so severely limited and populations are affected by broader sociopolitical factors such as violence, war, famine and government corruption.

Bishop Lekganyane, in his sermon at Moria, addressed the need for government to collaborate and engage with the church. This is because the church is trusted by communities, the government, medical professionals and social workers as the church is founded on the principles of tolerance, fairness, forgiveness, justice and mercy. The goal of the church historically and in a modern context has and always will be to alleviate human suffering. According to Pope John Paul II, “The cross and resurrection of Jesus Christ shed light on the true meaning and value of human suffering. The Lord invites everyone to join him on the road to Calvary and to share in the joy of Easter”.

Grace Long quotes Francis Peabody as follows “What then is the place of the Christian Church in the modern world? It is to use the language of our modern life, a power-house, where there is generated a supply of spiritual energy sufficient to move the world with wisdom, courage, and peace. Let this power fail, and the Church stands in the midst of modern life without adequate reason for existence” (Peabody 1987:597). This is the strength of the Christian Church; they have an example to follow, there is a “game plan”. Christian ethics is founded on the truth of the teachings of Jesus Christ to guide their action, an action which should take the behaviour of the church out of the speculative and abstract realm and into the activities of society. The ethic of Jesus was to do the will of God on earth. Human involvement and effort are required to give expression to the Kingdom of God on

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earth and such efforts are desperately needed in the crises now faced in South Africa. Human capacity is always imperfect and wanting; however, the biblical imperative to love, care and fight for justice for others is clear. The church cannot stand by while the vulnerable are tormented and kept in poverty, shame and utter helplessness. The failure of the church is an omission to employ policy which effectively educates women about HIV/AIDS, assists and helps them with abuse within their homes and communities. Moreover, the church must see care not only as an outside referral to an FBO or a clinic but care must encompass the preaching of a change in moral behaviour towards women and children.

If the church and Christians wish to avoid the weaknesses of governmental social programmes which, as Peabody says, bring with them a sense of limitation, insignificance and purposelessness, they would do well to avoid the pitfall of externalism. Jesus approaches social question from within. The teaching of Jesus is that a person can modify their environment and can transform conditions (Peabody 1987:421). Peabody suggests that no tendency in modern life is more destructive to social progress than the tendency to weaken the sense of personal responsibility for social imperfections and to fix the blame on unpropitious circumstances. He maintains that the responsibility lies in the passions and ambitions of individual people, and no social arrangement can guarantee social welfare unless a profounder sense of personal sin is brought home to vast numbers of individuals (Peabody 1987:422). The sinful nature is not irretrievable and the fear of God is the beginning of wisdom. If the church is to teach a new life in Christ then there has to be a response with a decision of the will to a new life and the way of Jesus.

The formation of Christian character is the province of the church and is central to its teaching. God motivates and empowers personal morality. With the power of God flowing into the lives of individuals who are delivered from despair through the gospel, there will be a motivation and reason for changing behavioural habits and actions that damage their wives or girlfriends. With a new life pattern in the example of the Son of God, human conduct will change. A commitment of the will to live according to the moral will of God will motivate new believers to put right relationships they have previously damaged. Moral and careful sexual habits will be a by-product of this life-changing relationship with the Spirit of God. This is a primary aspect of
the church's role in the prevention of HIV/AIDS: to lead those with whom it comes in contact to the God who changes lives and behaviour.

Christianity is an applied religion. Without the divided aims that hamper many governmental and nongovernmental projects, the church is single-minded in its desire to respond to human need with love and compassion. Jesus cared and this care was for the person, He was not an organiser of charity but He did tell His disciples that the Kingdom of God was within them, giving a new meaning to how to care for those who are in need of social intervention.

There is a complexity in the divine command to "love your neighbour" at the social level; Carl Michalson makes this comment:

To live with one's mind on things above the earth is to live in the earth with a new nature, a new kind of integrity, that is, a new perspective for all one's relations to others in the world. Quite clearly, the other worldliness in the Christian's life does not translate one out of the world, but more. The Christian's vision is bifocal. They are to keep one eye on the "the kingdom which is not of this world" and they are to keep the other eye on life in this world. From one eye one gets orders. With the other eye one develops the strategy along the lines of which the orders will be carried out (Michalson 1985:136).

