

**INVESTIGATING HIV AND AIDS EDUCATION IN uMGUNGUNDLOVU:  
PERSPECTIVES OF HIV POSITIVE PEOPLE IN  
A SUPPORT GROUP**

By

**ANNE NAMWAMBA – NTOMBELA**

**Dissertation submitted in partial fulfillment of  
the requirement for the degree of  
MASTERS IN EDUCATION  
In the  
School of Adult Education and Development  
University of KwaZulu-Natal**

**Supervisor: Dr. Peter Rule**

**2010**

## **DECLARATION OF ORIGINALITY**

I declare that this dissertation is my own work and that all sources I have used or quoted have been indicated and acknowledged by means of complete references.

---

A NAMWAMBA-NTOMBELA

December 2010

## **ABSTRACT**

Since HIV and AIDS became a health problem in the world in the early '80s, education has been identified as one of the ways to control the spread of the virus, for the virus is mainly spread through specific risk behaviors. uMgungundlovu district ranks as one of the worst-affected areas in South Africa, with HIV prevalence figures of 40% and above over the past five years

The study aimed to establish how people living with HIV acquired knowledge about the disease; to investigate how they responded to the knowledge acquired; and to identify factors that affect their implementation of the knowledge acquired in their daily lives. I hoped that this study would capture some of the realities that we live in, so that HIV education programme developers and implementers can start to grasp the factors that individual HIV positive persons experience, which can play a positive or negative role on how one uses the knowledge they acquire to improve their own health and also be able to protect the next person.

The study was a micro qualitative research, with a feminist approach, drawing on both interpretive and critical paradigms. It focused on a particular group of people in a specific area. Through my personal reflections, the semi-structured in-depth interviews, focus group discussions and the review of other existing literature (published and unpublished), the study attempted to investigate perspectives of people infected with HIV on HIV and AIDS education. The study was conducted with consideration of the positions of women and men in the diverse South African cultures.

The study findings showed how the intersection of gender, power and culture, the context of reception and implementation of knowledge, the individual's habitus and the multi-disciplinary support systems, impact on the reception, receptivity and implementation of HIV and AIDS education. The conclusion, recommendations and suggestions for future studies from the study are presented, positioning the person living with HIV at the centre of responses to slowing down the spread of HIV.

## ACKNOWLEDGEMENT

I would like to express my sincere gratitude to all those who have contributed to my completion of my Masters Dissertation. Particularly I would like to mention the following:

I first would like to thank God for his constant presence in my life, restoring my health through all the health challenges I have gone through and enabling me to complete this study.

I thank my supervisor Dr. Peter Rule for believing in me and encouraging me to carry on with this study when I felt I could not go on, on several occasions, and also for his patience and academic guidance to make this a worthwhile study.

I would like to thank all the study participants, for your time and braveness to share your lives with me so that together we can make a difference, never stop raising your voices. To Springs of Hope Support Group Project, thank you for giving me an opportunity to make meaning in my life and the lives of others who are infected and affected by HIV and AIDS.

I would like to thank my family for the continuous moral and financial support. Thank you for believing in me and accepting my openness as an opportunity to make a difference in other peoples live.

- To both my late parents for showing me the value of education and *ubuntu*.
- To my brothers and sister; Fulbert, Bosco and Caroline and your families for your endless encouragement through this study. To my eldest sister Susan and my sister in-law Grace for taking on the role of a mother in my son's life and for your encouragement in my mission.
- To my son Zolile for caring for me twice through AIDS – thank you for giving me a reason to live and continuously not letting me give up on life.

To all my friends, colleagues, neighbours and the community of people living with HIV, thanks for giving me an opportunity to learn through you all and for your support.

Particularly my friends Mrs. Dudu Dlamini-Knox and Mrs. Esther Mungai, you aligned yourselves in my life to show me true meaning of friendship, in my studies, illness and losses, thank you.

Lastly, to the Centre for Adult Education, thank you to all those who have continuously supported me in my studies and my health, the centre provided me with an enabling environment to learn and achieve, Thank you.

## DEDICATION

To my son Zolile Thulani Ntombela, you have encouraged me in many ways than you will ever know. Forgive me for stealing your childhood away in my struggles with AIDS. I pray that this study and our experiences of AIDS together will strengthen you to endeavor to become a real man, your gentleness, patience, humbleness and lovingness does not make you less of a man, it's by embracing these very characters that make you a real man. Thank you for your friendship and caring for me and many others who have come through our home. I also hope that you will find freedom in your own life; through education and the Godly path you have chosen.

To the both my late parents John and Sabina Namwamba thank for everything. To me you remain the greatest teachers ever; you believed in us and encouraged us all. Today the memories of your love and dedication to make a difference in other people's lives live through my daily work in the communities of people living with HIV across the world and also through this study. In bringing us up as equals (boys and girls) you planted in me a seed of self value as a woman. Particularly to Mama, thank you for making me the feminist I am today, I saw you assert cultural changes and so I believe that I too can do it.

To all those women who have experienced gender violence, particularly rape, I hope that through this study you gain your voices and break the silence, for the sake of all those who have not become victims of such acts, and also particularly for your daughters. Be brave and reclaim your rights to live again, for it is in our tears and pain that we can make a difference.

To the community of people living with HIV and those who have died of AIDS our lives, experiences and deaths are not in vain. They are lessons for the rest of humanity, we have an opportunity to force change in many ways as we share our stories. We have the power to stop the disease and should endeavor in all possible ways to be part of the solution.

To my entire family – may you learn and take courage from my life; join the struggle and help me and others break the silence at every possible opportunity.

## **TABLE OF CONTENTS**

<b>CONTENT</b>	<b>PAGE</b>
<b>Declaration</b>	<b>i</b>
<b>Abstract</b>	<b>ii</b>
<b>Acknowledgement</b>	<b>iv</b>
<b>Dedications</b>	<b>v</b>
<b>Table of Contents</b>	<b>vi</b>
<b>List of Figures</b>	<b>ix</b>
<b>Abbreviations</b>	<b>x</b>
 <b>CHAPTER ONE - INTRODUCTION</b>	
<b>1.1 Topic</b>	<b>1</b>
<b>1.2 Research Focus</b>	<b>1</b>
<b>1.3 Background – History of HIV and AIDS</b>	<b>2</b>
<b>1.4 Rationale</b>	<b>6</b>
<b>1.5 Research Aims</b>	<b>13</b>
<b>1.6 Research Key Questions</b>	<b>13</b>
<b>1.7 Research Design</b>	<b>14</b>
<b>1.8 The Direction of the Study</b>	<b>15</b>
 <b>CHAPTER TWO – LITERATURE REVIEW</b>	
<b>2.1 Introduction</b>	<b>16</b>
<b>2.2 HIV and AIDS</b>	<b>16</b>
<b>2.3 HIV and AIDS Education, Information and Communication (EIC)</b>	<b>23</b>
<b>2.4 The Role of People Living with HIV and AIDS</b>	<b>27</b>

<b>2. 5 Intersectionality – Contextualizing AIDS: Gender, Power and Risk Behaviors</b>	<b>29</b>
<b>2.6 Adult Learning and HIV and AIDS Education</b>	<b>38</b>
<b>2.7 Towards a Conceptual Framework</b>	<b>43</b>

## **CHAPTER THREE - RESEARCH DESIGN AND METHODOLOGY**

<b>3.1 Introduction</b>	<b>44</b>
<b>3.2 Research Methodology</b>	<b>44</b>
<b>3.3 Selection of Site</b>	<b>45</b>
<b>3.4 Sample</b>	<b>47</b>
<b>3.5 Data Collection Methods</b>	<b>49</b>
<b>3.6 Data Analysis Methods</b>	<b>52</b>
<b>3.7 Ensuring quality and trustworthiness of the study</b>	<b>53</b>
<b>3.8 Ethical and Validity Issues</b>	<b>53</b>
<b>3.9 The Limitations of the Study</b>	<b>54</b>
<b>3.10 Challenges</b>	<b>55</b>
<b>3.11 Methodology Summary Table</b>	<b>56</b>
<b>3.12 Conclusion</b>	<b>57</b>

## **CHAPTER FOUR - DISCUSSION OF RESEARCH FINDINGS**

<b>4.1 Introduction</b>	<b>58</b>
<b>4.2 Research Findings</b>	<b>59</b>
<b>4.2.1 How did the Person Acquire Knowledge about HIV and AIDS</b>	<b>59</b>
<b>4.2.2 Response to the Knowledge Acquired</b>	<b>67</b>
<b>4.2.3 Factors that Influence our Responses</b>	<b>71</b>
<b>4.3 Conclusion</b>	<b>91</b>



## **CHAPTER FIVE - SUMMARY, RECOMMENDATIONS AND CONCLUSION**

<b>5.1 Overall Summary</b>	<b>94</b>	
<b>5.2 A Reflection on Methodology</b>	<b>95</b>	
<b>5.3 Summary of Research Findings</b>	<b>97</b>	
<b>5.3.1 How did the person learn about the disease?</b>	<b>97</b>	
<b>5.3.2 How did the people respond to the knowledge acquired?</b>	<b>98</b>	
<b>5.3.3 What Factors influences their responses to knowledge acquired?</b>	<b>99</b>	
<b>5.4 Key Findings</b>	<b>104</b>	
<b>5.5 Recommendations and Implications for HIV Strategies</b>	<b>105</b>	
<b>5.6 Recommendations for Future studies</b>	<b>118</b>	
<b>5.9 Conclusion</b>	<b>119</b>	
<b>REFERENCES</b>	<b>120</b>	
<b>Appendix A</b>	<b>Ethical Clearance Certificate</b>	<b>131</b>
<b>Appendix B</b>	<b>Consent Form</b>	<b>132</b>
<b>Appendix C</b>	<b>Semi- Structured In-depth Interview Schedule</b>	<b>133</b>
<b>Appendix D</b>	<b>Participants basic information form – FGD</b>	<b>136</b>
<b>Appendix E</b>	<b>Focus Group Discussions Questions</b>	<b>137</b>

## **LIST OF FIGURES**

<b>Figure 1</b>	<b>Facets of Power</b>	<b>34</b>
<b>Figure 2</b>	<b>Conceptual Framework for Study</b>	<b>43</b>
<b>Figure 3</b>	<b>Methodology Summary Table</b>	<b>56</b>
<b>Figure 4</b>	<b>HIV and AIDS Management Education Support Systems Networks Model</b>	<b>110</b>
<b>Figure 5</b>	<b>Support Group as an Enabling Learning Environment</b>	<b>112</b>
<b>Figure 6</b>	<b>HIV Positive Person: Knowledge Reception, Receptivity and Implementation</b>	<b>114</b>
<b>Figure 7</b>	<b>Factors that impact on reception and implementation of HIV and AIDS Education</b>	<b>116</b>

## ABBREVIATIONS

AVERT	AVERTing HIV and AIDS
AIDS	Acquired Immune Deficiency Syndrome
ARVs	Anti-Retroviral Treatment
ATICC	AIDS Training, Information and Counselling Centre
CDC	Centre for Disease Control and Prevention
GIPA	Greater Involvement of People Living with HIV and AIDS
HAART	Highly Active Anti-Retroviral Therapy
HIV	Human Immuno-deficiency Virus
KZN	KwaZulu- Natal
NGO	Non-Governmental Organization
PCP	Pneumocystis Carinni Pneumonia
SAfAIDS	Southern Africa HIV/AIDS Information Service
SOH	Springs of Hope Support Group Project
STI	Sexually Transmitted Infection
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNESCO	United Nations Educational, Scientific and Cultural Organization
USA	United States of America
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

## CHAPTER ONE - INTRODUCTION

### 1.1 Topic

Investigating HIV and AIDS Education in uMgungundlovu: Perspectives of HIV Positive People in a Support Group

### 1.2 Research Focus

The study focused on: i) Human Immune deficiency Virus (HIV) and Acquired Immuno-deficiency Syndrom (AIDS) education provided in uMgungundlovu, ii) the people who are living with HIV in a support group, and iii) the factors that might affect how they implement the knowledge they acquire about HIV and AIDS. The study was particularly interested in how gender, power, and the cultures of people impact on the reception and implementation of this knowledge.

In the time since HIV and AIDS became a health problem in the world in the early 80s, education was identified as one of the ways to control the spread of the virus, as the virus is mainly spread through specific risk behaviors (Ntombela, 2008, p.3). It is hoped that if people receive the necessary information in relation to how the disease is spread and how the spread can be prevented, the knowledge might lead to change of the risky behavior.

Beyond the transmission and infection of HIV is the management of the disease amongst the persons who are already infected. HIV management education has primarily taken place in support groups with the aim of empowering the persons infected in managing other medical, social, psychological and related issues that might contribute to the progress of the disease. More focus on HIV prevention education is provided in work places and communities at large, usually with the aim of reducing the transmission of the virus and maintaining a healthy workforce.

### **1.3 Background - History of HIV and AIDS**

This section will look briefly at the history of the disease in the world, Africa and South Africa. It is important to understand the history of the disease for one to be able to understand the dynamics and challenges that surround the reception, receptivity and implementation HIV and AIDS education.

#### **1.3.1 Global Overview**

In 1979 and 1980, doctors in the United States started to observe clusters of diseases that were rare (Whiteside & Sunter, 2000, p.1). Initially most cases were seen among the homosexual men (Whiteside & Sunter, 2000, p.1; Karim, 2005, p.31). In 1982 it became evident that the occurrences of the disease clusters also affected other groups of people. It is at this stage that the first cases of injecting drug users were reported (Karim, 2005, p.32; Avert, 2007).

There are many theories linked to the origin of the disease; today there is scientific evidence indicating that HIV originated from Central Africa (Illiffe, 2006). HIV probably infected the first human being in the 1930s and by 1966 was reported to have occurred in Haiti (AVERT, 2007). There is very little documentation in the period between the 1930s and 1970s; hence it is hard to determine how many people developed AIDS in the 70s or years previous (Kanabus & Fredriksson, 2007, unpaginated).

Kanabus and Fredriksson (2007) quote Mann's (1998) statement that the dominant feature of this period was silence. Evidently people did not know about HIV and how it was transmitted, and there were no identified signs or symptoms that indicated the infection. It is suspected that HIV entered the USA in the 70s and it is during this period that African doctors started to see increased cases of opportunistic infections and body wasting (AVERT, 2007).

In June 1982, some evidence observed amongst homosexual men in Southern California suggested that the disease might be caused by an infectious agent that was

sexually transmitted (Kanabus & Fredriksson, 2007). More significant discoveries were made about the transmission of the disease in December 1982, when a twenty-month old child who had received multiple blood transfusions died from infections related to AIDS. Scientists developed a clearer awareness that AIDS was caused by an infectious agent. This reality raised additional concerns about the safety of the blood supplies. In the same period Centre for Disease Control and prevention (CDC) reported the first cases of possible mother to child transmission of AIDS (Kanabus & Fredriksson, 2007).

### **1.3.2 HIV and AIDS in Africa**

Towards the end of 1982 many more people started to take notice of this new disease. Reports from Europe suggested that there were two rather separate AIDS epidemics; in some parts of Europe most people with AIDS were homosexual with a history of sex with American nationals, while specifically in France and Belgium it was occurring mainly in people from Central Africa or who had links to the region (Kanabus & Fredriksson, 2007). In the latter case, the symptoms of the disease were similar to the former, yet these patients had no history of homosexuality, blood transfusion or intravenous drug abuse.

Following this evidence, scientists set out to discover more about the occurrence of AIDS in Central Africa. After the mid 1980s, more and more cases of AIDS-like diseases were being reported. According to Kanabus & Fredriksson (2007), scientists had collected enough evidence to form an overview of AIDS in Africa. This was based on medical records that indicated an increase in AIDS-related conditions in the late 1970s and early 1980s. Countries that first showed this evidence included Zaire, Uganda, Tanzania, Rwanda and Zambia. The name AIDS might not have been familiar to the people in Africa then, but in most of the above named countries it was referred to as '*slim*'; this was mainly due to the physical symptoms related to the disease.

### **1.3.3 HIV and AIDS in South Africa**

While there is varying information in the literature about when the first case of AIDS was reported in South Africa, it is clear that it was in the early 80s. The first case was

reported in 1982 (Pembrey, 2007; Karim, 2000, p.33; Gouws & Karim, 2005, p.54). Like the pattern in the rest of the world, the first cases of AIDS were among the homosexual groups.

Early occurrences of the AIDS epidemic in South Africa (1982-87) were associated mainly with homosexuals, blood transfusion recipients and haemophiliacs (Karim, 2005, p.31). Up to the year 1987 heterosexual cases were very rare. In 1985 there was 0% prevalence in rural communities and a study done in 1986 among almost 30,000 miners only found three men to be HIV positive (Gouws & Karim, 2005, p.55).

When HIV was identified and characterized, South Africa, like the rest of the world, was experiencing anxiety about the disease, while at the same time the country was going through its own challenges. Between the years 1990 and 2003 there was a dramatic increase in the HIV prevalence in South Africa. A number of factors have been blamed for the increasing severity of South Africa's AIDS epidemic. There were raging debates about whether the government's responses were sufficient. In 1997 a national review of South Africa's AIDS response to the epidemic found that there was a lack of political leadership (Pembrey, 2007). This lack of political will was demonstrated in a speech made by our former President (the then Vice President – Mr. Thabo Mbeki) at the AIDS conference in Durban. In the statement he said that HIV did not cause AIDS, poverty was the cause of AIDS.

With the pressure from civil societies and organizations of people living with HIV, in 2003 the South African government approved of a treatment plan to provide HIV treatment freely to people who were infected (Pembrey, 2007). Sadly, even today with the government's free-treatment programme, not everyone requiring this treatment has it. There are long lists of people waiting to access HIV treatment and many die before they get the chance to access the treatment.

### **1.3.4 HIV and AIDS Statistics**

#### **a) International Overview**

By the beginning of July 1982 there were total of 452 documented cases reported to the CDC, from 23 states in the United States of America (Kanabus & Fredriksson, 2007). These numbers have grown to millions. According to the UNAIDS (2009, p.7) report the global epidemic worldwide has continued to grow, and in 2008 an estimated 33.4 million people were HIV positive – a prevalence roughly threefold higher than in 1990.

#### **b) Sub-Saharan Region**

While no region of the world has been spared the scourge, sub-Saharan Africa is the worst hit. HIV and AIDS are now the leading cause of death in sub-Saharan Africa.

Sub-Saharan Africa remains the region most heavily affected by HIV. In 2008, sub-Saharan Africa accounted for 67% of HIV infections worldwide, 68% of new HIV infections among adults and 91% of new HIV infections among children. The region also accounted for 72% of the world's AIDS-related deaths in 2008 (UNAIDS, 2009, p.21).

#### **c) South Africa**

Despite the relatively late introduction of HIV in the heterosexual population, today South Africa accounts for 10% of the global HIV population (Gouws & Karim, 2005, p.55). A disease that was first evident among two cases in the 80s has now become pandemic in South Africa. It is now considered to be one of the countries worst affected by HIV and AIDS. South Africa is considered amongst the countries with the fastest growing numbers of HIV infection (Kalichman, 2007, p.20). In 2009 the HIV prevalence in the adult population between the ages of 15-49 was estimated at 17.8%, 5.63 million people were infected with HIV. Of these, 5.3 million were adults; an estimated 314 000 died of AIDS (Department of Health, 2010, p.2).

The epidemic might be stabilizing in South Africa, similar to many other countries in the world, but there is a concern that with new infections steadily increasing, the new infections outnumber the AIDS related deaths (UNAIDS, 2009, p.27). The AIDS



pandemic is very severe, with South Africa representing the country with the highest rates of infections in the world (Harrison, *et al*, 2001). And 1700 more are being infected every day (Campbell, 2003, p.13).

With the availability of the anti-retroviral medicines (ARVs), there is a reduction in the death rates, yet AIDS still remains a number one cause of deaths in sub-Saharan Africa (UNAIDS, 2009, p.27). The increase in the infections clearly challenges all concerned, hence it is imperative to review our education approaches to identify where there are gaps, and revise strategies to bridge these gaps.

#### **d) KwaZulu-Natal Province**

According to Noble (2010), between the years 2001- 2007 the province of KwaZulu-Natal (hereafter referred to as Kwazulu-Natal) had the highest prevalence of HIV infections among the antenatal clinic attendees in South Africa, with a percentage above 30%. The most recent Department of Health (2010, pp.43-45) report reveals an increase to 39.5% from 33.5 in 2001. Consideration of these statistics compels one to want to understand the context in which HIV and AIDS education is being implemented at two levels;

- The community at different levels and,
- The community implementation pertinent to the knowledge acquired with a specific focus on the people who are living with HIV.

The study also attempted to establish the relationship between HIV and AIDS education, and issues of gender, culture and power, as well as ways in which these factors affect the reception and implementation of the knowledge acquired by persons living with HIV in Pietermaritzburg.