If the church has its orders from its Lord to care for women who are sick, it will develop strategies and assume its responsibility as carers by providing facilities and counselling to the suffering. Not making them the grateful recipients of charity but a free response to God's grace that is freely shared, not out of a sense of compulsion or self-righteousness (Roberts 1985:141).

Caring is a central moral value for the church. It includes love, vision, responsibility, strategy, and power to change lives and circumstances. These are the strengths that the church brings to the HIV/AIDS pandemic. It is selfless, sacrificial in nature and pure in intent, it is focused on the person and her worth in the eyes of God and this renders the church particularly suitable to care for women who are marginalised, brutalised, alone, sick, frightened and deep in sorrow. The two care projects discussed in this dissertation analyse how Christians and churches can make a difference in the lives of women infected by HIV/AIDS.
5.4.2 What can individual Christians do?

The paragraphs below describe how Christians can become leaders in communities and societies. Below are a few ideas and guidelines for ways in which individual Christians can affect the lives of individuals and communities.

5.4.2.1 Initiate a new FBO

There are a few Christian individuals who may feel inspired to start their own FBO from scratch. From the numerous FBOs visited during the broad-based research, it would seem that many of the projects started out this way – through one or a handful of dedicated Christians. Usually the FBO commences along the lines of addressing one of the core ethical issues. Christians must plan and strategise prior to setting up a project. They need to access funding, logistics, policy and management. For example, the project can run youth education programmes by visiting homes, schools, Sunday schools, technikons or universities so that communities are better equipped in their overall knowledge of the disease and can thus take precautions and measures to prevent becoming infected. The project can focus on care initiatives by helping child-headed households gain access to child support grants and daily food parcels, assistance with education and overall physical care.

Care initiatives can be formulated around home-based care concepts, helping to train women and men to become care givers within their own community. Care can also address the social factors aggravating the spread of the disease, thus individual Christians can create an overall awareness about violence towards women and children. Christians can support and encourage places of safety for victims of violence and help victims through legal advice, social aid and police assistance.

The feminist ethic of care can be encouraged by initiating programmes which encourage storytelling and contextualising each woman’s history. A common feature amongst the FBO projects visited was the sense of community storytelling and female groups where women would sing, chat, sew and knit. This predisposition to forming female groups should be encouraged within an FBO. Groups can be formed such as cell groups, choirs and singing groups, arts and crafts groups in order for women to communicate and share with one another.
5.4.2.2 Join an existing FBO.
Individual Christians can also increase the capacity of existing FBOs by volunteering their time, talents and skills to an existing project. Likewise, donations can be made to existing FBOs for community members communicating with the project; donations can include monetary donations, food parcels, second-hand clothing, medical supplies for treatment and care.

5.4.3 What can churches do?
Churches can create their own CBP where the policy, funding, management and strategies of the project are organised by the leadership of the church as well as the congregation. Chapter 4 analyses the Catholic Church’s response to HIV/AIDS as one of the best models for addressing knowledge of HIV/AIDS, prevention of infection and care of sufferers. The strength of Catholic-run initiatives is the solid foundation on which every single project is based. The Catholic Church has not only taken into consideration the immediate problems of the afflicted, but has also painstakingly assessed community and society moral problems which are aggravating the spread of the disease and adding to the burden of infection.

The response of the church to the Aids pandemic is affected by sociopolitical influences and churches must abandon their reluctance to recognise the scope of the problem. As noted in chapter 2, which discussed the medical ethics of HIV/AIDS and the common sociopolitical factors influencing the spread of most diseases, appropriate action must be based on accurate information.

Below these social factors are taken into consideration and, in point form, a few proposals are given to assist churches to address these issues in a practical and affordable manner. Addressing these issues is imperative should any church wish to set up a CBP (or FBO) to help prevent the spread of HIV/AIDS and take care of the infected.

The church needs to respond to the ethical issues of knowledge of the disease, prevention of infection and care. However, the core ethical issues need to be looked at in the context of these deeper sociopolitical issues, otherwise it is unlikely that a CBP will succeed. By looking at the deeper sociopolitical issues which affect communities, the church can go a long way in dealing with the many factors that help
to spread the disease. It can then present a more integrated, caring and coordinated effort in addressing the pandemic.

There are two factors specifically related to women and how they are directly put at risk of becoming HIV/AIDS positive. These factors are

- poverty
- violence and gender discrimination

5.4.3.1 Poverty

The Human Sciences Research Council (HSRC)\(^{63}\) states that households living in poverty have sunk deeper into poverty and the gap between rich and poor has widened between 1996 and 2001. Poverty can be understood in both the strict economic sense of household purchasing power and in the reduction of the choices available to those within the household. Women in Africa are particularly vulnerable as they have limited legal capacity and usually have no control over property. Thus they are likely to find themselves in extreme poverty should their male spouse die or should they divorce their male partner (Joireman 2007:30).

Moreover, the primary role of mother and caregiver falls upon the woman of a household so they carry a further financial, emotional and spiritual burden. The political analyst, Sandra Joireman, claims there is a definite nexus between HIV/AIDS, poverty and women's property rights. In the article ‘AIDS in South Africa: Why the churches matter’, Ruden explains that HIV/AIDS in South Africa is linked to poverty. She states:

The prosperous here simply do not share the fate of the poor to the extent common in other African countries. The income gap is wider than in any other nation except Brazil, and the institutional divides left over from apartheid are immense. Almost 35 percent of South Africans are unemployed. These are the AIDS-vulnerable, uneducated black and "colored" (mixed-race) poor. AIDS is not causing, nor is it likely to cause, an economic crisis in southern Africa. That is the real reason why the epidemic is not being dealt with effectively there (Ruden 2000:566-570).

According to Ruden, the lack of decisive action and integrated, courageous policy to address the pandemic is due to the fact that the disease is largely affecting the poor – if the richer echelons of society were facing the same mortality rate, more action would be taken.

The National Catholic AIDS Network also says that poverty, oppression, alienation and marginalisation provide the perfect breeding ground for HIV/AIDS. Being a poor female puts that person at even greater risk due to a lack of choice-making capabilities regarding sexual encounters.

Therefore poverty and gender discrimination affect the prevention of the disease as well as re-infection, as women are under particular pressure to engage in unsafe sex. Moreover, poverty affects the care and treatment of HIV/AIDS because the poor public transport system makes it logistically difficult and costly for women to commute to find help and medical treatment. According to table 4.3, all of the caregivers interviewed felt that women were perennial victims owing to abuse, poverty and their vulnerability.

It is in response to this need that the Catholic Church has a Rural Development Support Programme (RDSP) to address poverty in rural areas. The programme works with community leaders and is a means of combating poverty in rural areas where logistics, poor roads and the vast distances between the city facilities and rural dwellings make access to the poor and vulnerable difficult and costly.

In adopting the RDSP programmes, churches could also look to integrating the work with leaders, schools, educators, NGOs and social services. Thus there is a need for government services such as health and social services to work closely with civil society, including Christians. By collaborating with these stakeholders the poor can be reached in a more integrated and dynamic way. A number of poverty-combating initiatives can be addressed together, from food parcels and clothing parcels to coordinating social grants such as the Child Support Grant.

In townships and urban areas, poverty is also extreme in South Africa with overcrowding, shifting populations and diseases such as cholera, typhoid and tuberculosis being prevalent owing to overcrowded living conditions and poor access to sanitation and clean drinking water. The one advantage here is that most townships are situated within an urban
area so that access to schools, churches, government hospitals and clinics is easier.

5.4.3.1.1 Strategies on how the church can reduce poverty affecting women and the spread of HIV/AIDS

Churches can model rural frameworks and policies on the Catholic RDSP model. This model is based on

- networking with community leaders
- the involvement of and working with the community
- collaborating with social services, health services and governmental departments
- collaborating with local businesses for donations of meals and to better equip churches in providing 'meals on wheels' to reach people unable to access shopping centres or unable to till the ground due to illness.

Churches can start working with medical specialists so that medical treatment is more effective by introducing treatment together with sufficient nutrition and overall health. Churches can look at specific hands-on ways to deliver food directly to communities through

- greening projects where communities are taught to grow their own food
- delivery of food parcels specifically to the most needy such as the terminally ill and Aids orphans
- collaborating with social services
- collaborating with schools by providing meals which can be a staple for the day.

5.4.3.2 Violence and gender discrimination

Frightening statistics gathered at both Sparrow Centre and St Francis Care Centre showed that 90% of the women patients were victims of abuse or rape and that 80% of these violent acts were perpetrated by the woman’s spouse or partner. This led to all caregivers volunteering an unequivocal 'yes' to the answer, 'do you believe women are perennial victims?'