#### **1.4 Rationale**

This section provides a rationale for my interest in this particular topic and the reasons for carrying out the research in uMgungundlovu. Finally it considers the reasons for my wanting to look at the perspective of the people infected with HIV in a support

group, regarding HIV and education. I indicate why I chose to use *Springs of Hopes Support Group Project (SOH)*.

#### **1.4.1 The Researcher – Anne Namwamba-Ntombela**

I have personal interests in this particular topic as a woman who has been living with HIV for over 19 years. I live in Pietermaritzburg-uMgungundlovu and am also a service provider in the HIV and AIDS field. I am a co-founder of *Springs of Hope Support Group Project (SOH)*, a support group for people who are infected with HIV.

For over a decade I have been involved in the HIV and AIDS field as an advocate, activist, educator, carer and counselor (locally and internationally) with the aim of breaking the silence that surrounds the disease. Silence is caused by the stigma attached to the disease. Silence and stigma are driving the disease, resulting in poor or/and lack of access to care, support, and treatment of HIV and other related issues. This is causing unnecessary deaths in our communities.

My interest in HIV did not only start when I was tested HIV positive, but long before when I heard of the disease in 1981 at the age of ten. Growing up, I thought I had learnt enough about HIV to protect myself from HIV infection. I was well behaved, not sexually active or promiscuous. I perceived AIDS as a disease for the homosexuals, prostitutes and the promiscuous people – sinners. However, my education was merely limited to the facts of the transmission of the disease. I was not equipped with the full knowledge of other realities of life that left me vulnerable to the disease ten years later.

In 1991 in Kenya, I went to a party with my South African friends (my university mates). There my drink was drugged and I was raped by the man who later became my husband and my source of HIV. I had the basic knowledge about HIV, yet I lacked life-skills which would have made a difference to me. In many ways I blamed myself for the rape, yet I know better today.

In 1992 at the age of 21, four months after I gave birth to my son, I tested 'HIV positive' - the same month I moved to South Africa with my family to face HIV and death in isolation. Afraid of stigma and rejection from my family and friends, I chose not to tell anyone. It was only later that year when I had my second test, was counseled, and heard a person saying "*it is okay*" for the very first time, that I decided to inform my family back in Kenya. I started to learn more about the disease.

My marriage, though short (2 years), exposed me to a great deal of issues which initially broke me, but with time I resolved to fight to survive. The same issues have become the basis for my activism and advocacy work. My late husband having returned from exile picked up with life where he had left off. His life was filled with women, and I had absolutely no knowledge about safer sex, so in the process I got infected with all sorts of sexually transmitted infections (STI).

In my struggles I learnt. I learnt about safer sex and HIV re-infection, and I introduced condoms in our relationship. This was a difficult process, accompanied by rape attacks from my husband. It was as if I was supposed to accept his promiscuous life and not protect myself. I felt even more ashamed and broken-down emotionally, yet one of us had to stay alive for our child. I chose life, but unfortunately my husband chose death – he became alcoholic, smoked more and continued with his promiscuous life. All this allowed HIV to overcome his system. In 1994 at the age of 23, I became a widow. He was 42 years old when he died.

Initially I thought I would die soon, as it was commonly assumed during the early 1990s that when one partner died, the other partners would die soon after. However, in my struggles and brokenness God had a plan for me. In the despair I found strength and courage; strength to insist on safer-sex and stand my ground, and courage to fight for my rights without even knowing that I had rights.

It is from such a back-drop that I became a fighter and defender of human rights. It is in these struggles that a feminist was born within me. I gained courage and found my position as a leader and a person infected and living with HIV. I made a choice to get out and change the face of HIV and AIDS, for I am that face.

I am a rape survivor outside and within my marriage. I have survived AIDS twice, gone through five operations and struggled through ARV side-effects. During these struggles I lost both my parents who were a strong source of support. At the same time, I also lost many friends and family to AIDS. I may not be sure what tomorrow holds for me as I am on the last ARV regimen, yet I choose to believe in now. It is only in this that I have a guarantee.

I strongly believe that I can make a difference now! My mission in life is to give hope to those infected and affected. My vision is to give courage to thousands of women experiencing abuse and to break the silence that surrounds HIV, sexual abuse and gender violence. Through education and such a study, I hope to give voice to the voiceless.

Considering all that I have said above, there are a number of disturbing of issues that I have observed as I work in the HIV field. These have motivated me to take on this study. I understand that my critique of the assumptions listed below might influence my study findings. I question:

- a) The assumption that once people get the message, they will change the risky behaviors they are engaging in. This assumption does not consider the circumstances surrounding the target groups' (persons living with HIV) lifestyles and the contexts in which they live. These are not taken into consideration when most programmes are put into place, thus they miss the target.
- b) The general assumptions by programme developers and implementers about HIV positive communities. There is very poor meaningful involvement of HIV positive people in finding solutions about a disease that we live with everyday of our lives. Most educational programmes tend to generalize our issues. My desire is that the information that comes from the study will help to improve the already existing educational programmes by bring understanding to programme developers and implementers about the role of HIV positive persons in developing effective educational programmes. The purpose is to slow down the spread of HIV infection and the rate of death in our communities related to AIDS.

- c) The predominant focus on slowing/stopping the infections from happening. At the same time, there is scarce support for the people infected; ensuring that the knowledge they have in relation to the prevention of HIV and other opportunistic infections is implemented effectively. There is a need for a balanced approach here for the reality of the matter is that as a person living with HIV, I remain the carrier of HIV and it has to come out of my body to infect the next person. Therefore there is a need to support me to contain it while I carry on with my life.
- d) The ABC (Abstinence, Be faithful and Condom use) approach is not a reality in our lives especially that of women. Neither is it sufficient, as our individual contexts vary. This needs to be brought into the picture and acknowledged if we aim to curb HIV. The magnitude of the impact of HIV has resulted in the avoidance, by many practitioners, to individualize the response to the disease. Yet, the key implementer of the acquired knowledge is an individual who sometimes has no power to make the right choices (whether HIV positive or negative). This results in the lack of effective impact of the education.

I hoped that this study would capture some of the realities that we live in, so that HIV education programme developers and implementers can start to understand the realities that individual HIV positive persons experience. These factors can play a positive or negative role in how HIV positive persons use the knowledge they acquire to improve their own health as well as their ability to protect the next person.

#### **1.4.2 uMgungundlovu: Pietermaritzburg - “*The City of Choice*”**

The fact that I live in Pietermaritzburg, where Springs of Hope is situated and functions made it easy for me to access the study site. Pietermaritzburg, well-known as uMgungundlovu by locals, is the political capital city of the province of KwaZulu-Natal. It is located in or rather forms part of the uMgungundlovu district.

uMgungundlovu district is among the worst areas hit with HIV and AIDS in the province. It ranks among the top three worst affected districts in KwaZulu-Natal. It has always reported prevalence figures above 40% - 44.4% in 2006, 40.8% in 2007

and 45.7% in 2008 (Department of Health: Kwazulu-Natal press release, 2009). The 2010 Department of Health (2010, p.44) report shows a drop to 40%.

A person visiting the Mountain Raise cemetery and other cemeteries in the city will note that the grounds are rapidly filling up with fresh graves. A close look at the crosses shows the birth dates of the deceased; it is sad to note that most of the dead are young men and women. Though in most cases the cause of death is not revealed, I strongly believe that most of them are “HIV” related. The reasons why I suspect HIV and AIDS include the following:

- Most people who are dying are young within a certain age group.
- The symptoms they die from are HIV-related, which include chest infection (TB and PCP), stomach infections and other forms of TB and cancers.
- There is a great deal of secrecy surrounding their sickness and death.

The study also attempted to understand the factors that impact on the reception of HIV education in uMgungundlovu district, as its capital Pietermaritzburg is a city that is well resourced. All the public hospitals provide HIV treatment, all municipality clinics provide HIV management programmes and there are many support groups to support persons living with HIV. In addition, we have an AIDS Training, Information and Counselling Centre (ATICC ) office and a Treatment Action Campaign (TAC) provincial office. All these programmes use education in different forms and at different levels to address HIV.

### **1.4.3 People Infected With HIV**

There have been many studies carried out around the issues of HIV and AIDS, but most of these studies have been focused on people who are not infected with HIV. There are few studies that have involved the people who are living with HIV but most of these are situated outside South Africa (e.g. Courtenay *et al.*, 2000; Baumgartner, 2002).

This study focused on the people infected with HIV because these people are the potential transmitters of the virus. Results from the study would help in understanding the realities that might allow them to practice or not to practice non-risk behavior.

A review of the research on youth and HIV and AIDS, including local South African studies, reveals that most researchers continue to explore knowledge, behavior and attitude to try to understand why high levels of awareness and knowledge amongst the youth have not led to any significant behavior change (Lerlerc-Madlala, 2002).

It is a fact that there are few studies that focus on people who are living with HIV. This is possibly due to the stigma attached to the disease, fear of disclosure, and issues of confidentiality. Most people who are infected with HIV are not open about their status to their families, partner or to the public as there is a tendency to focus on one's sexual lifestyle and moral behavior - which most consider private.

A great deal of effort has focused on the prevention of the virus, but the self-care of a person infected with the virus has been neglected and this has resulted in patients dying sooner than expected (Mubiru, nd, p.1). These deaths are a result of misuse of HIV drugs, lack of support, lack of understanding on aspects of how to care for themselves, lack of medical management, psychological effects of knowing their status, and high risk behavior.

I investigated the perspectives of HIV positive people on the AIDS education available as well as what they might need to be able to implement the knowledge they have acquired.

#### **1.4.4 The Springs Of Hope Support Group Project**

*Springs of Hope Support Group Project* (thereafter referred to as SOH) is a support group for people who are infected with HIV. SOH was founded in February 2003 by two young Christians who are living with HIV in an attempt to respond to HIV and AIDS from an HIV angle. It serves people from different areas of Pietermaritzburg.

The vision is that *“Through the love of Christ, support and education, create a community where people that are infected with HIV, or affected by HIV, will be able to lead comfortably, fulfilled lives without fear of discrimination”* (SOH, 2003, p.1). The core of all SOH activities is education at different levels and contexts. One very important part is to educate people living with HIV to be responsible, as they explore their rights to be and manage HIV in their lives on a daily basis. Some of SOH educational activities include support group meetings, home and hospital support, on-going counselling, awareness-raising in communities and clinics, advocacy, community openness, skills developments, food support and other material support, and HIV and AIDS workshops.

SOH’s key strategy is to use and position ourselves (people living with HIV) as examples - *“the face of AIDS”*. We use our experience to educate members of the community at local clinics, and many other audiences. Therefore, all SOH volunteers are living openly with HIV. Through support group meetings, we target persons living with HIV. We share our stories and experiences through mini workshops, to empower each other and correct misconceptions. Through the support group members, we aim to reach families and communities. The home support programme plays a key role in our understanding of the individual’s point of need. This way we can work with each person within their unique context and ensure more effective tailored support.

## **1.5 Research Aims**

This study aimed to:

- Establish how people living with HIV acquire knowledge about the disease.
- Investigate how they respond to the knowledge acquired.
- Identify factors that affect the implementation of the knowledge acquired in the daily lives of persons living with HIV.

## **1.6 Research Key Questions**

What factors influence the reception and implementation of HIV and AIDS education among people living with HIV in uMgungundlovu?



### **1.6.1 Sub Questions**

- a) How did the persons living with HIV learn about the disease?

This question focuses on the initial reception of information about HIV and AIDS.

- b) How did they respond to the knowledge acquired?

This question focuses on how they reacted to the information, both initially and subsequently.

- c) What factors influenced their responses to knowledge acquired?

This question focuses on why people respond as they do, including internal psychological factors and external social factors, and the interaction between them.

### **1.7 Research Design**

This study is a qualitative research study with a feminist approach, drawing on both interpretive and critical paradigms. Most previous studies on HIV positive people have been quantitative macro studies. This study was a qualitative, micro study which focused on a particular group of people in a specific area.

Through my personal reflections, in-depth interviews, focus group discussions and the review of other existing literature (published and unpublished), the study attempted to investigate perspectives of people infected with HIV on HIV and AIDS education. The study was conducted with consideration of the positions of women and men in the diverse South African cultures.

## **1.8 The Direction of the Study**

**Chapter One** describes the background of this study by emphasizing its main focus on HIV and AIDS education and its implementation in communities of HIV positive people in a support group. In addition it also outlines the motivation for the study and why it is important to the future responses to HIV and AIDS.

**Chapter Two** focuses on reviews of relevant literature and thereafter develops the conceptual framework on which the study is based.

**Chapter Three** outlines the research methodology and process. It justifies the rationale for doing a qualitative study, and the selection of site and sample. The use of the specific data collection methods is presented. The data analysis methods, ethical and validity issues and the limitations of the study are discussed. Finally the study summary is presented.

**Chapter Four** presents and discusses the research findings. The data collected during the in-depth interviews and focus group discussions and the personal reflections from the researcher are analyzed and presented in themes discussed in Chapter Three.

**Chapter Five** presents a summary of the study. This is followed by the researcher's recommendations on how to improve HIV and AIDS education provided in Pietermaritzburg. Finally the researcher's suggestions for future research are presented.

## **CHAPTER TWO - LITERATURE REVIEW**

### **2.1 INTRODUCTION**

In chapter one the background, rationale and considerations of the study were presented. It was stated that the focus of the study is an attempt to establish the relationship between HIV and AIDS education and issues of gender, power and culture; investigating perspectives of people who are infected with HIV on HIV and AIDS education.

The aims of this chapter are two-fold; relevant literature is reviewed and discussed so that the current status of knowledge is presented, and the conceptual framework of the study is established.

The literature review focuses first on the basic information about HIV and AIDS. Second it focuses on HIV and AIDS education, information and communication. Third I present literature on Persons living with HIV and Greater Involvement of People living with HIV and AIDS (GIPA). Fourth, the literature focuses on the intersectionality theory to contextualize HIV and AIDS, concentrating on the correlations between gender, power, culture and risky behaviors. Fifth, it reviews Adult education and HIV and AIDS education. The chapter ends with a diagram and a discussion that looks toward the construction of a conceptual framework.

### **2.2 HIV and AIDS**

HIV and AIDS education consists of basic facts about the disease and its progress. Therefore it is imperative that the review of the literature begins with basic HIV facts. This allows one to understand the disease and also on the other hand, allows us to understand what a person living with HIV is expected to learn to manage the disease in their own life.

#### **2.2.1 HIV**

HIV stands for Human Immunodeficiency Virus, a very small simple, weak germ that

we cannot see with the naked eye, which only occurs in human bodies. It is extremely dangerous as it attacks the immune system (CD4 cells), the very thing that would normally destroy it (AVERT, 2007).

According to Namwamba-Ntombela (2007, p.5-10), HIV cannot survive outside the human body for long. Additionally, it needs an exit point from the host body and an entry point to the next person. It needs enough time to attach itself to the new person and there has to be a sizeable amount of the virus for infection to take place. These factors make it very difficult to transmit HIV casually.

HIV was discovered in 1983 by Dr. Montagnier from France and Dr. Gallo from the United States; they both had a different name for it to begin with, but later came to a compromise and named it HIV (Karim, 2005, p.33).

There are two things that make it hard to control the virus. First is its “docking arm” which allows it to attach itself to the CD4 cells; this permits it to undermine the very system that should be controlling it. Second is that once it is attached to the cell, the virus mutates itself to appear similar to the cell - thus the immune system is not able to identify it. A CD4 cell has receptors on its surface to which the HIV “docking arm” fits, allowing it entrance to the cell (Wood, not dated). HIV has been referred to as “*a thief*” (TAC, 2006, p.18), and “*a thinking virus*” (Namwamba-Ntombela, 2007, p.5) because of its ability to enter and use CD4 to multiply, later destroying it. Because of its ability to mutate constantly to adapt itself to the new environment, even if a person is on ARV treatment, the virus can become resistant to the drugs. HIV has been referred to as the “silent killer” in many cases and this is purely related to the nature of the disease (Namwamba-Ntombela, 2007, p.8; Domrose, 2003, p.1; Wood, nd). HIV causes AIDS.

### **2.2.2 AIDS**

AIDS stands for Acquired Immune Deficiency Syndrome, which describes a medical condition in a person infected by HIV. It is a collection of opportunistic infections in ones’ body as a result of HIV breaking down the body’s immune system. A damaged

immune system is not only more vulnerable to HIV, it is also vulnerable to attack by other infections (AVERT, 2007).

It was first discovered in June 1981 in CDC Atlanta, USA, and was first named AIDS in 1982 (Karim: 2005, p.33). Namwamba-Ntombela (2007, p.6) and Wood (nd) present the development of HIV infection in five stages. These are: HIV infection and sero-conversion, the silent stage, the minor symptomatic stage, the symptomatic stage, and AIDS. Thirty years after the first clinical evidence identified HIV and AIDS, the scourge has become the most devastating disease humankind has ever faced.

### **2.2.3 HIV Transmission and Prevention**

Understanding how HIV is transmitted and how this can be prevented remains core to the fight against HIV across the world. This understanding has greatly contributed in reduction of stigma and discrimination that was initially associated to the people who are HIV positive and AIDS patients. On the other hand a person living with HIV can protect their loved ones and live a better quality lifestyle if equipped with this information. The foci on HIV transmission and prevention are central to HIV and AIDS education.

HIV is not transmitted by casual contact, such as ordinary day-to-day interactions with the person infected. Neither is it air bound. Current scientific knowledge shows that HIV is transmitted in these specific ways:

Unprotected sexual intercourse with a person infected with HIV, this includes all forms of sexual activities (virginal sex, anal sex and oral sex). It can also be transmitted by getting into direct contact with the blood or other body fluids of an infected person. This could be through blood transfusion or sharing of sharp objects e.g. injections, razor blade. Also a pregnant woman who is infected with HIV might transmit the Virus to the child during pregnancy, during delivery, during breast feeding (Namwamba-Ntombela, 2007, p.9).

There are other factors that may contribute to the rapid spread of HIV (AVERT, 2007; Fact, 2005). Gouws & Karim (2005, p.63) cite the high rates of sexually transmitted infections (STIs) and migratory labour in South Africa as some of the key factors that

influence the spread of HIV. Risky behaviors such as unprotected sexual contact and having multiple casual sexual partners can increase the risks of HIV transmission. In addition, some cultural practices can be risky and could promote the spread of HIV (these includes polygamy, widow inheritance, communal circumcision with one knife, ritual marks and ear pricking). These factors shall be reviewed further, later in this chapter.

Once a person knows how HIV is transmitted, it is easier to prevent HIV transmission. Sexual transmission still remains the predominant mode of HIV transmission, therefore abstaining from sexual intercourse, and being faithful to one partner whose status you know, ensures that one is not exposed to HIV (Namwamba-Ntombela: 2007, p.11). Condoms, when used properly, act as a physical barrier that prevents infected fluid from getting into the other person's body (AVERT, 2007, unpaginated).

The above mentioned methods used for preventing HIV being transmitted sexually is commonly referred to as “*ABC Approach*”. According to Karim Q. A. (2005, p.250) this approach is used widely at programming levels in HIV prevention. Silverberg (2006) states that there are two crucially different definitions of the “*ABC Approach*”, one by the UNAIDS and the other one from PAFAR; the PAFAR definition does not allow information about the use of condoms to be disseminated to young people or to those people perceived as being of low risk behavior. Earlier in Chapter one I raised my personal concerns regarding “*the ABC Approach*”; in Chapter four I engage again in further discussion about it.

Since HIV is not only transmitted sexually, there are other methods applied to ensure the reduction of risks of HIV transmission. In South Africa all blood donated is screened for HIV to ensure that the recipients are safe (Karim, 2005, p.41). To avoid direct contact with blood and other infected body fluids, a person can use rubber gloves or any other waterproof barriers. Without prophylactic HIV treatment, 15-30% babies are born HIV positive (Kanabus & Noble, 2007). Therefore to avoid transmission from mother to child it is important for the mother to know her HIV status so that the necessary precautions can be taken.

In the past years new developments have been made in relation to HIV prevention, thus requiring more learning for the community of people living with HIV. It has come to light that male circumcision reduces female to male HIV transmission (CDC, 2008; WHO &UNAIDS, 2007; WHO, 2010; and Williams B. G. *et al*). Yet still, male circumcision is more effective in reducing risks of HIV infections when condoms are used too.

Considering the facts that HIV thrives on gender, power and cultural inequalities and practices that tend to favor men, there is a need for female controlled HIV prevention methods. With no prospects for an HIV vaccine in the near future, there are high hopes placed on microbicides.

Microbicides are anti-HIV substances designed in various forms to provide additional protection against HIV. They are intended to be used as an additional prevention measure or in cases where a partner is not using condoms. Dozens of potential microbicides are in various stages of research. Once available, they could help women and men protect themselves. Microbicides may be especially important for women in developing nations who are not always empowered to require partners to wear condoms (The AIDS InfoNet, 2010).