The church has always been an ambassador for social justice and the protection of the vulnerable and the weak. The legacy of the churches' involvement in the quest for freedom and liberation was discussed in
Bishop Barnabas Lekganyane’s speech to the Zionists delivered at Moria in 2007. Lekganyane called for a moral regeneration, the need for ethical thinking and moral practices. He called on communities, especially the youth, to start conducting their lives by treating each other with respect.

His words cut to the core of the key ethical issues of knowledge of HIV/AIDS as well as how knowledge directly relates to a person’s ability to prevent the disease. He stated:

Let me start my sermon by praying for South Africa our beloved country, for its soul which used to be characterised by respect amongst individuals, parents, communities and the leaders. May the Lord God regenerate the moral fibre of our country which was a key success to liberating our land. This knowledge was and is still fundamental to peaceful co-existence in our country. This is knowledge; this is power; this is security; and this is safety. 65

This speech was published on the ANC website where the majority party acknowledges that government relies on and has a strong history with the church and church leaders. Thus the complexity of the breakdown of marital unions and the family unit is of concern to both the government and the church. It is a social dilemma which needs to be addressed with courage and determination. Lekganyane then discusses the antithesis of ‘knowledge’ which is based on mutual trust, respect and understanding and ‘violence.’ I quote further:

Morality refers to the right or wrong actions based on choices made by individuals or groups of individuals. As South Africa strives towards its noble ideal of a better life for all as enshrined in our Constitution, we are confronted by evidence of a moral degeneration in the form of domestic violence, rape, murder, robbery, theft, house breaking, drug trafficking and mainly women and child abuse. These are driven by individualism and selfishness, the breakdown of family life as well as lack of respect for the law. This is lack of knowledge; this is lack of power; and this is lack of security and lack of safety (ibid).

As has been discussed in chapters 1, 2 and above, African women are particularly vulnerable owing to their legal incapacity and their limited property rights. Ruden likewise (566-570) discusses the despair and isolation of African women who face decreased decision-making capabilities. According to Ruden, women in South Africa face the challenge of heterosexual intercourse which is either coercive or deceitful. Ruden explains that South Africa has the highest statistics of rape in the world and that the rumour of the ‘virgin cure’ has sent male Aids patients on the hunt for younger and younger girls to rape. Alternatively, and here again poverty is interlinked with gender discrimination, a woman is pressured socially and economically (Ruden 2000:566-570). The issue of obedience at all costs and the dependency of African women on their men is discussed in chapter 2 and is also why African women engage in unprotected sex for fear of ‘losing their man’. In chapter 4 half of the women interviewed had experienced an escalation of violence since their status was divulged to their male partner. According to Bishop John Ricard, “discrimination and violence against persons with AIDS and with HIV infection are unjust and immoral”.

The church can approach the issue of gender discrimination and violence in many ways.

5.4.3.2.1 Strategies on how the church can reduce violence and gender discrimination affecting women and the spread of HIV/AIDS

<table>
<thead>
<tr>
<th>Churches can model rural frameworks and policies off the Catholic RDSP model. This model is based on</th>
</tr>
</thead>
<tbody>
<tr>
<td>• networking with community leaders</td>
</tr>
<tr>
<td>• the involvement of and working with the community</td>
</tr>
<tr>
<td>• collaborating with social services, health services and governmental departments</td>
</tr>
<tr>
<td>• sermons and workshops against violence</td>
</tr>
<tr>
<td>• formulating and assisting women’s groups</td>
</tr>
</tbody>
</table>

Churches can look at specific ways of addressing violence and gender discrimination through outreach campaigns and forming groups where participants can share stories, gain support and receive shelter when cases of abuse occur:

5.5 THE EFFECTIVENESS OF THE CHURCH AND CHRISTIANS IN RAISING MORAL LEADERS AND ENCOURAGING MORAL CHANGE

As stated in chapter 4, both the Catholic Church run project, St Francis Care Centre, and Sparrow Village aimed to encourage leaders amongst their patients and caregivers. For Sparrow Village this entailed encouraging patients to become caregivers; for the Catholic Church this not only included patients in the role as caregivers but also to encourage community youth to participate in programmes and offer their services and assistance to numerous education and youth projects. From the preceding chapters, it is apparent that the Christian’s role in addressing the harm caused by HIV/Aids must include a moral reformation. A moral reformation can only be effected if social factors of gender inequality, poverty, violence, stigma, superstition and fear are addressed. These factors determine the core ethical issues of knowledge of the disease, a person’s ability to prevent infection through abstinence or safe sex methods and mechanisms to care and seek treatment.

The models and directives of chapter 4, seeks to make churches and Christians more effective. By more effective, I mean, more effective in causing moral and spiritual formation and change. The models, directives and discussions in each chapter can enable each Christian to create moral renewal without sermonising or judgementalism. This will encourage community leadership. As has been seen both at Sparrow Village and St Francis, the desire within and call on patients to become caregivers is strong and successful. This is positive proof that moral and spiritual awakening is happening at both centres.
Leaders have an important role to play in creating the state of mind that is the society. Competent and moral leadership can result in positive consequences for individuals and communities that can be seen in both projects. The preceding chapters concluded that through Christian action addressing the key ethical concerns of knowledge, prevention and care of sufferers, the Christian virtues of love, compassion, humility and kindness can become a living reality for those who are sick and desperate. Jesus never punished people with sickness. Jesus healed and loved unconditionally. Jesus was broken for our healing, and it is this which I see in every successful Christian initiative where despair, sin and fear cease. In the words of Isaiah;

Surely he took up our infirmities
and carried our sorrows,
yet we considered him stricken by God,
smitten by him, and afflicted.
But he was pierced for our transgressions,
he was crushed for our iniquities;
the punishment that brought us peace was upon him,
and by his wounds we are healed.
Is. 53:4-5.

This dissertation sought to find that elusive answer to why Christian run projects are so successful in dealing with HIV/Aids. This dissertation also sought to encourage Christians and churches to respond to the dire need of assistance throughout South Africa within an ethical framework with reference to the feminist ethic of care. The role of the Christian is to become a moral leader, because leadership encourages others to grow, unfurl and take risks. Thus new hope is being created through FBP’s and CBPs where Christian leadership is encouraged amongst individuals and communities. This is not just any leadership where the motive is profit or self-satisfaction; it is moral leadership and spiritual leadership. This was reaffirmed in chapter 4 where most of the caregivers spoke of a calling.

This is why Sparrow Village and St Francis Care Centre are an ongoing success, they take a sermon of words and live it by encouraging patients and visitors to become emancipated themselves in caring for others. Therefore, the virtue ethics spoken by St Paul in I Corinthians 13 become a dynamic living, breathing reality whereby those who are sick, desperate, lonely, ill and afraid become mobilised within their own homes and communities. Christian run centres are becoming safe
havens where women can gather, talk, sing and embrace one another in love and understanding without judgement or abuse. This means a climate is being and can be created where a 'safe space' is afforded to women affected by a wide array of social, cultural, political and medical misfortunes. This is the message of this dissertation, this is its value and ambition, to show how dynamic, creative and effective Christians can be when they embrace the calling and duty of Jesus Christ which is to humble ourselves, to protect and love the most vulnerable and reviled people of a society. It is through this that Christians themselves can undergo a moral change, throwing off their own fears, prejudices and judgements. Individuals visiting these centres can see the features of grace, patience and kindness which are so very unique to each Christian centre. They can experience a moral change and evolve into becoming independent, moral agents and leaders within their communities.
APPENDIX 1: INDIVIDUAL CHURCHES
This Questionnaire was filled in by social services person at individual churches.

Date __________________

1. Details of church:
1.1 Name of church?
1.2 Affiliation?
1.3 Name of person completing questionnaire?

2. Questions pertaining to the church:
2.1 Does the church have an integrated policy to deal with the problem of HIV/AIDS? – tick the appropriate box;

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2.2 Does the church make any of the following contributions?

Financial?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Care Centre?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Other?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2.3 Is there any assistance with regard to;

Medicine

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Education

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Counselling

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>
Community care

| Yes | No |

Home based care

| Yes | No |

Other

| Yes | No |

2.4 How, in your opinion, is AIDS contracted?

2.5 Do you feel that certain groups of people are more likely to contract AIDS?

| Yes | No |

If yes, please specify which of the following groups you would believe to be most vulnerable:

| Poor | Rural | Gender | Educated | Youth | Ethnic | Unmarried | Divorced | Married |

2.6 Do you think that most people who have contracted AIDS are essentially immoral?

| Yes | No |

2.7 If the church provides counselling to people living with AIDS, is there a counselling program for both Christian and non-Christians?