Most recently, trials have begun in South Africa for another type of microbicides –the vaginal ring (Brown, 2010).South African scientists have been running ARV-based microbicide trials in recent years. These have shown promising results, reducing the risk of women getting infected with HIV, up to 39% (Plunkett, 2010, unpaginated).

All in all universal precaution is highly recommended for everyone, as HIV has no symptoms in its silent stages and might take ten years or more before a carrier shows any symptoms. It is therefore imperative that we all take every necessary precaution to prevent possibilities of HIV transmission (Namwamba-Ntombela, 2007, p.11; Wood, nd, and CDC, 1996, p.1).

#### 2.2.4 HIV Testing

Due to HIV and AIDS education in the communities, more and more people are opting to go for HIV tests for there is no other way in which a person can know if she/he is infected with HIV other than when they have a blood or saliva test to determine their status. There are different conditions in which HIV testing is done. In whichever condition, it is recommended that pre-test and post-test counselling is provided for the person being tested, the counselling process allows one to learn more about the disease and also reflect on self at different levels in relation to HIV. UNAIDS/WHO HIV testing policy (2004, pp1-3) recognizes four types of HIV testing; Voluntary Counselling and Testing (VCT), Diagnostic Testing, Mandatory Screening and Routine Offer testing. It is important to know that there are conditions where mandatory testing may be done. HIV testing, and the associated counseling, is therefore another key aspect of HIV and AIDS education.

Free VCT services are provided to the public in most government clinics and hospitals, AIDS Training, Information and Counselling Centres (ATICCs), and at some private and non-governmental health facilities in South Africa. The decision for one to test should be voluntary; no one should be forced to have an HIV test, though the public should be motivated to do go for VCT. Springs of Hope clinic and community awareness programmes are aimed at encouraging people to know their HIV status, in order to ensure early effective management of the disease if person is infected.

There has been a great deal of development from the early 1980s when testing HIV positive was interpreted as “*a death sentence*”. Today HIV is slowly becoming a manageable disease. With the availability of free ARV treatment and VCT services, many people are voluntarily coming forward to test for HIV. Unfortunately the clinics are not coping and we see many people being sent back home without taking the test or accessing necessary post-test management support.

There are different levels at which HIV and AIDS Education is provided and two of the most common stages at which it is done are during the pre- and post-test process. Therefore the quality of the counselling services provided is very important in



ensuring that the client understands the implications of the step taken and those that follow there after. Therefore people should be assured of competent counselling and support from trained counselors (Jackson, 2002 p198). Jackson (2002) refers to a study done by Hagembe *et al* (1998) in Nairobi which revealed that the counselling provided was of poor quality with no consideration for the clients. Such a study highlights the importance of ongoing training, support and supervision of VCT counselors, to ensure that clients are effectively supported

### **2.2.5 HIV Treatment**

Beyond understanding the basics about HIV and AIDS, persons infected with HIV have to acquire knowledge on treatment for both opportunistic infections (OI) and HIV, this is referred to as treatment literacy. There are medicines now that can be used to treat HIV even though there is no cure. **Anti-Retroviral Treatment (ARVs) or Highly Active Anti-retroviral Therapy (HAART)** are drugs which are used to treat people with AIDS. Different ARVs have different functions in fighting HIV.

Core to the HIV treatment literacy is the knowing of the medications, understanding how they work, their side-effects and the importance of adhering to taking the medications well. If one does not adhere to the treatment programme he or she can develop resistance to the drug easily, therefore a person must take the drugs properly to ensure that they stay effective for a long time. While ARVs do not cure AIDS, they can control and reduce the virus in the blood and improve one's quality of life, improving the immune system. While ARVs work very well for many people, they do not work for everybody.

Many initiatives have been implemented, and much effort has been invested by the South African government and other non-governmental organization to fight the pandemic and HIV. The South African HIV government treatment programme provides three group types of ARV medicines (Namwamba-Ntombela, 2007, p.41; TAC, 2006, p.38). To date only 36% of people in South Africa who are eligible for ARVs have access to the treatment (UNAIDS, 2010, p.98).

Education has been identified and put at the centre of these efforts in the attempt to combat the spread of the virus. Therefore the next section will focus on HIV and AIDS education, information and communication.

### **2.3 HIV and AIDS Education, Information and Communication (EIC)**

Considering the aim of this study, it was relevant to review literature on HIV and AIDS education, information and communication. Pattman (2006, p.90) quotes Coombe & Kelly's (2000) description of education in Southern Africa; in the quotation the authors described education as a "vaccine against AIDS" in Southern Africa.

This section first identifies the purposes of HIV and AIDS education, information and communication. Second, it discusses different method of the education. Third, it presents some local examples of institutions/organizations that provide HIV and AIDS EIC in Pietermaritzburg. Last, it reviews literature on some of the challenges regarding AIDS education. In the review, different examples of targets groups to which EIC is directed are presented. In addition, the format and media in which it is represented is briefly discussed.

#### **2.3.1 Purposes of HIV and AIDS Education, Information and Communication**

Generally the methods, strategies and forms of media used to educate the community of Pietermaritzburg attempt to accommodate all groups of people; the youth, women, children, prisoners, educated and illiterate, HIV positive and negative. There has been a call to develop material to include the deaf and the blind as well.

HIV education is presented in different forms of media; written (poems, books, leaflets, billboards etc), audio (music, radio, tapes) and visual media (TV, movies, pictures, T-shirts, drama). In addition, people are used in different ways to helps drive the campaign (e.g. infected and affected) - the list is endless. AIDS education needs to be an ongoing process, as many people are still ignorant about the virus (AVERT, 2007). Moreover, the education should target different age groups, as each generation

of young people needs to be informed and older generations may need the message to be reinforced so that they continue to take precautions against HIV infection.

HIV education is provided for three main reasons which are: i) prevention of new infections, ii) improving the quality of life for the infected and, iii) reduction of stigma and discrimination (AVERT, 2007). While most interventions have focused on prevention, most support groups focus on positive prevention, which firstly focuses on the HIV positive person and encompasses all possible forms of intervention to keep the person healthy while at the same time protecting the next person. Rule (2007, p.79-81) identifies four purposes for which HIV and AIDS education is provided at work places in South Africa. These are: i) education for prevention, ii) human rights, iii) damage control, and iv) community engagement.

### **2.3.2 Different Methods of the Education**

Below are some HIV and AIDS EIC methods suggested by (AVERT, 2007,).

- a) **Peer Education** is an on-going social form of education without classrooms or notebooks, where people are educated outside a 'school' environment but still have the opportunity to ask questions. The peer educators provide a credible link between the target audience and the education project, by which the educator is trained.
- b) **Active Learning** allows people to both remember information and to relate it to themselves if they are given an opportunity to put it to use as they learn.
- c) **Blanket Learning** is a general message aimed at the population as a whole. In many countries, the general population is seen as being at a fairly low risk of HIV infection. Blanket education usually aims to inform the population about which behaviours are risky and to give them support in changing these behaviours. This gives people who are already infected with the virus the opportunity to avoid transmitting it to others, and people who have not been infected the opportunity to protect themselves.
- d) **Targeted Learning** is a type of strategy that is usually used to speak to social groups who are perceived as being at a high risk of HIV infection. This type of

education tends to focus on risky activities particular to the specific target group.

Peer education is commonly used in schools, work places, institutions and so on. The educator is usually a person within the targeted group. A good example of active learning in HIV education can be observed in support groups of people living with HIV. In addition, active learning can sometimes link to peer education, especially when AIDS education is aimed at young people - as one of the best methods of learning something oneself is to teach it to others. The best examples of blanket learning are *Khomanani*, a government sponsored program, or *Soul City*, a local TV program. Target education in South Africa is evident in programs that are targeted to women at antenatal clinics, STI clinics and TB clinic. SOH has also used the same audiences to motivate them to have an HIV test so that they can have a more effective health management approach.

Another method that can be used to educate people is counseling. It is primarily used to educate people who come for an HIV test about the management of the disease, to ensure that they understand their risks and adopt safer sex behaviours. It is also aimed at helping them to cope with the positive results, enabling them to lead a full and healthy lifestyle. Counselling can also be incorporated in the other methods mentioned above.

#### **2.3.4 Local EIC Institutional/Organizational Examples in Pietermaritzburg**

In Pietermaritzburg-uMgungundlovu district, there are many institutions that provide HIV and AIDS EIC. Their EIC programmes combine different strategies/approaches, methods and media to disseminate the information. These EIC service providers in the city include the following:

The Department of Health awareness programmes provide education to the public through the *Khomanani* approach. These include Voluntary Counseling and Testing (VCT), and talks to patients at different levels of intervention, specifically targeting Tuberculosis (TB) patients or clinics, because most HIV patients are at high risk of getting infected with TB; Sexually Transmitted Infection (STI) clinics for make it for

one to get infected with HIV and Ante-natal clinic (ANC) patients. Also both STI and pregnancy are indicators of unprotected sexual practice, thus increasing high risk of one being infected with HIV.

Treatment Action Campaign (TAC) provides treatment and advocacy literacy to communities of people living with HIV and those affected. While support groups for people living with HIV are all over uMgungundlovu district - Springs of Hope (SOH) is one of these groups. SOH provides HIV management education to its members (persons with HIV), as well as education to the general community through churches, schools, local communities. SOH mainly uses people living with HIV to educate the community; they combine their experiences with facts about the disease, t-shirts and posters to destigmatize HIV encouraging people to know their status so that they can access relevant care and support.

Other forms of education are provided by local drama groups, schools, and work places. They follow the government health and wellness programs and use these opportunities to encourage employees and their families to get tested for HIV so that early intervention is possible or begun. Over the years, most of the institutions mentioned above have produced different forms of media to educate the community. These include pamphlets, brochures, T-shirts, articles, books, as well as TV and radio dramas.

#### **2.3.4 Challenges Regarding HIV and AIDS Education, Information and Communication**

There are challenges that affect the reception and implementation of HIV and although there is a great deal of effort from the South African government to create awareness about HIV and AIDS, the number of people infected with HIV seems to increase daily (Mlomo-Ndlovu, 2000, p.27; AIDS Foundation, 2005, unpaginated) According to Innes (2006, unpaginated) there are still many people who lack access to the right kind of information on HIV and AIDS. These findings indicate a gap in HIV education.

Over the past few years, efforts to combat HIV and AIDS are focusing beyond education alone. SOH (2003) raises the issue of looking at HIV in an individual's context and in so doing providing the right kind of support to an individual to ensure that they do not pass on the virus to the next person. AVERT (2007, unpaginated) recommends that when planning HIV and AIDS education, one must consider the target group (e.g. age, availability, culture, literacy levels, gender etc). There is a need, therefore, to develop different messages for different people. More importantly, it is necessary to consider the relevance of the information, to incorporate life skills into the program to help the learner apply new knowledge acquired, and finally to consider the availability of necessary resources (e.g. condoms, VCT centres etc).

One of the reasons why HIV and AIDS education might not be reaching many people who are illiterate (Mlomo-Ndlovu, 2000, p.27) is that most of the education information is on pamphlets, newspapers, television and radios, which some have no access to. Namwamba-Ocharo (2009, p.87) in her study on communication with the youth about HIV and AIDS, points out that the new technologies and electronics (e.g. mobile phones, internet, DVDs) are distracting the youth from listening to the AIDS message; she recommends that we could use the very technologies and electronic devices to direct AIDS messages to the youth instead of using the traditional methods only.

The increase in HIV infections over the past years indicates that either people are not learning the message about the dangers of the disease, or for some reasons they are unable or unwilling to act on it. In addition to the factors mentioned above, there are other factors that might cause the person receiving HIV and AIDS education not to use this knowledge. AVERT (2006, unpaginated) states that even though education is an important part of AIDS prevention, it is only one part; there are other aspects of prevention. Nonetheless, education is a crucial factor in preventing the spread of HIV, and its effects cannot be overestimated.

#### **2.4 The Role of People Infected with HIV in HIV and AIDS Response**

HIV and AIDS education provided by persons infected with HIV who work as individuals, through support groups, civil societies, parastatals e.t.c. has played a great

part in changing how HIV is perceived. Unfortunately each year there are more and more new HIV infections (AVERT, 2007). As we look at the history of HIV over the years, we see how people living with HIV are presented and handled in different ways. Initially there was considerable stigma and discrimination directed at people who are infected with HIV. In later years, there has been a change in perceptions and roles.

When receiving an HIV positive test result, many people feel that they have been given a death sentence. In view of this reality, HIV and AIDS education and counselling for HIV positive people has several main goals; to prevent new infections from taking place, to improve the quality of life for HIV positive people, and to reduce the stigma and discrimination around the disease (AVERT, 2007; Mlomo-Ndlovu, 2000, pp. 27-28).

Considering all the literature presented up to this point, a person infected with HIV needs to be continually equipped or educated at different levels (examples of these include the nature of the disease, treatment, their rights, services available, and life-skills to assert behaviour change, and so on), so that they can manage the disease effectively, lead a quality meaningful life, and so that they can play an important role in addressing the spread of HIV. Such knowledge can determine who lives or dies. It also positions a person living with HIV in different roles - such as patient, contributor, carer, educator, implementer and also a decision maker.

The greater involvement of people infected with HIV (GIPA) is a principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and meaningful participation in HIV response (UNAIDS, 2007, p.1). This was formalized at the 1994 Paris AIDS Summit when 42 countries agreed to support a greater involvement of people living with HIV, at all levels. Later more countries have joined the commitment to apply GIPA in HIV responses (UNAIDS, 2007, p.1).

GIPA supports networks of people living with HIV (Jackson 2002, p.231). It also encourages them to get involved in national responses to HIV and AIDS, to ensure that the voices of the affected and infected are heard where it counts most. The GIPA principle recognizes that people who are living with HIV and those with AIDS should

share and lead the responsibility of responding to the HIV and AIDS epidemic - and that society needs to create the space for this important role. The GIPA pyramid of involvement helps one to understand the different roles that people living with HIV can play in addressing the HIV epidemic and its impacts; these range from being the target audience, contributors, speakers, implementers, and expert advisors to decision makers (Jackson: 2002, p.231).

People living with HIV have great emotional needs and require support to come to terms with their infection (AVERT, 2010; Mlomo-Ndlovu, 2002, p.27). Support groups for people living with HIV and AIDS have a positive psychosocial impact on the members' quality of life (Mwala & John, 1998, p.1). Despite the fact that support groups have been proposed as key intervention for persons with HIV, there is limited literature to provide a scientific basis for their usefulness and effectiveness (Spirig, 1998, p.1). Persons infected with HIV are encouraged to join support groups to get in touch with other persons infected with HIV, for these people understand how it feels being HIV positive. A person learns to come to terms with their own issues and HIV status through listening and asking questions (TAC, 2003p.2; Jackson, 2002, pp. 211-256). TAC (2003 pp 66-67) states that with the high number of HIV positive people living with HIV, support groups can play the following roles; promoting awareness and openness about HIV and AIDS, and fighting discrimination and fears related to AIDS thus facilitating disclosure. Support groups should be practical and empowering, effecting positive change within an individuals' life and their community as well.

## **2.5 Intersectionality - Contextualizing AIDS: Gender, Power, Culture and Risk Behaviours**

Gender, power and culture are greatly intertwined and very difficult to discuss separately when addressing the reception and implimention of HIV and AIDS education. Nonetheless, I will attempt to, for each is playing a major role in driving the spread of HIV while simultaneously feeding into each other to make the situation worse in South Africa; undermining all the education efforts to curb the disease, and contributing to failure in changing risky behaviours. Therefore in this section I will use **the concept of intersectionality** to review literature on gender, power and culture



showing how these factors intersect in the lives of HIV positive people, making it difficult to implement knowledge acquire. I will also review literature on stigma and discrimination, which are issues related to power and they both play a major role in driving HIV forward.

Initially intersectionality was introduced as ‘intersection’ in the American sense of the word, to denote ways in which colour intersects with gender for the poor and marginalized coloured people (Crenshaw, 1989). Intersectionality may be defined as a theory to analyse how social and cultural categories intertwine. The word intersection means that one line cuts through another line, crossing each other. In the American concept of intersectionality, the focus was on race and gender. Since the studies concentrated on the poor and marginalized coloured population, the class dimension was often implied in the theoretical reflections and analysis (Crenshaw, 1995).

The theory of intersectionality stresses complexity. Although because of its origin it primarily refers to race, gender, ethnicity and related social categories, it allows for other categories to be integrated as well, depending on what is important, and the ongoing discussion between researchers (Borgström, 2005). In this study I will be using the concept of intersectionality to review and present literature related to gender, power and culture and later in chapter four I will use the concept to present my findings to discuss the complex context in which people living with HIV in a support group acquire and implement the knowledge about HIV, with particular focus on the “*ABC Approach*”.

Additive intersectionality means that both the subject formations based on gender, race, ethnicity, sexuality, and so on, and the orders of power that create them, are analysed as separated structures and limited units which do interact, but not intra-act, (Lykke, 2005, p.9 cited in Knudsen, 2006, p. 63). Therefore the concept forces me to not review data blindly, but to view the male and female HIV experiences separately and how these (male/female) impacts, linked to the culture and power of an individual, affect one’s knowledge reception and implementation.

There are many complex reasons underlying why South Africa has a high prevalence of HIV. According to the UNAIDS operational guide to gender and HIV and AIDS

(2005, p.43), there is a growing recognition that the epidemic thrives on and is exacerbated by socio-economic inequalities. Within a perspective informed by intersectionality, my discussion below will attempt to present some of the factors as I review literature on gender, power and culture, and HIV and AIDS education.

### **2.5.1 Gender and HIV and AIDS Education**

The UNAIDS operational guide to gender and HIV and AIDS (2005, p.11) presents gender as the rules, norms, customs and practices through which the biological differences between males and females are transformed into social differences between men and women, boys and girls, which in turn results in them being valued differently and thus having unequal opportunities in life. Traditional gender roles can be harmful to both men and women in this era of HIV. When developing and implementing HIV education, therefore, one has to keep these complexities in mind.

While at the beginning of the disease (1980s) HIV affected men most (UNFPA, 2005, unpaginated), today women form 50% of the world's HIV population. Women are more vulnerable to HIV than men for biological, socio-cultural and economical reasons.

In sub-Saharan Africa, women and girls continue to be affected disproportionately by HIV; women account for 60% of the HIV positive people (UNAIDS, 2009, p.22). Presently HIV is very high amongst the heterosexual adults, particularly women, because of the cultural reality in Africa that accommodate men's multi-sexual behaviour. This exposes women to HIV.

The physiological factors result in more efficient transmission of HIV (UNAIDS, 2009, p.22). A woman's genital tract is internal and has a large surface of tender membrane. This breaks easily allowing easy entry of the virus into her blood system. Moreover, the slow discharge of the male ejaculated fluids allows the virus enough time to attach itself. Women are twice as likely to acquire HIV from men during sexual intercourse, than men to acquire it from women (amfAR, 2005, p.1).

The economic factors that expose women to HIV are as a result of high poverty which results in women depending on their male partners. I will discuss this later in the chapter when I look at power related factors.

Discussions about women's vulnerabilities to HIV without mention of men who are the drivers of the epidemic are incomplete (UNFPA, 2005). Flood (2003, pp.10-11) argues that men form both part of the problem and part of the solution to HIV and AIDS. Therefore it is crucial to include men in dialogues that are aimed at achieving successful HIV prevention, as men engaging in risky behavior are also vulnerable to HIV. The HIV and AIDS epidemic has put men's sexual behaviour in the spotlight (Drennan, 1998).

According to the study done by Campbell among sex workers and mine workers in South Africa (2003 ), most men have to prove their masculinity by becoming involved sexually and having multiple partners. The role of men as decision-makers in sexual relationships needs to be emphasized when developing prevention strategies (Campbell, 1995). The study done by Dunkle *et al* (2006) recommended culturally tailored interventions to address the intersection of violence perpetration and high risk behaviors amongst young South African men.

This study explored the multi intersectional gender implications in relation to HIV and AIDS education.

### **2.5.2 Culture and HIV and AIDS Education**

The challenges associated with HIV and AIDS have proven to be especially difficult because they differ from culture to culture, and given the wide range of dynamics which culture may include, designing culturally appropriate programs for HIV and AIDS education can be extremely challenging ( UNESCO, 2010). Cultural practices play a huge role in exposing people to HIV (Innes, 2006).

While it is known that HIV is mainly transmitted through unsafe sex practices, unfortunately it is a taboo in most African communities to discuss sex as a subject. This silence has to be broken in order to realize effective means of intervention. The

need for people (especially the youth and women) to talk more about their sexual behaviors and the challenges they are facing in their relationships is urgent in addressing HIV, as this is the only way one can assess individual risk levels. With more of these kinds of cultures slowly being ‘broken’, possibilities for South African women to find their voices and implement the knowledge they may have about HIV could be expanded. Thus they could be able to negotiate safer sex amongst other things that put them at risk of getting infected in their relationships.