| Yes | No |

2.8 Does your church place high importance on listening in your counselling?

| Yes | No |

2.9 How does the church plan to counsel people living with AIDS with regard to the following issues or any other issues you feel are pertinent but are not listed below:

2.9.1 Guilt

2.9.2 Stigma

2.9.3 Family relationships

2.9.4 Death
2.9.5 Burial

2.9.6 Pain

2.9.7 Fear of death

2.9.8 Fear of leaving children

2.9.9 Fear of whether they have infected their children

2.9.10 Fear of intimate partner abuse on disclosure

2.9.11 Fear of family rejection

2.10 Does the church assist with orphans?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If yes, how?

2.11 If yours is a church hospice are there protocols in place to protect and counsel the care givers?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2.11.1 Specify what is in place;

**Protect:** A support system e.g. transport or accommodation to caregivers who are being victimised because of their working with Aids patients?

Other:

**Counsel:** Spiritual guidance in dealing with death, forgiveness, non judgmentalism, prayer, retreats, Bible teaching on love and teaching on forgiveness of sins and eternal life in Jesus Christ.

Other:

2.12 If a hospice situation is there a rotation of staff?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2.13 Are there plans in place for growth of existing facilities?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>
2.14 Does the church have congregants who have confided their HIV status to the clergy of the church?

Yes  
No

2.15 Have they confided to other members of the church?

Yes  
No

2.16 Is there a guideline available to members regarding the way HIV should be treated in the church?

Yes  
No

2.17 Does the church have programs promoting AIDS awareness and prevention?

Yes  
No

If yes, what are these programs?

2.18 Does the church have a protocol for dealing with the associated factors?

<table>
<thead>
<tr>
<th></th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homosexuality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Promiscuity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intimate partner violence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rape</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Victim support program or assistance</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2.19 Is there guidance/assistance for women who are diagnosed positive?

Yes  
No

If yes, please specify what type of guidance/assistance is provided?

<table>
<thead>
<tr>
<th>Shelter</th>
<th>Spiritual</th>
<th>Financial</th>
<th>Assistance with grants</th>
<th>Medical</th>
<th>Counselling</th>
<th>Burial</th>
</tr>
</thead>
</table>

2.20 If there are none of the above in your church at present, are there any plans to provide them in the future?

Yes  
No

2.21 Other – please add any additional comments or notes.
1. Personal background of caregiver:
1.1 Age of Caregiver?
1.2 How long have you been a Caregiver?
1.3 Are you trained as a nurse?

2. Care information:
2.1 Type of facility you are working at – tick the appropriate box:

<table>
<thead>
<tr>
<th>Hospice</th>
<th>Care Centre</th>
<th>Clinic</th>
<th>Home based care facility</th>
</tr>
</thead>
</table>

2.2 Can the people you care for infect you through day to day contact?

| Yes | No |

2.3 Can you tell me who the funders are for your facility?

| Yes | No |

If yes, please list funders.

2.4 How many patients do you care for in your section?

2.5 What is the total number of patients in the facility?

2.6 What is “care” and how do you believe you can give a caring service to the people in your section of this Care Facility?

2.7 Is it common that women admitted to the Facility are victims of violence?

| Yes | No |

If yes; which is the most common;

| Intimate Partner Violence? | Y | N |
Rape?  

Child Molestation?  

Assault?  

Other?

2.8 Do you believe that all the women admitted are essentially victims?

Yes  

No

2.9 If no then do you believe that they have behaved in a way that has caused their condition?

2.10 Do you consider the women immoral?

Yes  

No

2.11 Or would you consider the women weak?

Yes  

No

2.12 Or would you consider the women unfortunate?

Yes  

No

2.13 Do you find that some people are more vulnerable than others?

Yes  

No

If, Yes which of the following;

Educated  

Poor  

Married  

Unmarried

Other?

2.14 Why are you working in this Facility?

Job for Money  

Sense of Duty  

Close to Home  

Spiritual Calling

Other?

2.15 Do the people you care for have other common infections?
<table>
<thead>
<tr>
<th>Disease</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Herpes / Sexually transmitted diseases?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tuberculosis?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Pneumonia?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Other List?</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

2.16 Do you feel medical treatment is effective?

Yes | No

2.17 How often are the people you care for seen by a doctor?

Only when they deteriorate?

Yes | No

Routinely?

Yes | No

If routinely, how often?

2.18 Is there a policy in your hospice regarding counselling you the caregiver after the death of a patient?

Yes | No

2.19 Is there spiritual support and guidance available to you?

Yes | No

If yes, specify;

<table>
<thead>
<tr>
<th>Prayer &amp; Bible reading?</th>
<th>Counselling?</th>
<th>Spiritual healing?</th>
<th>Forgiveness of sins &amp; eternal life in Jesus Christ?</th>
</tr>
</thead>
</table>

2.20 Do you have a rotation of staff in the critical wards?

Yes | No

2.21 Do you feel that there is a humane atmosphere in the facility with regard to the sick and the dying?

Yes | No

2.22 Is there anything that you would suggest to ease the burden of people who are very ill in the facility?
If, Yes list suggestions.

2.23 Do you conduct any home based care activity?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If yes, in which areas?

2.24 Who is financing your home based care activity?

2.25 Does your facility offer any counselling or assistance for victims of rape or intimate partner abuse?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If yes, what assistance is given?

2.26 Do you administer or have Post Exposure Prophylaxis (PEP) available for such women?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2.27 Is there a follow up with victims of violence or access to any shelter for women and children subjected to violence?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>
APPENDIX 3: PEOPLE LIVING WITH AIDS
This Questionnaire was filled in by women living with Aids at St Francis Care Centre and Sparrow Village.

Sensitivity and anonymity are prerequisites to questioning people living with Aids as many do not divulge status to their community due to fear of stigmatisation. All Questionnaires are anonymous.

Date of interview____________________

1. Personal background of interviewee:

1.1 Age of participant?

1.2 Do you have children?

| Yes | No |

If yes, their ages.

1.3 Education of participant?

1.4 From which Province do you come from?

1.5 What is your marital status?

| married | divorced | single | in a relationship | widowed |

2. Participant information:

2.1 Do you know what infection you have?

| Yes | No |

2.2 What causes Aids?

2.3 Are you aware how Aids passes from person to person?

| Yes | No |

2.4 Are you aware of what treatment is available?

| Yes | No |

2.5 Are you receiving treatment?

| Yes | No |
2.6 What is ante retroviral therapy?

2.7 Have you heard of post exposure prophylaxis?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2.8 Do you know what your rights are regarding?

2.8.1 Counselling? | Y | N |
2.8.2 Consent? | Y | N |

2.9 How did you find out about your HIV status?

2.10 How long have you been infected?

2.11 Did you confide in your;

| 2.11.1 Husband? | Y | N |
| 2.11.2 Family? | Y | N |
| 2.11.3 Employer? | Y | N |
| 2.11.4 Children? | Y | N |
| 2.11.5 Church leaders? | Y | N |
| 2.11.6 Friends? | Y | N |

Other?

2.12 Were you comfortable confiding to these people?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If yes, say why?

2.13 Did they react by?

| 2.13.1 Professing their support? | Y | N |
| 2.13.2 Blaming you for your status? | Y | N |
| 2.13.3 Rejecting you? | Y | N |
2.13.4 Avoiding you?

<table>
<thead>
<tr>
<th></th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
</table>

2.14 Do you belong to any church?

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<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If yes, which church?

2.15 Do you feel welcome in your church?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2.16 Has your minister continued to support you and encourage you?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2.17 Are you a member of a cell group in your church?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2.18 Do you belong to a women’s group in your church?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2.19 Are the women supportive in your group?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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</thead>
</table>

2.20 Have you experienced violence from your partner?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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</thead>
</table>

2.21 Has this escalated since you have known your status?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2.22 Has your partner been tested for HIV?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2.23 Is your partner positive for HIV?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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</table>
If Yes, is your partner receiving treatment?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
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</table>

2.24 In this Care Centre are you receiving spiritual support and advice?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If yes, specify the type of spiritual support that your church provides;

| 2.24.1 Prayer and Bible reading | Y | N |
| 2.24.2 Counselling | Y | N |
| 2.24.3 Guidance and advice regarding family issues | Y | N |
| 2.24.4 Advice on dealing with fear and guilt | Y | N |
| 2.24.5 Direct ministry regarding forgiveness of sins and eternal life in Jesus Christ? | Y | N |

2.25 What should the church be doing for people who are living with HIV that they are not currently doing?

2.26 In your experience have you experienced love and acceptance from the church?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>
BIBLIOGRAPHY

Biblical references are taken from the New International Version.