There are certain common cultural norms and practices associated with sexuality that contribute to the risk of HIV infection. Innes (2006) provides examples which sum up these challenges well. These include negative attitudes towards condoms, certain sexual practices, virginity factor, fertility, polygamy and urbanization.

While proper and consistent use of condom is proven to be one of the most effective way of preventing HIV men in southern Africa regularly do not want to use condoms, because of beliefs such that “flesh to flesh” sex is equated with masculinity and is necessary for male health. The negative attitudes towards condoms, as well as difficulties negotiating and following through with their use, expose men to HIV and thus expose their female partners to HIV infection. Unfortunately the use of condoms is strongly associated to unfaithfulness, lack of trust and love, and HIV.

Sexual practices, such as dry sex, and unprotected anal sex, carry a high risk of HIV because they cause abrasions to the lining of the vagina or anus. In cultures where virginity is a condition for marriage and girls are regularly subjected to virginity testing, girls may protect their virginity by engaging in unprotected anal sex.

Fertility in many African communities may hinder the practice of safer sex, thus exposing both men and women to HIV infection. Newly married women and young women tend to under pressure to prove their fertility to their in-laws or prior to marriage by try to fall pregnant, therefore they may choose not to use condoms or abstain from sex. For men fathering many children is also seen as a sign of virile masculinity. These results sometime into engaging into unprotect multi-sexual relationships; increase their risks of getting infected with HIV. Some parts of southern Africa practice polygamy and this includes the Zulu people. In some case men use the

services of sex workers. This is condoned by the widespread belief that males are biologically programmed to need sex with more than one woman.

Lastly other interlinked factors raised by Innes (2006) are urbanisation and migrant labour which cause separation of families and regular/ steady partners. This leaves them vulnerable to engage in sexual relationships with new people. It exposes people to diverse new cultural influences, which can result either in cultural erosion or the co-existence of traditional and modern values. As modern values are incorporated, it can result to one disregarding safe traditional practices such as abstinence from sex before marriage and staying faithful to one partner.

### 2.5.3 Power and HIV and AIDS Education

There are many facets of power playing a part in the spread of HIV; these include gender, culture, socio-economic and human rights factors. In the diagram below I attempt to present different facets of power as I perceive it. All the different aspects placed in ovals around the word power can position a person in a place of power or powerlessness. In the literature review that comes after the diagram I discuss these facts. It is important to note that there are strong links between the different aspects.

**Facets of Power**

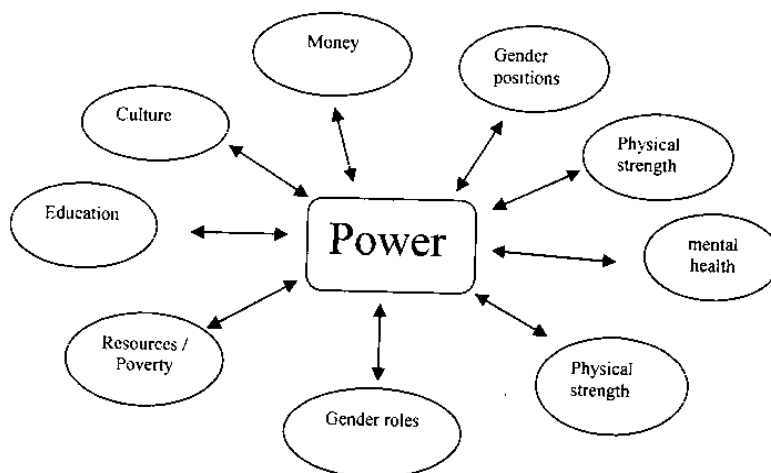


Figure 1. Facets of Power

In most sub-Saharan African countries, gender and culture have placed men in a very powerful position. Tuyizere (2007, p.108) states that gender is a powerful ideology which determines the choices and limits that are predicted by our sexes (male/female), in which case males are privileged. The 'feminization' of the AIDS pandemic is a reminder that in many places women do not have the power to protect their own health.

At different levels in the community, men often control access to all forms of resources, wielding enormous power over many aspects of women's lives (UNFPA, 2008). The systems in which we live place women in a disadvantaged position - not only can they not protect themselves, but they also experience difficulties in protecting their girl child. Gender inequity gives men an upper hand in relationships and decision-making; women have no voice and their views are not welcome in most cases.

The co-relation between the poor and the rich and the spread of HIV is well documented; those with money having power over those without. Many African women are disadvantaged due to lack of education. Lack of education can result in economic insecurity which forces some of the women to take desperate measures, including high risk behaviors such as sex work, to fund their daily lives (Gray, 2009 unpaginated).

Linked to factors of physical strength, gender-based violence is a common phenomenon that increases women's risk for HIV infection.

Gender-based violence refers to a range of harmful customs and behaviors against girls and women, including intimate partner violence, domestic violence, assaults against women, child sexual abuse and rape. It is generally derives from cultural and social norms that imbue men with power and authority (The amfAR symposium, 2005: Krug *et al*, 2002; Martin & Curtis, 2004, p.1410; Boonzaier & Rey, 2004, pp. 443 – 463; Dunkle *et al*, 2004, 1416).

A large survey of South African men showed that more than four-in-ten men have been physically violent to their intimate partner; of the men in the study, a quarter reported to have raped a woman, and the general high HIV prevalence among the men

surveyed indicates that there is a good chance that a man who commits rape has HIV (AVERT, 2010).

According to WHO (2010) and Gordon (2009, p.32), women who fear or experience violence, lack the power to ask their partners to use condoms or to refuse unprotected sex. The fear of violence can prevent women from learning and/or sharing their HIV status, and accessing treatment.

Women with a history of being sexually abused are more likely to engage in risky behavior and unsafe sex, have multiple partners, and trade sex for money; this could be linked to the post-traumatic impact of the experience (Cunningham *et al*, 1994, pp. 233-245). The study done by Goodman & Fallot (1998) supports these findings, stating that both childhood sexual and physical abuse are linked to HIV high risk behaviours which include: substances abuse, prostitution and having sex with high risk partners. The amfAR symposium (2005) states that forced or violent intercourse can cause abrasions and cuts which help HIV to enter through the vaginal mucosa. Forced sex clearly limits a woman's ability to successfully negotiate safer sex.

The spread of HIV is also fuelled by inequalities which restrict what women can do to protect themselves from infection. Protecting and promoting human rights should be an essential part of any response to HIV and AIDS. Women's inferior status affords them little or no power to protect themselves by insisting on condom use or refusing sex. The financial dependency is a result of illiteracy, lack of job opportunities for women, and poor salaries due to lack of skills. A numbers of studies cite the fact that sometimes women lose their jobs due to retrenchment, poor skills or poor health or leave their jobs to care for a sick member of the family (Gray, 2009; Dibua, 2010; Inungu & Karl, 2006).

While women are most vulnerable and men drive the disease, the power position men hold makes them vulnerable as well. According to the study done by Campbell (2003) in the mines, there are other socio-economic factors such as poverty, poor living conditions and high risk working conditions which make men feel powerless - in these cases drinking and sex are sought out as diversions to ease stress. This is not only a common trend at the mines but in any other areas that are affected by poverty, high-risk living and working conditions. In the study some of the miners viewed HIV

and AIDS to be a lesser risk than death underground. These issues highlighted by Campbell (2003) on the pressures put on men by society and the socio-economic demands, render men powerless. At the same time, most women depend on men for financial support and this gives men an upper hand in relationships.

Although the pressure on girls and boys overlap, they also differ in crucial aspects. Girls often have far less about the conditions of sex; they have far greater exposure to sexual abuse; their lower social economic status and lack of economic options drive them more readily than boys into transactional sex and final injury, girls are more easily infected than boys by unprotected sex that even if motivated, they may lack the negotiating skills and power to avoid. (Jackson, 2002, p. 123)

The fact that the South African government recognizes the rights of women does not mean that these rights have been implemented; the Human Rights Watch (1995) denounced the widespread of violence against women in South Africa, calling for the government to respond to the problem stating that women are not safe in their homes, their places of work or in the streets. It has been estimated that one in three women gets raped in South Africa, and one in six South African women is in an abusive domestic relationship. Women who are beaten or dominated by partners are nearly 50% more likely to get infected with HIV (*Sapa-AFP*, 2004), for gender-power differences are linked to factors that increase risks of HIV and STI infections (Kalichman *et al*, 2005, p.1). A study done by Kalichman *et al* (2007) showed that most men who abused women had a history of being abused and also engaged in high risk behaviors and substance abuse.

The factors above play a considerable role in the reception and implementation of HIV education - in most cases, negatively resulting in the increase of HIV infections in South Africa.

#### **2.5.4 Stigma, Discrimination and HIV and AIDS**

AIDS-related stigma and discrimination refers to prejudice, negative attitudes, abuse and maltreatment directed at people living with [HIV](#) and [AIDS](#). This can result in their being shunned by family, peers and the wider community; poor treatment in healthcare and education settings; an erosion of rights; psychological damage; and can negatively affect the success of testing and treatment (AVERT, 2010). The UN



Secretary General Ki-Moon (2008) stated that one of the biggest global hurdles to HIV responses is stigma, as discrimination as a result of stigma remains a daily experience of people living with HIV. He further stated that stigma is a chief reason why AIDS continues to devastate the world. Stigma and discrimination can hinder access to care and support for people living with HIV.

Skinner & Mfacane (2004, p. 157- 158) state that the potential impact of stigma and discrimination has been of ongoing concern to those involved in addressing the HIV/AIDS epidemic, as they both play significant roles in the development and maintenance of the HIV epidemic. HIV epidemics thrive on discrimination and stigma directed toward infected and affected people.

## **2.6 Adult Learning and HIV and AIDS Education**

UNAIDS (2009, p.29) quotes Hargreaves (2008). Hargreaves (2008) points out that while studies done prior to 1996 showed no relationship between education and the HIV epidemic in sub-Saharan Africa, the recent meta-analysis of 36 studies carried out in 11 countries between 1987 and 2003 clearly show a relationship.

One key approach to AIDS in adult education is feminist pedagogy, which relates feminist themes to contexts of education and learning. There are numerous strands of feminist pedagogy. The three key themes in the **feminist theories** referred to while doing this study are race, class and gender. According to Merriam and Caffarella (1991) these themes are highly interrelated; it is not possible to talk about racism, classism, sexism and other “isms” without reference to power and oppression. Feminist pedagogy focuses on the experiences and in particular the oppression, of women in the context of education. Feminist pedagogy frameworks relate well to my discussion on gender, power (class) and culture (race), to look at the position of women in the study and how these aspects of their lives intersect to affect their reception and implementation of HIV education. Examining transformational learning theories, Merriam, Caffarella & Baumgartner (2007) discuss both Mezirow and Freire adult education approaches that impact on women’s position. While Mezirow psychocritical education theory approach is more focused on an individual’s transformation (in this case a person living with HIV), Freire’s social-emancipatory

theory is based on the belief that education was for conscientisation (raising awareness about people's situations of oppression) and should result to collective action to change the world (HIV education focused on changing oppressive cultural behaviors). The literature presented earlier on gender power and culture highlights boldly how HIV impacts on women and our communities and how the three intersect to contribute to the spread of HIV. Feminist pedagogy link well with both Freire and Mezirow educational theory, for HIV impacts on an individual and also on the community.

Mezirow's transformation theory forms a framework for how adults interpret their life experiences, and how they make meaning. In fact he defines learning as a meaning making activity: "[L]earning is understood as the process of using a prior interpretation to construe a new or revised interpretation of the meaning of one's experience in order to guide future action"(1996, p.162).

Freire (1972) insists that a final outcome of transformative learning must be the instigation of change within the socio-cultural reality via how a person is able to influence change within his environment. Freirean concepts are important in adult education because the transformative process itself is paramount in leading one toward behavioral change and social action. Furthermore, Freire believed that all transformational learning ultimately results in action, the principle he termed "praxis," and that without this external reflection (action) of internal paradigm shifts (beliefs), the process is neither complete nor effective.

Mezirow (2000) acknowledges context as a major contributor to transformative learning, however, he paints the picture of context in broad strokes rather than giving specific details in his own research. A valuable contribution to the literature on transformative learning theory is found in a three-part longitudinal study of HIV-positive adults (Courtenay, Merriam and Reeves, 1998; Courtenay, *et al*, 2000; Baumgartner, 2002) which explores meaning-making and perspective transformation in a group of HIV-positive adults over a four-year period. The study participants had joined groups that fought for causes such as money for HIV and AIDS drugs, acting on their new perspective of needing to be of service *to* others; their collective actions helped others in the local HIV and AIDS community (John & Rule, 2008, p.83).

Baumgartner's (2002) study confirmed that the continued meaning making added value to transformational learning. While transformational learning experiences never changed in the study participants, the meaning scheme changed continuously, which resulted in action which is part of the process. She also points out that educators should never take for granted the role played by group activities in fostering the transformational learning.

By doing semi-structured interviews and focused group discussions with people living with HIV, hopefully they will be able to learn from their past and possibly attempt to identify ways of implementing the knowledge they have acquired in HIV and AIDS education. According to Mezirow, the transformational process is most often triggered by a disoriented dilemma (in this case HIV infection, gender, cultural or power situation). The study will investigate how these issues impact on HIV education and how the study participants make meaning of the knowledge acquired at different stages of learning about HIV.

As stated earlier, HIV is highly transmitted through sexual contact. The sociologist Bourdieu's notion of 'habitus' allows us to see people's attachment to nation as learned and habituated; it helps us understand the sexual habitus produced in South Africa (Rule, 2007, p.82-83). While looking at the issues of power, gender and culture, I will review how the sexual habitus in South Africa impacts on how men and women implement the knowledge they have of HIV and AIDS. The issues of gender, power and culture intersect to contribute to the South African sexual habitus. The embedded traditional gender and cultural roles and expectations in our society place men and women in certain positions (consciously and unconsciously). Children grow up in these settings, learning and accepting their ways of being. They embrace certain ways unconsciously; these ways automatically placing the men in powerful position and the women in submissive roles.

A common example relates to the situation where a Zulu man is having multiple sexual relationships and the women in the relationship accept their positions as the other woman in the man's relationship. The 'complex competitive' relationship with the other woman places one in a very vulnerable position. Such complexities push the women to go out of their way to please the man, neglecting the knowledge they

possesses about HIV, compromising on safer sex, accepting other forms of abuse, and in the process denying to recognize the high risk relationship she is in.

In sum, a patriarchal society such as South Africa produces a certain kind of sexual habitus, comprising both of conscious and unconscious dispositions, which generate the following practices and representations; unprotected sex; multiple sexual relationships; taboos around talking openly about sex; power imbalances between men and women in making decisions around when, how and with whom to have sex. In its more pathological forms, patriarchies also contribute to a habitus in which the practices of rape and the belief that unprotected sex with virgins will cure AIDS become possible. All these conditions contribute to the AIDS epidemic (Rule, 2007, p.83).

The theory of **Reasoned-Action** is a psychological theory which states that an individual's performance of a given behavior is primarily determined by a person's intention to perform that behavior using all available information whether internal or external (knowledge). This intention is determined by two different factors: first the person's attitude towards the specific behavior and second, the influence of the person's social environment or subjective norm - this includes what others think the person should do, as well as the person's motivation to comply with the opinion of others (Denison, 1996).

Link ABC approach and reasoned action, and discuss its limitations, need to place in context, link to intersectionality, habitus.

Healthy living and risk taking behavior can be explored using this theory (Tsevere, 2000). It also takes into account various factors that play a role in shaping behavior. Even though HIV and AIDS is a medical problem, it is transmitted through specific risk behaviors which are influenced by psychological, as well as socio-cultural forces in the social environment the person lives in.

ABC approach is based in the Reasoned-Action theory, considering the literature on the gender, power and culture intersectionality review and the South African sexual habitus; this theory has limitations in regards to HIV prevention education. "*ABC approach*" teaches us about specific behaviours that need to be applied in our lifestyles, so as to stop the spread of HIV, yet it does not put into consideration the psycho-social and economic dilemmas the people with HIV live through daily in their home, community, hospitals, relationships etc, that might affect the receptivity of the knowledge acquired.

This study attempts to understand why, in the case of HIV education (transmission and prevention), individuals infected with HIV fail to use knowledge acquired to prevent transmission of HIV to the next person - why does the knowledge they have not produce expected behavior change – ABC approach, which aims to produce change in behavior? In this study I will closely look at the factors that might influence or contribute to the research participants' risky behaviors, including the context and dynamics in which the person lives in, thus highlighting gaps that contribute to poor receptivity.

## **2.7 Towards a Conceptual Framework**

The figure below consists of a circle and two triangles. The figure summarizes the context in which HIV and AIDS education is disseminated and applied, the different concept used to approach the study and how this concepts link up or rather compliment each other to make sense of the HIV and AIDS education receptivity and dynamics in which it happens.

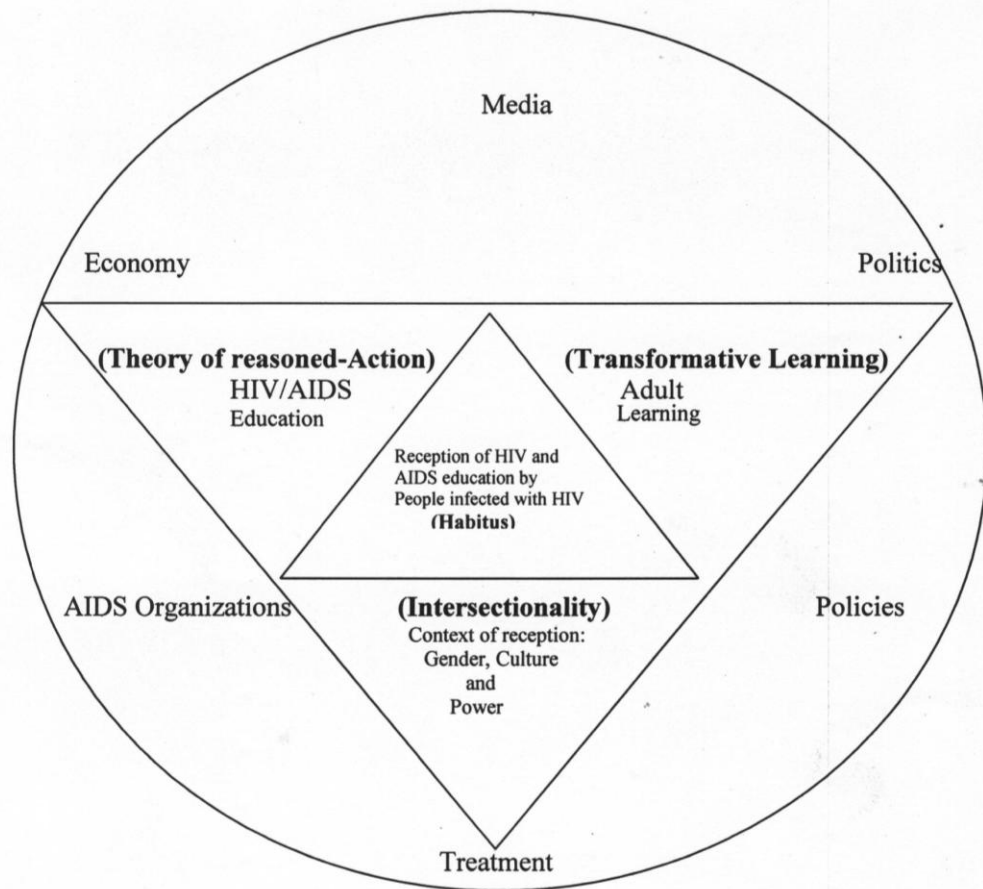


Figure 2: Conceptual framework for study

The figure focuses on the HIV positive person and the overall factors and environment in which the person receives HIV and AIDS education. The smaller triangle in the centre of the figure presents the person living with HIV. The bigger outer triangle presents HIV and AIDS education, adult learning and the different socio-economic context (gender, power, culture and poverty). The circle presents the big outer factors that impact on the individual's life and learning process at different levels – directly and indirectly. The figure summarizes the framework in which the study is positioned. The framework is used later to present the data findings and analysis. It assists in understanding the contexts in which persons living with HIV and AIDS receive and implement HIV and AIDS education. Furthermore, it assists in identifying the impact of each aspect of the framework on the learning process.

## CHAPTER THREE - RESEARCH DESIGN AND METHODOLOGY

### 3.1 Introduction

Having examined the relevant literature to explore the current knowledge and to form a theoretical framework for the study in the previous chapter, this chapter outlines the research design and methodology. The rationale for selecting a qualitative methodology is discussed. This is followed by the selected research design, and then a focus on the selection of site as well as the sampling of the study participants. The use of participant in-depth interviews, focus group discussions and my journal as the main data collection instruments is explained.

Finally, the methods of data analysis are described with particular reference to validity and ethical issues. At this stage, the limitations encountered during the study are presented. At the end of the chapter, a summary of the study methodology is presented and a conclusion drawn.

### 3.2 Research Methodology

As stated in **Chapter One**, I used a feminist approach to do this study; I positioned myself as one of the primary data sources, as a woman living with HIV in a support group. Feminist research acknowledges that my personal opinion and point of reference will influence the study; most importantly this approach emphasises giving voice to underprivileged groups (Ulin *et al*, 2002 & Letherby, 2003, p.6). Both women and persons living with HIV are underprivileged in our society.

This is a qualitative research study, drawing on both interpretive and critical paradigms. According to Miles & Huberman (1984, p.15), qualitative research captures in depth what people's lives, experiences and interactions means to them in their own terms and in their natural settings. Within the interpretive paradigm, the study attempted to investigate the perceptions of HIV positive people on HIV and AIDS education in uMgungundlovu through interviews and focus group discussions. It also investigated how they perceived the relationship between HIV and AIDS education, gender, culture and power. According to Cohen *et al* (2007, p.21), an

interpretive paradigm is characterized by concern for an individual, it endeavors to understand the subjective world of human experience, it aims to retain integrity of the phenomena being investigated and its main focus is on study participants.

Within the critical paradigm, the study attempted to identify how issues of gender power and culture impact on the implementation of the HIV and AIDS knowledge acquired by people living with HIV. By talking about their experiences regarding these matters, the people were able to reflect on their lives and sexual behaviors in relation to their own power positions, gender, culture, and HIV, and perhaps decide to change some things in their social context. Cohen (2007), states that within the critical paradigm reflexivity is high and the focus and process are political at heart, concerning issues of power, domination, voice and empowerment. It aims to move participants towards emancipation and freedom. The people being studied are located in contexts of power and interest, and the contexts need to be exposed, their legitimacy interrogated and the value base of the research exposed (Cohen, 2007, p.186).

### **3.3 Selection of Site**

The research site for this study was a support group for people infected with HIV in Pietermaritzburg - uMgungundlovu. The support group in the study is known as Springs of Hope Support Group Project (SOH). At the time of the study, SOH offices were located in the city centre at Tembaletu Educational Community Centre. From these offices SOH served people infected and affected with HIV from all the communities around uMgungundlovu, including the suburbs, locations, semi-urban and rural areas. Tembaletu facilities provide a neutral support environment, as it is home to the offices of many community-based organizations. This allows people to come in and out without drawing any attention.

I chose this particular support group for the following reasons: first, I am a founder and a member of this group, so I was familiar with the people; second, being the group leader at the time of the study helped me to establish a very close trusting relationship with most of the members of the group, this was mainly due to very open relationship I had established with the members – showing the members my



vulnerabilities which they too identified with. This also allowed for transparency from the participants during the interviews and focus group discussions; and the third reason was linked to the fact that all of the support group's activities and programs included HIV and AIDS education for the people infected, and society as a whole. The first two reasons gave me an advantage, since being an insider (HIV positive and member of the group) I had been able to establish trust between the support group members and myself long before the study.

The main disadvantage of doing the research in a group in which I knew the people was more linked to the ethical and confidentiality factors. My role as a friend, leader, counselor and group member had already exposed me to deeper knowledge about most of the issues the participants were facing, yet when I stepped in to my role as a researcher, the participants withheld some vital information that I knew that would bring value to the study, yet, I could not compromise on the well established trust. The tensions between roles: on the one hand, researcher; on the other hand, leader, facilitator, confidante, left me frustrated at times. Yet I felt honoured as well to get the data I got.

Other challenges that could have resulted from my engaging in a research in an organization I founded and worked in, was the issue of staying impartial, but I went into the study with a determination to bring forward the voices of the people living with HIV without being biased. While I have positioned myself as a feminist and use my experiences as part of the primary source of data, I involve both men and women to ensure balanced voices. At times I was too close to the issues raised by some participants and the issues raised a lot of emotions in me. I chose to acknowledge those feelings, sometimes with participants, if it helped them positively, yet at times I chose to acknowledge them internally, 'park' them and deal with them in my personal space. Acknowledging these emotions and examining how they affected me as Anne, allowed me to be aware of them as a researcher. The support of my supervisor also helped a lot in keeping me focused on what the study was all about (i.e. HIV education, perception of PWAs and factors that affect the reception and implementation of the knowledge acquired).

### 3.4 Sample

By the time I started the study, Springs of Hope had about 200 members of which 95% were female and 5% were male. These numbers have grown greatly but the proportions of female to male still remains within the same range. The attendees are mostly blacks, with three Indians and three coloured. Of the black membership, there are also foreigners from other African countries, but this group forms a very small part of the group. The majority of the members of the group come from a low economic class. Although I use racial categories here, I do not understand race as an essentialist biological category, but rather as a fluid socio-cultural construct which participants themselves use and which points to some important commonalities of contextualized socio-cultural experiences (Erasmus, 2008).

I first approached the support group members at one of our support group meetings and presented the fact that I was doing this study and I was looking for people to participate in the interviews and focused group discussions. I explained to them the aims of the study and how the study could contribute to the voices of HIV positive people in the future development of HIV and AIDS education. I made an open invitation to group members, encouraging different racial groups to participate in the study. It was also important to explain to the members why at this stage the study had to involve a small number of people (10 -12). All the study participants volunteered.

The study drew six semi-structured interviews and one focus group discussion from this wider group. In addition, I kept a journal. The interviewees in the study consisted of three men and three women. The three men were from different racial groups – black, Indian and coloured. The women were all blacks. Their socio-economic backgrounds varied from one person to the other. All had some form of secondary education. The profiles of the interviewees below are maintained as per the time of the semi-structured interviews in the period of 2005.

### **3.4.1 The Semi-Structured Interview Participants**

Six persons living with HIV who are members of Springs of Hope volunteered to participate in the study. The study sample consisted of three women and three men from different socio-economic backgrounds.

**Interviewee 1:** Female, in her early 20s, Zulu speaker, single parent, working and still lives with her parents in a one of the black townships in Edendale valley. She is open about her HIV status.

**Interviewee 2:** Female, 40 years old, half South African (mother), half Zambian (father), married to a coloured man. She was self-employed, but due to her poor health she was in the process of selling the business. She is mother of three daughters and is a grandmother. She lives with family in a flat in town. She is not yet public about her status, only a few people, mostly family members and very close friends, know about her status.

**Interviewee 3:** Female, 48 years old, a Zambian working as a nurse in one of the local hospitals in Pietermaritzburg. She is widowed with four children and one grandchild. She lives in a flat in the city centre. She is not yet public about her status, only family and very close friends are aware.

**Interviewee 4:** Male in his late 20, Zulu speaker, single. He works in one of the big supermarkets in town. He lives alone on his own property in a local location. He is also a co-founder of Springs of Hope. He lives openly with HIV.

**Interviewee 5:** Coloured man in his 40s, married with children. Presently he is not working due to retrenchment from work. He lives in Woodlands, which is a predominantly coloured community. He is not yet open about his status. He is very comfortable about his status, yet he felt at the time that he had to protect his family from the stigma and discrimination in their community. Also his children are not aware of the situation. His wife is HIV negative.

**Interviewee 6:** Indian young man in his early 20s, single and still lives with his parents, currently working with a car spare parts shop in town. Lives in Northdale, which is predominantly an Indian community. He is not yet publicly open about his status, but his immediate family knows about him.

### **3.4.2 Focus Group Discussion Participants**

The focus group discussion participants consisted of five females ranging between the ages of 26 to 42 years and three men between the ages of 28 to 36 years. The common factor amongst all the participants was that they were all HIV positive; also they were from the black race group and members of SOH. Three of these participants had also participated in the interviews.

Of the eight participants, five were already on ARVs. Their educational level varied (grade 5 – grade 12), and most of them had temporary employment with low paying salaries. They came from different communities in Pietermaritzburg. Under my guidance they discussed key topics that were related to the research topic.

### **3.5 Data Collection Methods**

To collect the data I used: i) semi-structured interviews (see Appendix C) , ii) focus group discussions with the people infected with HIV (see Appendix E) and, iii) my personal reflections. The reason why the study used the three methods was to ensure that a range of data related to the topic was collected, that the data were not biased particularly considering that my personal experiences contribute to this study, and it also helped to confirm the data collected through the use of any one method.

The initial plan for the data collection was to first do the focus group discussion then the interviews, but due to individuals' time constraints, the data for the study was first collected through the in-depth semi-structured interviews then through the focused group discussions. I kept a journal of my reflections of my experiences on the same topics; my focus was on my life, my work and what I observe in the community.

### 3.5.1 Semi-Structured Interviews

According to Borg (1963, p. 222-223), three types of interviews are used in research methodologies (structured interviews, semi or unstructured interviews). He recommends that people who are doing educational research should use the semi-structured interviews as they allow for the gathering of valuable data and also provide a desirable combination of objectivity and depth. Thus one of the tools used in this study to collect data was the semi-structured interview, though it took the form of unstructured interview when the researcher did the actual interview. According to Borg (1963, p.223), this approach does not employ a detailed interview guide, nonetheless, it has a plan and usually asks questions or makes comments intended to lead the respondent toward providing data to meet the interviewer's objectives.

The first reason why this study used the semi-structured interview with this group was to get to understand their perceptions on issue of gender, power, culture and the implementation of HIV and AIDS education in their lives. How do these issues apply or affect each other? The use of open-ended questions permitted the participants to reflect and explore their responses. Second, while I had some form of structure, the semi-structured interview allowed me to probe and clarify the interview participants' responses as we carried on with the interviews. The interview questions were intended to serve as a guide to ensure that we stayed within the scope of the study. Third, it allowed flexibility for me and the other study participants, giving us the freedom to move beyond the questions scheduled - we were not restricted to the issue I had initially asked them about. Whenever something relevant came up, I was able to follow up on it. Mouly (1978, p.203) says that the greatest strength of the unstructured interviews is its undoubted flexibility; not only does it allow the investigator to get more adequate answers, but, more importantly it enables one to follow through on what might be very significant ideas.

HIV and AIDS discussions tend to raise and touch personal sensitive issues in a person's life and in the society, especially issues around one's sexual behavior and intimate relationships. For a person to disclose these personal matters there is the need to develop a trusting relationship between the interviewer and the interviewee. Being a person living with HIV and having worked in the field for a while helped me to

establish a rapport with the interviewees. The trust, support and understanding that we had between us helped to contribute to collecting rich quality data. Mouly (1978, p. 204-205) states that the interviewer must be a person who knows the subject to be discussed, should reflect integrity, objectivity, tact and and have the ability to make the interviewees feel at ease. The success of an interview greatly depends on the rapport established; the establishment of great rapport allows the respondent to divulge confidential and in some cases, semi-illegal matters. In addition, interviewees are less suspicious and more willing to discuss their perceptions. A tape recorder was used to record the interviews, which were later transcribed.

### **3.5.2 Focus Group Discussions**

Another tool that was used in the study to collect data was the focus group discussions (FGD), which lasted around three hours. According to Gibbs (1997, p.1), the aim of using focus group discussion is to find out about people's experience and thoughts about a specific topic. They are suitable for obtaining several perspectives regarding the same topics. According to Bloor *et al* (2001, p.90) and Race *et al* (1994) focus group discussions are useful for a number of reason: i) they are a means for democratic participation in research, ii) they allow genuine representation of the group's view point which can be used to challenge experts and, iii) they can be a starting point for transformative collective action, because during the discussions, the group can develop an awareness of a common problem and attempt as a group to address the problem. Bloom *et al* (2001, pp.89-98) further states that focus group discussions have a less important role as a standalone method in research. It should be used with other methods for triangulation. Thus I used the focus group discussion, the semi-structured interviews and my personal reflections.

The FGD participants firstly filled up a "participants' basic information form" (Appendix D) which was intended provided me with the necessary background information on the participants and allow them time to precess as individuals. All generated data during the FGD was recorded on a flip chart as the discussions went on, and was compiled thereafter and compared to the data collected in the interviews.

### **3.5.3 Personal Reflection**

I kept a journal of personal reflections on my own experiences and encounters on issues related to gender, power, and HIV and AIDS education. I used observation techniques and personal experience to collect data. According to Marshall and Rossman (1991), observation entails the systematic description of events, behaviors and artifacts in a social setting chosen for study. Observation can range from highly structured, detailed notions of behavior, to more diffuse, ambiguous descriptions of events and behavior. Throughout the study I stayed alert to ensure that I was able to observe non-verbal events and behavior.

On a personal level, I allowed myself to walk backwards through memory lane, to remember as far back in my life as I could, though the main focus of my reflections was on my HIV knowledge, issues of gender, culture and power. I further gave more attention to my adult life, marriage and line of work, for it is in this period of my life that I have been most exposed to these issues. At times I struggled to reflect on some areas of my experiences due to the emotional pain linked to the experiences. I documented my memories when I felt inspired to; at times this inspiration would be as result of a talk with close friends and family, sometimes due to observing a similar situation in the community. At times I put myself in the position of my interviewees and reflected on the questions on the interview schedule. Throughout the process I tried to stay as objective and open minded as possible.

### **3.6 Data Analysis Methods**

There are different ways in which data can be analyzed. Strauss & Cobin (1990, p.63) state that data analysis means taking a part in, an observation, a sentence or paragraph, and giving each discrete incident, idea or a name, something that stands for or represents a phenomenon.

In this study, data was analyzed by looking out for common themes and factors that are related to HIV and AIDS education, with an emphasis on gender, culture and power. I looked for repetitions of information and language variations that were used to describe a situation by interviewees and participants in the focus group discussions.

Being a qualitative study, the data was thoroughly analyzed to allow for multiple interpretations towards a collective perception.

Cohen (2007, p.461) states that in qualitative research, data analysis involves making sense of the data in terms of the participants' definitions of their own situation. After transcribing the data, I went through each script to identify themes occurring in relation to the study questions. The use of research questions as a guide to identifying relevant data for analysis helped to reduce data and also keep me focused. I coded key themes throughout the data for easy use. I used colour and initials to code (e.g. gender – G, Power – P, Culture – C). There were other themes that I identified, which were useful, yet not necessarily relevant for the study. After coding, I grouped similar data together in relation to the study question. This process allowed me to identify cross-cutting factors. Cohen (2007, p.468) points out that it is important for a researcher to decide whether the data analysis is driven by the issues or the participants. There is also a need to practice great caution while analyzing data, for the researcher is the driver of the study. Therefore it is important to use methods that will ensure study validity, trustworthiness, and ensure no bias.

### **3.7 Ensuring Quality and Trustworthiness of the Study**

The fact that I was one of the primary data sources meant that I had to exercise extra caution to ensure that I stayed impartial and did not let my experiences crowd my data collection, analysis and presentation process. Therefore I used different methods to cross-check the data (personal reflection, semi-structure in-depth interviews and focus group discussion). I also interviewed both men and women to ensure a balance of views. While I stayed aware of my personal issues, I managed to stay impartial in my analysis by ensuring that I discussed every process with my supervisor. This ensured that I would be continuously re-focused and balanced.

### **3.8 Ethical and Validity Issues**

Since HIV and AIDS is a very sensitive issue which requires confidentiality in most cases, participant in the study were assured that their names would be kept confidential unless they gave permission for their names to be used. The sensitive



nature of the information clearly refers to the shame and fear-provoking nature of the information shared by participants. Thus, participants' confidentiality was assured.

Many people are reluctant to disclose their HIV positive status, therefore informed consent from the respondents was requested prior to the interview. This was done verbally on tape and each participant had to sign a consent form (Appendix B). Prior to interviews and the FGD, the participants were fully informed about the scope and intent of the research. The interviewees were expected to sign a consent form that permitted me to collect and use the information I received from them. Informed consent is the cornerstone of ethical research (Miller, 2008, p.48). The principle of informed consent protects and respects the right of self-determination and places some of the responsibility on the participant should anything go wrong in the research (Diener and Crandall, 1978).

With an exception of one interviewee, the rest of the interviewees were comfortable to use their names in the study. After lengthy consideration with my supervisor, we agreed that I should use pseudonyms as we do not know what changes might happen in the future. At the end of the interviews and the FGD, each participant was offered a reimbursement of R50.00 to cover their transport expenses.

### **3.9 The Limitations of the Study**

During the study I experienced the following limitations;

While I received a bursary to support my studies at the university, I worked as a volunteer at the time the study; therefore I had limited funds to carry out the actual research. This forced me to narrow down the scope of the study and I had to focus on one support group in Pietermaritzburg.

Also I had to work with a small group of the support group members, thus the results of the study can only be interpreted in relation to this specific group. In order to strengthen or verify the findings of this particular study, there is still a need for further investigation on these matters, and with a larger group of people infected with HIV from a variety of support groups.

### **3.10 Challenges**

Due to limited funding I could not buy quality equipment, thus it was very challenging to capture data effectively. I had to repeat two interviews because the quality of the tapes and the recorder was poor and the recorded material was not audible.

The nature of HIV as a disease and AIDS as a condition, coupled with the fact that discussions of issues of sex are personal and intimate, meant that a limited number of people were willing to participate in the study. Such a study brings people's sexual behaviors under scrutiny. The confidentiality and the silence that already surround the disease and sexual matters also contributed to the participants not fully participating.

While knowing research participants personally was supposed to be an advantage for me to get data effectively, I struggled with the knowing that some of participants' responses were different from what I already knew about them. This made me realize that while they were comfortable to share their issues with me in the support group, they were not ready to share them with the rest of the world.

One of the participants was very ill at the time of the in-depth interview. This particular interview went on over three days, as she wore out very quickly due to a very low CD4 cell count (10). Luckily she was staying with me at the time of the interview while waiting to start her ARV treatment.

Time constraints were also a challenging factor for both the participants and me. Most of the participants were working and we had to schedule the interviews at very odd times, for which I was very appreciative. Due to individuals' time constraints, it was very hard to schedule the focus group discussion meeting; therefore I had to do the interviews before the FGD as originally planned.

My own health also was a challenge from time to time. First it was due to AIDS – my immune system collapsed and opportunistic infection took hold. Second, when I started to take ARVs I experienced severe side effects and I had to change drugs four times within a period of 18 months. Also the loss of both my parents and many

friends had a severe impact on my health which resulted in depression. This forced me to suspend my studies twice. I struggled to maintain a balance between the studies, my family and a full-time job. Also during the past few years I changed jobs several times.

### 3.11 Methodology Summary Table

Key Research Question	Sources of Data	Instruments and Methods	Data	Analysis
<p>What factors influence HIV and AIDS education in uMgungundlovu?</p> <p><b>Sub Questions</b></p> <p>How did the persons living with HIV learn about the disease?</p> <p>How did they respond to the knowledge acquired?</p> <p>What factors influenced their responses to knowledge acquired?</p>	<ul style="list-style-type: none"> <li>• People infected with HIV.</li> <li>• Myself.</li> <li>• Other Literature &amp; Other Scholarship</li> <li>• The Internet.</li> </ul>	<ul style="list-style-type: none"> <li>• Focus Group Discussions.</li> <li>• Semi-structured Interviews.</li> <li>• Participants information form in FGD</li> <li>• Recording of interviews.</li> <li>• Writing down data during FGDs</li> <li>• Journal</li> <li>• Literature Review</li> </ul>	<ul style="list-style-type: none"> <li>• Information from people infected with HIV.</li> <li>• Personal reflections.</li> </ul>	<p>Data will be analyzed by looking out for common themes and factors that are related to HIV and AIDS education.</p>

#### Primary Data Sources

The primary sources of the data were people infected with HIV from Springs of Hope support group and myself.

## **Secondary Data Sources**

Secondary sources of data included literature review, other scholarship and the Internet searches.

### **3.12 Conclusion**

Methods used for data collection seemed to be appropriate for this study.

Triangulation through use of different tools and sources ensured the validity of the data. The next chapter presents the findings of the research results, from which the later chapters draw their analysis and final recommendations.

## CHAPTER FOUR - RESEARCH FINDINGS

### 4.1 Introduction

This study investigated HIV and AIDS education in uMgungundlovu. It specifically focused on the perspectives of HIV positive people in an identified support group.

This study aimed to establish:

- How people living with HIV acquire knowledge about the disease.
- How they responded to the knowledge acquired.
- The factors affect the implementation of the knowledge acquired in the daily lives of persons living with HIV?

The key question was: What factors influence the reception of HIV and AIDS education among people living with HIV in uMgungundlovu?

The sub-questions related to the main research question are:

- a) How did the persons living with HIV learn about the disease?
- b) How did they respond to the knowledge acquired?
- c) What factors influenced their responses to knowledge acquired?

In this chapter, I first present my study findings in relation to these questions above. Second, I focus the presentation on the “*ABC approach*” and support systems. The discussion will link these matters to the intersection of gender, power and culture and examine how these impacts on the reception and implementation of HIV and AIDS education.

I will present an interpretation of how gender, power and culture issues intersect to impact on the implementation of the “*ABC approach*” in the lives of the study participants. I will also review the necessary support systems required by the study participants and explore ways in which the intersection of gender, power and culture impacts on the support systems which are necessary for the implementation of the “*ABC Approach*”.

As I stated earlier in chapter two, these issues (gender, power and culture) are very closely intertwined; they feed and drive each other to impact negatively on the successful implementation of HIV and AIDS education. Therefore I will present the data to embrace these co-relations.

## **4.2 Research Findings**

In this section I will present data findings according to the participants' responses to research questions. One of the aims of the study was to establish how people living with HIV acquire knowledge about the disease. The findings are as shown below.

### **4.2.1 How did the Person Acquire Knowledge about HIV and AIDS**

The data indicate that the people got their knowledge about HIV at different stages. These include:

- The first time a person heard about HIV
- Knowledge acquired between that first time and before testing for HIV
- Circumstantial knowledge that triggered the step to have test
- Knowledge from testing
- Knowledge after testing

#### **The First Time the Person Heard about HIV**

The data shows that there are various sources from which the research participants learnt about HIV; for example I first heard about AIDS at home. Others in the study heard from workplaces, schools or through the media.

My interest in HIV did not only start when I was tested HIV positive, but much before when I heard of the disease in 1981 at the age of ten.  
(Own journal)

I first heard about HIV as far back as 1984. In the hospital that I was working in, back in Zambia. 1984 85 it was coming a lot on media and we were working among the people infected with HIV.  
(Interviewee 3)

Early 92... When I was still at school but then I did not understand fully about HIV or AIDS. No one around where I lived had ever been infected. A group of actors came to our school with a play on AIDS  
(Interviewee, 4)

The initial information that people heard about AIDS was very frightening, stereotypic, discriminative and not necessarily accurate.

It was more like a rumour... among the children and it was very hush, hush! It can kill you... it can kill you, so there is not cure. And I remember it was something about homosexuals...yeah that it was a homosexual disease and ahm...  
(Interviewee 6)

HIV was first highlighted... it was treated like... something you don't talk about... and ah... also ehm... you didn't want to be associated with people that had it, coz of the stigma that HIV was ah... yeah...one was discarded by their community. (Interviewee 4)

Initially it was very frightening, people were scared to touch, eat or live with a person living with HIV. HIV was treated as a highly contagious disease but as years passed I started to have better knowledge. (Interviewee 3)

It is clear from the data above that HIV and AIDS were associated with death, thus causing a lot of fear in the people. On the other hand, it was associated with certain groups of people (homosexuals, prostitutes, promiscuous, sinners), which gave most of us false assurance because we did not belong to those groups. This misconception left us vulnerable to becoming infected with the disease.

### **Knowledge before Testing**

It is clear from the data that most of us did not have sufficient HIV education before testing.

Not a lot, but I didn't know exactly what AIDS was. It was the stigma of saying "death"...I just saw AIDS as a disease, which killed people. I didn't really understand what AIDS was.  
(Interviewee 2)

I was not equipped with the full knowledge of other realities of life that left me vulnerable to the disease ten years later (own journal)

As the data below illustrates, one of the interviewees stated that she had sufficient knowledge.

**A.N: Before testing, do you think that you had enough knowledge about HIV and AIDS?**

Interviewee 3: Yes and that is why I had to have the test, in fact even before I had the test I had it in my sub-conscious that I had it coz my husband had already started getting sick.

**Circumstantial knowledge that triggered the step to have HIV test**

To determine whether the knowledge acquired initially played a part in our step to go for the HIV test, the last quotation above and also the data below shows the circumstantial knowledge that triggered the step to take the HIV test.

I just wanted to know what was happening in my life for the future so that if I happen to get married, also partly I was experimenting... Curiosity on how oral quick test works.

(Interviewee 4)

This data indicates that the interviewee had some knowledge about HIV and its implications in his future life and that of others. Other than the obvious reasons that the interviewee stated for going for HIV test in this data, the step he took to go for the test can also be viewed as a step to acquire more knowledge in his life (health). It also indicated self-reflection with regard to his past risk behavior which could have had implications to his health and his future.

The reason to why I decided to go for HIV test was that I developed shingles on the left side of my abdomen. At this point I did not understand what was happening to me, but when the doctor started asking about my sexual behavior and relationships, I started to get concerned. He wanted to know how long I knew my late husband and his past relationships. I actually got angry and asked the doctor what he was trying to imply. Instead he asked what I thought he was implying... *"I told him that it is seems like you are implying that I have AIDS."* He told me that shingles are a common HIV symptom, yet it could be caused other medical issues. I was later advised to go home and discuss the issue of testing with my husband so that we can both go for HIV test.

(Own journal).

While the circumstantial triggers for testing, in my case, were medically related and the test was recommended by the doctor, it is clear that had it not been for the shingles on my body or rather going to the doctor, I had no reason to consider going for an HIV test. Note my concern as I listened to the doctor. It is clear that I did not consider



myself a possible HIV patient and the anger was more linked to my ignorance – “how dare the doctor to imply such a thing? I am a good girl”. I had to read between the lines to interpret what the doctors questions were implying. The knowledge I had at that point did not give me any reason to go for a test, yet what I had learnt forced me to read between the lines of the doctor’s questions.

**A.N.: Why did you decide to have an HIV test?**

**Interviewee 6:** I was... I noticed that there was something that was wrong with me...

**A.N.: When you say that you noticed that there was something wrong with you... what are some of the symptoms you were experiencing?**

**Interviewee 6:** The symptoms I was noticing on myself...other virus...so I went for check up.

**A.N.: You went for check up...**

**Interviewee 6:** Uhm...

**A.N.: So is it you or the doctor who suggested the HIV test?**

**Interviewee 6:** I decide... I decided (more firmly, nodding)

(Interviewee 6, 2005)

In the case of interview 6, the trigger was also medical, yet from the data, his responses indicated that the medical symptoms and the level of knowledge he had motivated him toward taking the step to go for HIV testing. The decision to have the test was his.

Yeah...I had a fair amount of knowledge but then you must remember that I didn't like...how can I say it...I didn't go willingly for an HIV test, nor to satisfy my personal curiosity, but it was a necessity from my insurance broker. It is not like I educated myself before going for the test...the knowledge I had was more from the media.

No I was not counseled, what actually happened I wanted to upgrade my policy so I went for the blood test and eh...I was wondering why my broker was not getting back to me or the insurance company writing to me telling me that my application for upgrading is being rejected. So somewhere along the line I started to think that I did speak to the broker and asked him to cancel and that was in February. It was just by chance that in May that I saw my GP and he was under the impression that I knew and when he spoke to me he realized that, that was the first time I was hearing that I am HIV positive. There was like three months between testing and knowing that I was positive...

(Interviewee 5)

Unlike interviewee 6, the case of interviewee 5 was mandatory, which involved a service provider and an insurance policy. The interviewee had no choice in the matter; he was required to take the test as a condition for his policy to be upgraded.

It is clear that different circumstances and levels of knowledge led to participants taking the test.

### **Knowledge from Testing**

In chapter two, the literature review on counselling accentuates the importance of pre-test, post-test and ongoing counselling. Counselling provides quality learning opportunities that help one to plan and make decisions about their lives and others within their lives.

Yes, some of the counselors are very informed. And I was lucky to get a counselor who was well informed and elderly and she was like a mother to me and the session was more comfortable. She gave me most of the basics I needed to face the future. (Interviewee 4)

A well-informed counselor will equip one with information which will give them confidence to face HIV. The environment in which the counselling happens has an effect on the reception of the knowledge transferred.

One of the things that trouble me is the young counselors that are not mature and at times they are not well informed. For example when I went for a post-test counselling, the counselor learnt a lot from me instead of being there to support me, something needs to be done to ensure that the counselors are well equipped. (Interviewee 4)

Unfortunately for interviewee 4, he had a different counselor for post test counselling.

One of the things that trouble me is the young counselors that are not mature and, at times they are not well informed. For example when I went for a post-test counseling, the counselor learnt a lot from me instead of being there to support me. (Interviewee 4)

A poorly resourced counselor cannot effectively support a patient, thus there is a high probability that a patient will not deal well with the HIV positive results. A new (second) counselor also could pose a threat to the process as the client has to relate their issues again, whereas a relationship of trust could have already been established with the first counselor.

It was only later that year, when I had my second test that I was counseled and heard also for the very first time a person saying “*it is okay*” that I decided to inform my family back in Kenya. I started to learn more about the disease.  
(Own journal)

There was definitely a great difference in my life emotionally, between my first test and second and this was because of the counselling factor. It was during this process that learning took place and I made decision. Unfortunately, similar to my situation, a number of other interviewees were not offered counselling at testing.

I was not counseled and in fact the doctor who did the test just told that “you know my dear we all are HIV+, had you gone for insurance?” I said yes, and he told me that I am HIV+ and must go to king Edward Hospital where they have a clinic and I can receive counselling. That is the way it was told to me so casually. But I thank God... I went and shared with my prayer partner the one I was praying with.  
(Interviewee 3)

No... I never got counseled because, through all the reading...you know when my GP told me about it the first time he looked at my whole facial expression and he asked me if I already knew, and he wondered if I needed counseling, I told him I did not need counseling. I spoke to my pastor and he said that maybe I am being a bit too hard on myself, but what are they going to tell me that I don't already know...  
(Interviewee 5)

Luckily for these interviewees, unlike me they had someone to talk to. In the case of interviewee 5, he opted out of being counseled. He seemed to be clear about what he required.

While counselors are on the frontline to educate the people about HIV and AIDS, there were some concerns raised from the study participant regarding their qualifications and knowledge. This was particularly in relation to the quality and authenticity of the HIV and AIDS information transferred to the patient (learners).

### **Knowledge after Testing**

The data shows that we all grew in our knowledge of HIV at testing and afterward. Some of the research participants learnt more about HIV during the pre-and post-test counselling as is evident in the data above. Others obtained new knowledge from the

hospitals, clinics and other institutions (workshops) as they sought treatment or other forms of support.

Being HIV positive, it requires that you continuously get new knowledge. One can't afford to stay without learning continuously. The information that I have been getting is updated. I can't compare it with the original information I had.  
(Interviewee 4)

Others learnt more about HIV management at the support group, either at the meetings or during ongoing counselling.

I would say coming to the meetings has made a difference, it starts to reassure you, if you want to know more you guys have been able to answer some of the questions that I have asked (*laughs*) meeting some of you who have been living with HIV for long helps.

He told me that with proper treatment I could live to +-15 years with HIV. And at the support group I learnt that I could have children. This had been an issue that had caused me a lot of distress.  
(Interviewee 6)

But as I always say to the support group members, that once you are tested it is as if you are born again. This means you have to be informed. HIV becomes an enemy, for me reading, talking; sharing with other people in the community has improved my knowledge in dealing and living with HIV  
(Interviewee 4)

The learning in support groups happened through listening to others and sharing stories. As data below shows, others learnt from their peers and friends who are also HIV positive, outside of the meeting.

The knowledge that I have been getting is from mainly my friend Anne, because she has been there... as soon as I found out that is the first person that I tried to phone. She is very calm, she tells me when what is what...I have been getting a lot of knowledge from her. She has been there for me  
(Interviewee 2 - talking about me to the tape recorder as if I was not there)

Generally, there is an indication among respondents of the need for more knowledge. Most of us have taken the initiative to find more information through other sources such as the media (reading, watching TV etc).

I read a lot of magazines, if I see “HIV” I read, I just have to go through it coz I know that this is a disease that everyday there are new change and we just have to read it to manage it. There are many ingredients put together to make someone survive. The diet, health, many things... and you hear of the stories of other people who have come out, how someone has survived this disease and you feel encouraged (Interviewee 3).

The knowledge acquired is broad, beyond just self-care as demonstrated by the data below; the person also acquires knowledge in other areas so as to support others who are HIV positive.

In the support group we get guest speakers, e.g. TAC, in Christian Listeners course I have been trained as a listener, also recently I got trained as a home based carer; we were taught how to care for people who are sick.  
(Interviewee 4)

As the knowledge grows, the people start to become more aware and even challenge the quality of educational resources available.

We were given a certificate, which was great, but the tutors were not well informed to be transferring knowledge. In fact from time-time we had to challenge their explanation. This has becoming a common thing that people run course without proper qualification thus transferring wrong information to learners. (Interviewee 4)

However, it is sad that some people had to learn about the deadly disease from reality - being forced to learn more, either by losing a relative to HIV or learning that family a member is HIV positive.

It only struck home in December 2003 when my brother died, that is when it woke me up, coz AIDS was right there at my door step.  
(Interviewee, 6)

Yes and that is why I had to have the test, in fact even before I had the test I had it in my sub-conscious that I had it coz my husband had already started getting sick (Interviewee 3)

One of the interviewees said that in her line of work she had to learn about HIV.

Even before testing I had gone for some counselling courses at home and I would do counselling at work... (Interviewee 3)

Generally it is clear that all participants have changed - from being observers to patients and thus learners with the will to stay alive. The impact of learning about their own HIV positive status has forced them to learn more about the disease in order to stay alive.

#### **4.2.2 Response to the Knowledge Acquired**

With regard to how the participants responded to the knowledge they have acquired about HIV and AIDS, I will again present this in separate categories:

- Initial response to knowledge acquired
- Response at testing
- Response beyond testing

It is very clear from the data that there have been different responses to the knowledge acquired about HIV in these categories.

#### **Initial Response to Knowledge**

Initially the information received about HIV and AIDS was frightening; it instilled fear of the disease in people. This also caused fear of those infected;

Initially it was very frightening, people were scared to touch, eat or live with a person living with HIV. HIV was treated as a highly contagious disease but as years passed I started to have better knowledge.  
(Interviewee 3)

On the other hand, the information tended to create a false sense of safety for some of us;

I was well behaved, not sexually active or promiscuous, for AIDS was a disease for the homosexuals, prostitutes and the promiscuous people – sinners; but my education was merely limited to the facts of the transmission of the disease.  
(Own journal)

No, I did not have very much information about AIDS. I remember when growing up my (Zulus) people used to say that one gets infected only when one ejaculates inside a woman. There were a lot of myths and most cases

though we had information in the community we chose to take the information that favoured a certain gender and I chose to believe that as a man I was safe as long as I do not ejaculate in a woman.

(Interview 4)

Also there was denial that HIV could happen to us or people close to us. HIV was a disease far from us;

Actually my late husband presented with all the symptoms related to HIV and maybe it is because I was too close to see or I was too ignorant to imagine that HIV could happen to me or to someone so close to me. Like many people I have seen today, you live in denial of what you actually can see, but choose to ignore it.

(Own journal)

Definitely people when they look they say oh, it could never happen to me. Like me, I never thought that I could be HIV +. “oh! Me? I can never have HIV...?” but I was wrong...

(Interviewee 2)

### **Response at Testing**

With the overwhelmingly negative presentation of AIDS, most of us experienced different forms of fear. The fear experienced was not only of the disease, but also the fear of rejection and death;

Maybe...maybe subconsciously I am...but yeah...there is an article I read that says, we prepare ourselves so much for the afterlife but yet we are so scared of dying

Disclosure has been a big problem. We have fear of being rejected and in the end we die not being taken care of properly

(Interviewee 5)

Because of its mode of transmission and the disdain for the groups that were initially found with the disease, it caused stigma towards self and those infected;

In 1992 at the age of 21, four months after I gave birth to my son, I was tested as ‘HIV positive’, the same month I moved to South Africa with my family to face HIV and death in isolation, afraid of stigma and rejection from my family and friends, I chose not to tell anyone.

(Own journal)

I looked at those people like eh... I always stigmatized them and said look at that one there... now I'm in the same boat, in a way it's like God has put me in that position so that I should be able to appreciate life more often  
(Interviewee 2)

Sadly, accompanying the entire above negative attitudes and reactions, there was also blame which hindered some from seeking further support. This interviewee talks about accessing ARVs;

So when it comes to that point in time when... the health authorities will say go ahead, I am not sure I want to... because the thing is ... I know what I have done... so why do I want to prolong my life for? (Smiles as he says this)  
(Interviewee 5)

I had the basic knowledge about HIV, yet I lacked in life-skills which would have made a difference to me. In many ways I blamed myself for the rape, yet I know better today.  
(Own journal)

When I came to discover that he (late husband) was getting sick, there is one question I kept on asking myself... Why? Because we were very knowledgeable, HIV came when we knew exactly, and above all before we got infected, we had many people who were dying who did not know about the disease, but why should we die while we knew... you see?

He comes home, he is yours... condoms are like... lets just do it without... you make that one mistake, and yet you never knew, that we getting in deeper and deeper... (Interviewee 3)

### **Response to knowledge Beyond Testing**

Beyond the fear of death, rejection and stigma, it is clear that we all took a step forward - to apply our knowledge about being HIV positive, and to search for more knowledge to survive.

In my struggles I learnt. I learnt about safer sex, HIV re-infection and introduced condoms in our relationship.  
(Own journal)

The participants further revealed that their knowledge had widened after finding out that they were HIV positive, and as they learnt more, they came to understand the disease better.



I have read “Soul City” books and I have found them very informative, very very educative, like thing you didn’t know of it teaches you, things like you don’t get HIV on the caps etc. all this things they do not exist but before I believed in them, I thought t HIV could be passed on in these ways.  
(Interviewee 2)

HIV becomes an enemy, for me reading, talking; sharing with other people in the community has improved my knowledge in dealing and living with HIV.  
(Interviewee 4)

Strength to insist on safer-sex and stand my ground, basically I started to fight for my rights without even knowing that I have rights.  
(Own journal)

The data also shows that having the knowledge does not always guarantee safety, for sometimes there are factors that are beyond our control;

Well condoms will be a second way of prevention, but it doesn’t guarantee that you are 100% safe... as I have shared with you, I always used condoms and I got infected  
(Interviewee 6)

Exactly it was one thing that I had always thought about, but we had been having a strong relationship and I trusted him (late husband) and when I asked him he would say he was not having extra marital sex... it was a trust issue.  
(Interviewee 3)

In my struggles I learnt. I learnt about safer sex, HIV re-infection and introduced condoms in our relationship. This was a difficult process accompanied with rape attacks from my husband.  
(Own journal)

Without the right support system and cooperation from ones partner, it is very difficult to implement the knowledge received. The data shows that all the research participants had sufficient knowledge about HIV as a disease, knowledge about caring for themselves to manage HIV and to support others.

While the study did not focus on race as a primary category, I found that I needed to refer to ‘race’ in discussing findings. I acknowledged that ‘race’ in a South African context was a construct of apartheid, but use the terms ‘black’, ‘coloured’ and ‘Indian’, for want of better terms, to refer to the social and cultural backgrounds that inform participants’ reponses to HIV and AIDS education. I noted from the data collected from the men that their level of knowledge and application of knowledge

varied from one participant to another depending on the cultural (racial) background of the participants and also the length of time that they had known their HIV positive status. For example where the coloured and Zulu participants raised issues of not using condoms, the Indian participant informed of the fact that, condoms are commonly used in the Indian community to prevent pregnancy.

Most of the black race group participants had more knowledge about HIV as compared to the coloured and the Indian, yet the level of knowledge implementation in this particular group was not necessarily consistent due to cultural pressure and expectations. The higher level of knowledge could be due to the fact that this is a group that is most affected, thus more education, attention and effort have been directed to their communities, as well as accessible areas of service. On the other hand, the Indian and coloured men highlighted a deeper level of silence and stigma related to HIV in their communities. This could be a limiting factor for accessing information about HIV.

#### **4.2.3 Factors that Influence our Responses**

From the data, a number of factors emerge as influences on the people living with HIV in terms of their knowledge reception and implementation. It is important to capture these factors before moving on to the gender, power and culture intersectionality. The data above show that the context in which the learning happened and the content of the information had a great impact on the receptivity of the knowledge sourced. On the other hand, the context in which the person is meant to apply the knowledge might also have great impact on the willingness to implement knowledge. Another evident aspect has to do with the person learning - what are the reasons behind the particular person learning (the need, drive)? Are they will participants? The dynamics within the individual will determine the receptivity. Therefore it is important to take note or give attention to;

- The learning environment
- The learner's background and immediate living environment where the knowledge should be implemented
- The large environment that has impact on the knowledge implementation

- The source of knowledge, who is conveying the message (doctor, counselor, fellow person living with HIV)
- How the knowledge is being passed to the people (methods, language, educators attitudes to the topic, rapport)

Throughout the education process, it is important to consider and be aware of the receiver of knowledge at the different levels. While some of these factors come up in the above discussions in responses to the sub-questions one and two. The next section will give more focus on intersectionality of gender, power and culture, establishing from the study data how it impacts on the HIV education – particularly “*ABC Approches*” which are mostly directed to sexually active adults.

#### **4.2.3.1 Intersectionality: Gender, Power and Culture and “*ABC approach*”**

Earlier in chapter two, the literature review established that;

- HIV is mainly transmitted through sexual contact with an infected person, and most of the campaigns have focused on the ABC (abstinence, be faithful and condoms) approach.
- Gender, power and culture are inextricably intertwined and extremely difficult to discuss separately while addressing the reception of HIV and AIDS education. Each plays a major role in driving the spread of HIV. They feed into each other to make the situation worse in South Africa, undermining all the education efforts to curb the disease, and contributing to failure in changing risky behaviours.

In this section I will focus my discussion on the ABC approach and how, according to the study participants’ gender, power and culture, these factors impact on the ABC approaches in their lives. I will also discuss the role of effective support systems in the implementation of this approach. Through the use of mini-narratives and other necessary data, I show how gender, culture and power contribute to risky behavior.

Except for one participant who was not sure how she was infected, all the other participants in this study stated that they were infected with HIV through sexual contact, though not all were sure from whom or when it happened.

### **“Abstain”**

While education about abstinence has mainly focused on the youth with the hope of delaying their first sexual encounter, some these study participants - despite having been infected with HIV during the time they were sexually active - made decisions to abstain from sex at some point in their lives, due to a number of reasons. Some of these reasons included the following:

The fear of being re-infected, or transmitting the virus to others;

This is the way I got infected so I am afraid of being re-infected. I have been down with AIDS and my partner neglected me, so I am so afraid of being sick again. I am also afraid of infecting another person. Maybe one day I will meet a person who will be understanding and supportive. At the moment I am not ready.

(Male – FGD participant, 2007)

The strong need to live or survive has given some women strength to abstain sexually in their relationship. The following statement illustrates this best;

Because when I look at it my life is more important. I have got only one life, not nine lives like a cat, so I have got to protect it. I have to protect my life...if my husband doesn't want to sleep with me using a condom, then I would rather abstain.

(Interviewee 2)

I was tired of being infected with STI, the humiliation of going to doctors week after week with new infections; I knew that I had to protect myself... I still wanted to see our child grow. I gave my husband the freedom he so craved (the extra-marital relationships). At that point I opted to abstain from sex, if he was not going to use a condom.

(Own journal)

Most of the participants stated that it is difficult to abstain from sexual intercourse once one has started.

It is not very easy, being Christian single man. It is easy to learn about these things but the reality is not easy especially if one has been exposed to sexual activities. It requires practice, determination and strategies on how to control oneself, but it is not easy.

(Interviewee 4)

### **“Be Faithful”**

Faithfulness or rather unfaithfulness and safer sex by use of condoms was discussed a great deal by most participants, as most of them were in a sexual relationship. Thus this section of analysis and interpretation will focus on unfaithfulness, safer sex and support systems.

Central to HIV prevention education, staying faithful to one faithful partner whose HIV status you know will reduce the risks getting infected with HIV. Yet it seems that unfaithfulness in relationships and marriages is a significant problem.

(Long silence) the only lesson that I have learnt is that I should have stayed faith full in my marriage, coz when I did speak to somebody, I said “what is wrong with us men that we can never be satisfied with one woman

(Interviewee 5)

My late husband having returned from exile picked up with life where he had left. His life was filled with women, and I had absolutely no knowledge about safer sex so in the process I got infected with all sorts of STI.

(Own journal)

According to most of the study participants, in the greater number of cases it is primarily the men who tend to be unfaithful, getting involved in multiple sexual relationships and disregarding the knowledge they have about HIV. This factor was raised by participants from all races who participated in the study, as well as by both male and female participants.

Women tend to be faithful while a man might have five women. A woman does not see where the boyfriend is gone or doing and when he comes back to her, he comes “as clean as a dove”, the woman does not suspect anything. For women there is much risk.

(Interviewee 4)

As I said, I feel sad for other women, coz it seems like there are some people who are ignorant about this thing HIV and AIDS, my boyfriend has got two children, two children while he knows that he is HIV positive...

(Interviewee 1)

One female interviewee said that women can also be unfaithful, yet men have a greater tendency to be unfaithful. In the focus group discussion, more than half of the women confessed to being unfaithful to their partners at some point.

No I think it is both ways, they can be faithful, but by the end of the day, men are the ones who go out and you are left and at the end of the day they can do whatever they want to do and they come and say that I was just with my friends. They lie a lot, very few men...I am sure... don't lie.

(Interviewee 2)

All the male participants in the study (Indian, coloured and black), confessed to either being unfaithful to their partners at a certain stage of their relationships, or having had multiple relationship at the same time, as it is acceptable in their culture.

In my case I only took chances once, but most of the time I was faithful. I think after that I grew up and more focused to my ex-girlfriend, I was very faithful, so it is possible.

(Interviewee 6)

I have said it before and I will say it now, that since I have been positive... (looking down) I have actually still slept with somebody else outside my marriage, and I had unprotected sex... (Long silence)

(Interviewee 5)

While unfaithfulness and multiple sexual relationships seem to be common and acceptable amongst the men, some men expressed regret for their behavior. As one interviewee stated, "*I should have stayed faithful in my marriage.*"

The reasons cited by the study participants for unfaithfulness to their partners or for being in multiple sexual relationships included the following;

The cultural and societal expectation on men that 'prescribe' that a man is seen to be a man by the number of women he is involved with, puts men under pressure to prove their manhood and protect their image as men.

No it is not easy, in the society I live in, I find that there is pressure on the young guys, it like you have to be a playboy or something like that...they are forced to be like that, they are careless...  
(Interviewee 6)

These cultural expectations combined with misconceptions about HIV and AIDS is one of the main causes of the high spread of HIV.

No, I did not have very much information about AIDS. I remember when growing up my people (Zulu) used to say that one gets infected only when one ejaculates inside a woman. There were a lot of myths and most cases though we had information in the community we chose to take the information that favoured a certain gender and I chose to believe that as a man I was safe as long as I do not ejaculate in a woman.  
(Interviewee 4)

Attached to these cultural expectations and demands are homophobic complexities and peer pressure that drive men to prove their manhood to other men (his peers). If a man does not behave in a certain way - in this case engage in sexual relationships or worse multiple sexual relationships - his peers look down upon him, subjecting him to insults and ridicule. These coerce or pressure him to engage in sexual relationships in order to prove his manhood

Coming from the African (Zulu) background a man is seen by the number of women/ girlfriends, having a lot of relationship. Men boast to their friends about the number of women they are in relationship with. This creates a lot pressure around abstaining and being faithful. It does not sound great to say to other men that you do not have a girl friend. One is viewed as if something is wrong with them, the questions that might be asked include questions like; - are you gay? This creates a certain level of pressure from peers to indulge in to multiple relationships. It is not very easy.  
(Interviewee 4)

A man who stays faithful to his partner is generally perceived to be weak, useless and loses self-respect amongst his peers. Peer pressure plays a great role in influencing

male sexual behavior and attitudes towards relationships, causing most men to disregard the knowledge they have about HIV and AIDS.

The general immorality that is taking place all around - in the community, within families and in the media, which seem to be well accepted in our societies - adds to the pressure.

When we see what is happening around us, so how can you be faithful. And TV is not helping because on the TV '*soaps*' the women and men are jumping into bed with different partners everyday...

(Interviewee 5)

While aiming to seek respect amongst his peers, a man engages in high-risk behavior that put both him and his partner(s) at risk of getting infected with HIV and other STIs. All it takes is one man having multiple unprotected sexual relationships; where one woman is HIV positive, the other women are at risk of getting infected.

There seems to be double standard in cultural tolerance regarding the issue of unfaithfulness and sexual behavior. The male interviewees also acknowledged the double standards at work regarding multiple partners, which place women at a high risk of HIV infection. Women were expected to be faithful, whereas men could be unfaithful.

I think I am correct in generalizing that men often seem to be like animals and if women do this, it is not accepted. So why should something not be good for our women if it is good for us?

(Interviewee 5)

This double standard for behavior makes it hard for men to be a positive influence on their children. In fact it makes it hard for them to discipline their children in some cases. The comment from one of the interviewees below sums this up very well.

Because...how do you tell someone don't do something when you are doing the same thing...and there was a good clip that I read that said, "My father never spoke to me about life, he lived life..."

(Interviewee 5)



One of the female interviewees placed the blame of double standards on our parents. She gave a typical example of when a girl child falls pregnant; she is subjected to negative treatment and attitude from the parents. However, when a son gets someone else's daughter pregnant, there seems to be a sense of joy for the coming grand-child.

Me as a woman experiencing those things, it has given me another picture, it is right for a boy or a man to make another person's daughter pregnant, but it is wrong for me to get pregnant".

With anger, she further says,

If it is wrong it is wrong, not just for me but for both of us. Because both of us are not married... to him they will say wow! (Claps as sign of cheering) thank you!

(Interviewee 1)

The family backgrounds, broken family structure and functions play a great role in how one grows up, learns, regard others, and behaves as an adult. These factors were raised by one of the study participants. They may indirectly play a part in the high risk behavior that contributes to the spread of HIV in Pietermaritzburg.

**A.N.: Let's look at the culture you were brought up in...what does it mean to be a man?**

**Interviewee 5:** Well in our house hold as I told you before we were twelve of us and not fathered by the same man and...in my personal childhood there was no father...because the person that I believe was my father, died in 1964...and I was around five years old then. The only males in the house when I was growing years were my elder brothers, I had two brother older and two younger than me...so...so we were brought up with a majority of women folk around us and...there was no negatives in that and it is not like the women folk tried to make us like them. But maybe we did lack a bit of input on extra guidance from a male, though when I look back now I ask myself "would it have made a difference if we had a father in our house hold..."

**A.N.: Do you think it would?**

**Interviewee 5:** Because with my upbringing I think I missed something, so I can see if I had a father maybe it would have really made a difference, you know...ah...in all that happened ...there would have been somebody that maybe would listen to me, that ... because I had a very bad temper and my brother as big as he were, he was too scared to reprimand me because I would turn on him...so probably ...in that respect maybe a father would have controlled me...just to deal with my anger...but the way we were brought up I

think we turned out okay, whatever would have been done by a father was done by the women folks

**A.N.: Do you think that something could be done differently to reduce the increase of infections in Pietermaritzburg?**

**Interviewee 5:** (Long silence) I don't think so really...because...(long silence again)...it would have been much simple if there was a way in which us men would be brains washed (laughter from both) and reprogrammed (laughter again)...so that we have a totally different attitude, because it is all about attitude and also...there is nothing new that can be done, what needs to happens is to continuity because ah...getting back to the family life, because that is where everything has broken. So if we can get back to the family... the whole family going to the park...doing things together. It still happens today that when we have functions at home, you see all women in the lounge and the men are either in the other room or outside drinking. It is no combined socializing and I think that is a breakdown...we...the society has to pull itself together. We need to get back that sense of family. I don't believe totally that in a house hold a woman must have her friends and a man must have his friends, I believe that all times the woman's friends must be the family friends and vice visa. Things like when women go out and have women's night out, I don't know how good it is...I think that is where trouble starts as well, because this is an opportunity to do what you want to do when your spouse isn't present.

**(Interviewee 5, 2005)**

It was also found out that broken family structures and function, lack of positive role models and one's background are factors that that contribute to certain behavior (unfaithfulness in relationships, abstinence). One of the interviewees stated that *"...it is hard for us to be faithful, because ah...if we look back, a lot of our families...ah...the children don't come from the same parents...so automatically what has that taught you?..."* (Interviewee 5, 2005)

### **"Condomise"**

Despite of the evidence and the knowledge the study participants have that consistent use of condoms reduces the transmission of HIV and STIs, most men and women in the study reported still not using condoms consistently. A number of reasons are presented in the data below. The following is a discussion about condoms use in one female respondent's marriage;

**A.N: But now, I am speaking about you in your life...**

**Interviewee 3:** Me...?

**A.N: In your life, if I look at your partner...**

**Interviewee 3:** me... if I had used a condom with my husband in 1995/6 I would not be infected. My husband traveled as a businessman in 1994 and each time I asked him, he wasn't frank to tell me if he was having extra-marital sex and also after I had come here in 1996, if I had used a condom when I went home I would not have been infected, but we continued to have unprotected sex coz there was still that trust that my husband is keeping himself for me as I am keeping myself for him. When I came to discover that he was getting sick, this is one question I kept on asking myself... Why? Because we were very knowledgeable, HIV came when we knew exactly, and above all before we got infected, we had many people who were dying who did not know about the disease, but why should we die while we knew...you see?

**A.N:** Ahm... **just to bring up a question... had you brought up the incentive to use the condom in 1994 or wherever do you think that as a woman in marriage do you think it would have been easy for you as a married woman?**

**Interviewee 3:** Yeah...my husband. For us, my husband and me we used to be very good and most of the time we would use the condoms. Only when it came to these issues... but most of the time we would use condoms, had we been consistent because I never liked to have family planning that's why in 1996 I had my tubes tied. So...come back to me again?

**A.N:** **Do you think it would have been easy for you to bring in the issues of condoms in your relationship, on the ground that you don't know where he has been?**

**Interviewee 3:** exactly it was one thing that I had always thought about, but we had been having a strong relationship and I trusted him and when I asked him he would say he was not having extra marital sex... it was a trust issue.

**(Interviewee, 2005)**

The interviewee above raises a number of issues which are representative of the views of the other women in the study regarding condom use in marriage or steady relationships. These issues touch on gender and power issues, particularly the position of a woman to a man in a relationship.

In this case she raises the issue of trust as "power" in a stable relationship, in this case marriage, where a woman simply trusts her partner. Even when she suspects he is unfaithful, his word is good enough - a woman demanding the use of condoms would indicate she does not trust her partner. On the other hand, it could be taken as a sign of that she is being unfaithful. Therefore to prove ones love and trust, condoms are removed from the relationship.

In this particular study, trust in a relationship seems to be one of the strongest factors that contributed to women not insisting that their partners use condoms. According to

a number of the interviewees and FGD participants, the introduction of condoms in a relationship raises the issue of trust in the relationship, especially if it is the woman who is introducing it. One of the female interviewees stated that;

And when we come up with the issue of condoms as a woman you are implying that you don't trust your man. That is how most men think, that if a lady comes up with the issue of condom, it means she does not trust you.  
(Interviewee 2)

Interviewee 3 raised the issue of inconsistent use of condoms in relationships and how this resulted in her becoming infected with HIV. She trusted her husband, and the role of condoms in their relationship was for contraceptive purposes only. The issue of condoms as contraceptives was also raised by the Indian male interviewee. He said, "*Condoms are used a lot coz pregnancy in the Indian community is not acceptable, it is a very serious issue...*" (Interviewee 6); this statement implies that where a couple is sure that there is no risk of pregnancy, they would engage in unsafe sex.

While in this particular case the interviewee states she had no challenges negotiating safer sex, the statement below shows how much the cultural practices we grow up in contribute to our vulnerability to HIV infection;

**A.N: So it was not the issue I see over and over again the women not being able to negotiate the use of condoms issue.**

**Interviewee 3:** no! This was a trust issue... and even if, even if you have sense you know, you know this is your husband, you know... you know Anne... you say this is your husband, he come home, you want to have him all, as I have been telling you he worked all over. He comes home, he is yours... condoms are like...let's just do it without...you make that one mistake, and yet you never knew, that we getting in deeper and deeper...

**A.N: Umm... umm... (Long silence from both, emotions are heavy)**

**A.N: Well here we are and we are fine... I know how it is, I am sorry to make you walk ten years back... anyway let's move on. Let's look forward.**

(Intewrviewee 3, 2005)

She had the knowledge or rather her suspicions, yet this is her husband. She repeats this to stress this relationship, seeking my acknowledgement in what this relationship means; no barriers, openness, wholeness... in other words no condoms.

Also the data shows that closely linked to trust are insecurities and denial which sometimes cause women to not insist on the use condoms in their relationship. While many women are aware of their husbands' or partners' unfaithfulness, most still give them the benefit of doubt, compromising on the one thing that could have prevented them from getting infected with HIV.

The data also points to migratory labour, travelling partners and any other form of separation that can result in unfaithfulness and vulnerability. When the partners come back together, condom use is not discussed.

Nooo...(shaking her head) nooo! And that is painful. This a terrible situation that we are living in today, maybe a husband is living in Jo'burg or Durban and as a wife you see him only once a month, and maybe he comes at the end of the month to see you the wife, what is he doing there the rest of the month? It is very scarily ...

Other participants raised the issue of women lacking the power of condom negotiation in relationships. One of the female interviewees said that generally most women in this study faced challenges to get their partners to use condoms. One of the interviewees' stated that the culture of '*lobola*' (dowry) takes away the power to negotiate safer sex from women.

Another thing is that if a guy marries you, there is that thing they buy... no they pay... that they call it '*lobola*', that should not mean that now he paid for me so I should abide to everything he says, for example when he does not want to sleep with a condom, he is going to say... he is going to say... "Oh I paid for you..."  
(Interviewee 1)

The second issue is the spread of HIV, a Zulu man has a certain degree of power over the woman and if a man does not want to use a condom the woman has no say. I am aware of the women's rights, but these are things that are not practiced in our communities. These are stuff we view on TV. Our culture has a great influence on the spread of HIV. The '*lobola*' issue gives Zulu men power over the women where men view '*lobola*' as tool of power over the women.  
(Interviewee 4)

These statements from both interviewees imply that '*Lobola*' seems to give men in different African cultures power over their wives or fiancées. Unlike the old days

where dowry was paid in the form of animals and gifts, in contemporary contexts it is paid in the form of money, which puts strain on a man and his family.

Money has become a powerful tool of control, even in condom negotiation in marriage and relationships. One of the male interviewee states;

**A.N.: Do you think financial power in a woman hands make a difference in her vulnerability in the infection of HIV?**

Interviewee 4: Yes, for example if my girlfriend is not working she would be depending on me for provision, what I say would go because I am controlling and providing her needs. She has little say in our relationship because she has got no money. But as the world is changing we see a shift of this power, we see more and more women gaining financial power and this women are in a better position than those who are not working.

**A.N.: Why do you think that number of people getting infected with HIV in KwaZulu-Natal is on an increase?**

Interviewee 4: This is very sad. There are a number of reasons. Unemployment is resulting to relationships where women are getting hooked in relationship, unfaithfulness in relationships and condoms are expensive and when people are unemployed they cannot afford to buy condoms. The government condoms are not of the best quality (the smell, the thickness etc) result to people not liking to use them. In most cases women who introduce condoms, might bring the government ones; which are freely available. Because of the facts I have mentioned the partners might refuse to use the condom. Overall people do not simply like to use condoms. These has promoted the spread of HIV...there is ignorance about HIV.  
(Interviewee 4, 200)

The discussion above raises number of issues relating to power and gender.

According to the interviewee, money has given men more power over women, and on the other hand poverty and unemployment has stripped women of their power to negotiate safer sex. It has placed many women in a vulnerable position.

The interviewee also raises the issue of condom quality, stating that good quality condoms cost. The free government condoms are perceived to be of poor quality, and people do not like to use them.

He also raises an interesting fact that women who introduce condoms might bring home the government condoms which are perceived smelly and of poor quality, and the partners might refuse to use them.

In my journal I raised the issues around the challenges women and men face in condom use, drawing on my own experiences and what I have heard from clients in my line of work.

While the governments continuously promote condom use, they have not looked at the challenges that women and men face while using condoms. Some of the challenges I personally experienced included;

- An unwilling partner
- Allergy from the lubricant
- Condoms not being able to prevent all STI's

In my line of work with HIV positive people I have come across a lot of people who do not use condoms, than those who use them. Some it is due to lack of proper knowledge of using condom, particularly the female condoms, while others despite of the knowledge they have, they make joint decisions with their partner not to use condoms.

(Own journal)

The issue of allergy to the lubricants on condoms varies with different people; this is an issue that has been raised by many women and some men within the support group.

A number of interviewees raise issues of male attitudes towards condoms as a cause of men's reluctance or refusal to use them. A male interviewee refers to a condom as a hindrance. He says,

Look as I said, a condom is a hindrance because...uhm... it can spoil the whole occasion, I find that every time I have to put on a condom I lose interest, but have to and we should ...use condom, especially if you are HIV positive and also if you are not in a permanent relationship because...if we have to stop the spread of HIV we can't live without it.

(Interviewee 5)

Another interviewee shares what she has heard said by some men in the community when they talk about condoms;

When you talk of condoms you will hear them say "*I cannot eat a banana with its peels, or can't eat a sweet in its paper*".

Interview 1: Some men say "*the same way I came I will go...*"

**A.N: What do they mean by this?**

Interview 1: They mean that they came through sex; one cannot conceive a child while practicing safer sex. They are trying to say that my parents

conceived me through unprotected sex and I will die practicing unprotected sex.

(Interviewee 1)

Lack of knowledge about the role of condoms in HIV prevention was also cited as a reason for not using the condoms, before infection. However, these people changed to using condoms after becoming informed.

It is interesting that it was after several months of practicing unsafe sex that I got information about HIV re-infection. That every time I get in contact with HIV the circle of infection occurs again. It suddenly started to make sense to me why my husband and I were continuously sick, more so he had extra marital sexual relationships which made it even worse.

(Own journal)

Some of the female interviewees mention the fact that they only started using condoms after they started to suspect that something was wrong, either with them or their partners.

Despite convincing data from several studies collated in a Cochran review, indicating that consistent condom use reduces HIV incidence by at least 80%, within the context of the varying levels of effectiveness described in different studies (Karim, Q: 2005), it is clear from this study that most men and women who participated in the study are not using condoms consistently due to different factors linked to gender, power and culture.

#### **4.2.3.2 Support Systems**

While the “ABC approach” should be effective theoretically, the realities in which the research participants live sometimes make it difficult for them to implement this approach. One of the male participants stated that, “*It requires practice, determination and strategies on how to control self, but it is not easy.*”

The practice, strategies and control requires support from family, partners, peers and community. Most of the participants have disclosed their HIV positive status to their families, friends and health practitioners where they access medical care.



HIV impacts on us emotionally, spiritually and physically (Namwamba-Ntombela, 2008, p.14). Most of the struggle is emotional, which if not dealt with manifests physically leaving us vulnerable to disease. Therefore there are different psycho-social and economic forms of support we require. The interview extract below captures most of these needs.

**A.N.: Are they supporting you in any way?**

**Interviewee 6:** Yes, financial support. My sisters chip in to buy my ARVs as I told you I am not working at the moment.

**A.N.: How did they react to your disclosure?**

**Interviewee 6:** Normal... just normal and I should say that, that is the way I like it. I don't want to be treated differently.

**A.N.: Okay...and in the community?**

**Interviewee 6:** Nobody... nobody knows. There is still so much silence in the Indian community and nobody just tells.

**A.N.: I would like to open your eyes to another community that you have outside the Indian community- Springs of Hope, us a group, you have been here once?**

**Interviewee 6:** Once or twice...

**A.N.: Do you feel it has been useful coming to the meetings?**

**Interviewee 6:** I would say coming to the meetings has made a difference, it starts to reassure you, if you want to know more you guys have been able to answer some of the questions that I have asked (laughs) meeting some of you who have been living with HIV for long helps.

**A.N.: Is there any form of support you feel that you lack?**

**Interviewee 6:** Oh yeah! I do lack in some ways... (Laughs) I have already spoken to you about it (looks a bit embarrassed about the issue).

(Before the interview, Interviewee 6 had shared with me that his girlfriend left him after disclosing his HIV status to her. He is at the moment experiencing a lot of loneliness and wishes to be in a relationship. He is definitely going through a tough time presently.)

**A.N.: Can we just talk about this for a moment... coz this is an area where many people are silent about.**

**Interviewee 6:** It was very hectic...

**A.N.: And you are finding it a bit hard to cope a lone?**

**Interviewee 6:** Yeah you know it is good to have someone there... your parents and your family, there is a limit to how far they can support or you can talk to them, they can only do so much, but there is a line... a limit to...

(Interviewee 6)

The data above presents some of the needs that most of us in the study stated we required. This includes financial support, medication, knowledge, counselling and most importantly, a person to lean on. The data also shows that different people play different roles of support in our life. Without this support network it is so easy for a

person to give up on life. In this case, rejection from a girlfriend resulted in the interviewee becoming suicidal. Unfortunately, the people who we may want to seek support from may be the same people who will strip the support from us.

In this study, it was primarily women who went for testing first before their partners. Unfortunately such a situation places a woman in a vulnerable position. According to the FGD, a number of women said they were afraid of introducing the use of condoms in the middle of a relationship that has been ongoing due to fear of:

- Disclosing their HIV status
  - Losing their partner once their partner knows their status
  - abuse or murder if the partner was to know their status
  - losing financial support
- (FGD female participants)

The fear in these women's lives is real. They are not able to source support from their partners, neither are they able to implement new knowledge acquired (in this case, practising safer-sex).

It is clear though from the data that the people drew a lot of support from the support group. The following data illustrates different aspects and perceptions about SOH support group.

I love my support group and I enjoy what I do to inform people about HIV and I do this not only with my mind but with my heart as well. The problem with many people that are teaching people they come with their mind only, they are not willing to know the people, if only they could teach with their heart, and put themselves in to the shoes of the people living with HIV know them, love them and understand their lives. Do not just give information to people but love them too.  
(Interviewee 4)

The interviewee talks of his role in the support group – “what I do to inform people” and also talks of his level of involvement (my mind and my heart). He further points out the advantages of educating with both intellect and emotions.

I would say coming to the meetings has made a difference, it starts to reassure one, if you want to know more you guys have been able to answer some of the

questions that I have asked (laughs) meeting some of you who have been living with HIV for long helps.

(Interviewee 6)

The interviewee positions himself as a learner in the group. Being in the group has reassured him; he has been able to ask questions from people who have lived with the disease longer than him and this has made a difference for him.

**(Interviewee 3):** It was very nice to be in the group coz you meet people whom you are in the same category; it was nice to be there, but at some stage due to the pressure at work and so on I haven't been an active member this year but I love the group. Wherever I met those guys we always hug and it is nice. (Visitors come in to bring Christmas presents so we stop for a while).

**A.N: We are talking about Springs of Hope and the kind of support you receive from there, do you find it is useful to be a member of the support group?**

**(Interviewee 3):** Indeed AIDS is a reality it is real but when we compare it with the word of God, the word of God says it nothing, but then we are seeing people dying eh!.. We sit and talk and joke about HIV, our enemy, which is taking us, that is killing us. So that is one thing I have told you today, why I have not been attending the meetings. It was conflicting with what I should believe in and in what I should do, yet I know that it is healthy to be there, because you can share in lots of things, but it has been difficult for me to put the two together. Yes.

**Interviewee 3)**

This particular interviewee appreciates the relationships and health benefits she used to draw from the support group members, yet she confessed to not attending anymore as she felt that it conflicted with her religious beliefs.

Support group members have a responsibly if one is not well to give one prayer, visiting each other at home, other support include food, clothing, blanket etc. if one does not have these things ,the support will vary. For me I have received moral support because I am still okay. When we meet we share our stories and experiences, this could be a good or sad story and through this we are able to support each other.

(Interviewee 4)

The interview touches on a key aspect of the support group, which is the responsibility of members for each other. The support provided varies depending on an individual's need. Sharing stories and experiences facilitated the learning and support process. The interviewee below sums it up well, when he said;

I think that there is no support that I am lacking...because support is there, this things are there but it is up to you as an individual to make an effort and reach

out...so to a degree I am handling it, though sometimes I am not handling it and it is in such situation that I realize that I need a support group, I just need to step forward.  
(Interviewee 5)

Unfortunately in some case, there are factors which restrict us from stepping forward and accessing this support. One significant factor that is evident in the data is the issue of gender violence. Therefore before drawing the conclusion, it will be worth discussing this specific challenge.

#### **4.2.3.3 Gender Violence**

There four are main forms of gender violence; physical abuse, sexual abuse, psychological abuse, and economic abuse (Watts and Zimmerman, 2002, p.1233). From the data collected in the study we see how gender violence contributes to the spread of HIV and undermines receptivity to HIV and AIDS education.

Yes, because when somebody tells... like I am talking like this now, if my husband was to listen to this tape he would say "*how can you say that...?*" I need to stand up with my two feet and say who I am because by the end of the day women get scared of getting beaten, or sometimes he will say... "*I won't give you money because you talk too much*", It is like gambling...at night he might say, "let's make love..." and if you refuse, in the morning he will refuse to give you even money to buy bread...it is unfair...Yeah...to control a woman ...yes. It is very, very unfair and I get very angry...because if he does not buy bread for his children, it is like I am feeling guilty because my children will not eat because I did not sleep with him, so in the end I am forced to give in, I sleep with this man so that in the morning, he can give me money to buy bread so that the children can eat, this is unfair.

(Interviewee 2)

Most of the women mentioned that they have experienced some form of sexual abuse at some point of their lives, which then stripped them of the power to abstain, practice, negotiate or demand safer sex.

In my struggles I learnt. I learnt about safer sex, HIV re-infection and introduced condoms in our relationship. This was a difficult process accompanied with rape attacks from my husband. It was as if I was supposed to accept his promiscuous life and not protect myself too. I felt even more ashamed and broken emotional, yet one of us had to stay alive for our child.  
(Own Journal)

Because of the silence surrounding sex and sexual abuse, most the women had never discussed the matter before. Gender violence is not only perpetrated by men, in some cases it is carried out or endorsed by our own families, directly or indirectly.

(Laughs) And you mother will sit down and tell you everything that happened to her, in her time... “You see... even your father did this and this to me, and this and this...look I am here still... I am here, so go back and make it work. Just obey your husband, respect your husband...” but your husband is not doing this to you.

(Interviewee 1)

The data above is not unique; we hear it so often in the society we live in. According to the data, women have been socialized to embrace the abuse, thus sending their own daughters back to an abusive relationship.

I think one of the key solutions would be to create work for women so they do not prostitute or get controlled by their partners. Women need to be empowered to stand up for their rights.

(Interviewee 2)

While Interviewee 2 points out the issue of human rights, Interviewee 4 in the data below brings to our attention the realities in which we live in. He states that,

I am aware of the women’s rights, but these are things that are not practised in our communities. These are stuff we view on TV. Our culture has a great influence on the spread of HIV.

(Interviewee 4)

The following statement he makes indicates that it is not all bleak;

This seems to be changing slowly; if one looks around town we see a lot of young women driving lovely cars. Women are starting to gain power in sense of money. So I feel that is giving them some form of power. Even democracy is equipping.

(Interviewee 4)

The data seem to indicate that the women who have monetary power have a better chance of negotiating safer sex, and not engaging in abusive relationships. This also reduces their risks of being infected with HIV.

Linked to gender violence is substance abuse (alcohol and drugs), which according to the FGD participants and the interviewees, can interfere with the intention to practice safer sex. One of the interviewees states this;

Of course, I can say that because in a relationship I can say what helps to spread the infection... let me tell you something I have experienced in my relationship, when I am drinking and my boyfriend is drinking, there is no ways that we can use a condom and that how the spread of HIV is increasing very fast. Sometimes when drunk a guy meets a girl and he even does not know her but sleeps with her without any protection, picks the virus and passes it on to his or her steady partner at home. That is how the virus is spreading.

(Interviewee 1)

### **4.3 Conclusion**

This study aimed to answer the key question, What factors influence the reception and implementation of HIV and AIDS education among people living with HIV in uMgungundlovu? The sub-questions related to the main research question: (How did the persons living with HIV learn about the disease? How did they respond to the knowledge acquired? What factors influenced their responses to knowledge acquired?) Seeking the answers to these questions enabled me to gain insight and respond to the questions. Using the sub-question as a guide I have presented the relevant common themes that arose from data collected.

From the data collected it is clear that all the study participants at the time of the study had sufficient knowledge about HIV transmission and prevention. From the data collected in response to the first sub-question, I realized that I had to acknowledge and present the findings under five separate subtopics for the data showed that, the knowledge was obtained from different sources, at different stages and through different processes. The findings were presented under the following topics: the first time a person heard about HIV; knowledge acquired between that first time and before testing for HIV; circumstantial knowledge that triggered the step to have the test; knowledge from testing; and knowledge after testing.

In regard to their response to the knowledge they acquired, the data showed that the individual response varied and this also was captured in three stages, which included: their initial response to knowledge acquired; response at testing; and response beyond testing. Their knowledge had grown from one stage to another, as participants had

moved from being bystanders who heard about AIDS, to observers seeing it happening to someone else, to patients and participants in the responses. Most of the participants have grown to become experts in matters related to HIV management.

Regarding the response to the third sub-question, the findings clearly indicate that there are various technical adult education/ learning factors as well as varied psycho-social and economic factors that influence the reception, implementation and receptivity of the HIV and AIDS education of the study participants. The data presentation focuses on the intersection of gender, power and the culture and how these factors influence the participants' reception and receptivity to the knowledge acquired about HIV prevention, particularly the "*ABC Approach*"; a second focus is on necessary support systems and how gender violence particularly affects the support systems that are necessary for the effective implementation of the "*ABC Approach*".

Some of these factors were far beyond the participants' control. However, in other cases and for reasons stated, a person would choose to disregard the knowledge they possess. The data above shows a clear power imbalance between men and women as a result of the culture in which the participants live. These imbalances are worsened by low socio-economic status amongst the women. The data also indicated that cultural and gender inequities that promote casual sex and multi-partner sexual relationships by men, placed most women in the study at more risk of getting infected and re-infected by HIV. Unfortunately, these risk behaviours also increase the risk of reinfection among men.

The data presented in this chapter illustrate the complex learning environment in which knowledge about HIV and AIDS has been acquired by the study participants. It is clear from the data that this process has to be a continuous one, corresponding with the progression of the disease in our lives, social and political changes, and scientific developments in our understanding HIV and AIDS. Therefore the people living with HIV in this study require continuous support from different disciplines in order to be able to implement the "*ABC approach*" and the general HIV and AIDS management in their daily lives as individuals, for each participant experiences HIV uniquely and thus responds individually, yet at some point there is a need to involve "other" significant persons, such as partners, family members and medical personnel.

In the next chapter I will summarize the study findings, discussing them in relation to the relevant literature and theories; make recommendations drawn from the study; and present my final conclusion.



## CHAPTER FIVE - SUMMARY, CONCLUSION AND RECOMMENDATIONS

### 5.1 Overall Summary

The study investigated HIV and AIDS education in uMgungundlovu. It specifically focused on the perspectives of HIV positive people in an identified support group. The key research question was, What factors influence the reception of HIV and AIDS education among people living with HIV in uMgungundlovu? The sub-questions related to the main research question were: a) How did the persons living with HIV learn about the disease?; b) How did they respond to the knowledge acquired?; and, c) What factors influenced their responses to knowledge acquired? At the beginning of this study there were a number of concerns I raised in my rationale as a researcher, these included the following: a).The assumption that once people get the message they would change the risky behaviors they are engaging in; b).The general assumptions by programme developers and implementers about HIV positive communities arising from very poor meaningful involvement of HIV positive people in finding solutions about a disease that we live with everyday of our lives; C).The considerable focus on slowing/stopping the infections from happening, and scarce support to the people infected to ensure that the knowledge they have in relation to the prevention of HIV and other opportunistic infections is implemented effectively; d).The ABC (“*Abstinence*”, “*Be faithful*”, and “*Condomise*”) approach.

The study being a qualitative research with a feminist approach that drew from both interpretive and critical paradigms. I used my personal reflections, in-depth interviews (3 women and 3 men), and a focus group discussion with 8 members of SOH to collect the data. I hoped that this study would capture some of the realities that we live in, so that HIV education programme developers and implementers could start to grasp an understanding of factors that individual HIV positive persons’ experience, for these can play a positive or negative role regarding how HIV positive persons use the knowledge they acquire to improve their own health as well as their ability to protect the next person.

This chapter presents a reflection on methodology: being an HIV positive researcher, what I have learnt, summary of the findings of the research, key findings,

recommendations and implecations for HIV and AIDS strategies, future study recommendations ans the conclusions of the study.

## **5.2 A Reflection on Methodology**

I have spent time reflecting at my different roles in this study and what those roles meant to me, the community of people living with HIV, women, a primary study participant and a research. In chapter one I positioned myself myself in the study as a feminist researcher and also a study participant. As a woman and a person living with HIV, there were many times when I felt like giving up, but my personal experiences were a driving force behind every step I took in this study. I had to stay aware of all these experiences as a researcher, lest they over crowded my objectivity as a researcher. The issues reaised, the other study participants and the organization I selected to study were too close to me, causing emotional turmoils from time to time.

The silence and secrecy surrounding HIV and AIDS, makes it a very sensitive topic to research, someone had to break that silence. Being an insider in a group gave me an advantage. I could collect data from people whom I knew and they new me well. In other word trust was paramount for me to acces such rich data. Sometimes I wondor if I had done the same study with a group of people whom I did not know and who did not know me, nor trust me if I would have gotten such data.

My choice of the data collecting methods (personal reflection, in-depth intererview and FGD) and the use of both men and women helped me to collect well balanced rich data, it also allowed both male and female voice to be heard and also these brought balance to my thoughts. Having known the study participants as friends, work mates, equals as HIV positive persons, gave me an advantage as an inside, but I realized that as a research, they were very cautious of what they shared with me (or the rest of the world). Their awareness that I would use the data for my study brought caution to there openness. This particular factor frustrated me sometimes, but I did not take what they shared with for granted. My being HIV positive, my openness to them gave me an advantage as a researcher. There is a greater need for more HIV positive researchers, to be used to do research in the communities of HIV positive people, this will allow more indepth insight into this community.

Whenever I have positioned myself as a feminist, most people assume I am a man hater, and I am hoping that this study make people aware of the role of feminism in restoring power balance in our communities. Interviewing the men in the study made me aware of issues which are not spoken openly, yet leave men vulnerable to the societal pressure. I hope that I was able to capture these issues in relation to this study.

As an academic research I believe that the methods and tools I used to do the study were effective, the participants responded to the questions openly, they had the freedom to explore issues as we spoke and also I was able to probe on issues that come up, which I though were useful, yet not considered previously. One particular area that I had not initially given deep thought on was issue of effective support systems, it is an area I have worked in with passion yet never reflected on before on its role in HIV education as I have during this study.

All in all I realize that this study has brought to light some insight to issues that affect us – people living with HIV in impelementing the knowledge we acquire in HIV prevention and transmission. I hope that this study opens door to more studies and opportunities for people living with HIV to participate in studies. The choices I have to make as a woman, a researcher, a leader, activist etc to step out of my safe space to the public are not just for me, but for the other as well. I aimed at using the academic platform to force for change where it matters most, so that our voices can be heard and taken seriously.

The research process has taught me more about myself as an educator. I have learnt also to be open to differences. Generally my different roles demand different aspects of me to achieve, which applys to other persons living with HIV. I have learnt, or rather I am still learning to separate this role and still understand, that each one of them contribute to the other. I am grateful to the study participants for their willingness to share with others their experiences. For this is what gives value to the study.

The issues of gender power and culture were so entangled that at times I would get lost in them and loss track of my study. This just goes to show how magnitude the HIV issues are. Ii am grateful to my supervisor for his academic guidance. I have

grown as an academic and more improved in my researching skills. The key findings from this study clearly show that the methodology was suitable for the study, in fact with the support of my supervisor I have developed from the study some models which can help to improve the HIV and AIDS Education strategies.

### **5.3 Summary of Research Findings**

The findings of the studies were presented in accordance with common themes that were raised from each sub-question, under the sub-question. It was evident from the data that at the time of the study all the study participants had sufficient knowledge about HIV and AIDS and its management. This knowledge varied from one participant to another depending on culture/race and also the period of their knowledge about their HIV positive status. Most of the black race group participants had more knowledge compared to the other groups. While the focus of the study was not on race, this particular finding is more to do with the source or availability or accessibility of HIV and AIDS knowledge. This could be due to the fact that the group is most affected, thus more education, attention and effort has been directed to their communities and areas of service access. On the other hand, the Indian and coloured men highlighted a deeper level of silence and stigma related to HIV in their communities, which could be a limiting factor for their accessing information about HIV. It is important to note that the findings cannot be generalized due to the fact that this was a micro study involving a very small number of people. Although this was a small study, it confirms Innes' (2006) statement that even though it appears that many South Africans know about AIDS, there are still many who lack access to the right information about the disease.

#### **5.3.1 How did the Person Learn about the Disease?**

The data indicate that the study participants acquired their knowledge about HIV at different stages. These include the following: as observers, at testing, as patients, as implementers and as experts. They learned about HIV from different sources. The initial information the people heard about AIDS was very frightening, stereotypic, discriminative and not necessarily accurate. The disease was associated with certain

groups of people (homosexuals, prostitutes, promiscuous people and sinners). This confirms findings by Rule and John (2007) regarding stigma and othering.

Before testing, most of the study participants did not have sufficient knowledge about HIV and AIDS but the knowledge grew and improved at different stages. This growth was mainly related to each individual's point of need. The major learning happened after HIV testing. The findings showed that all participants' knowledge about HIV increased with the knowledge of learning they were HIV positive. The new knowledge was acquired from ongoing counselling, reading, media, support groups, workshops, clinics, hospitals and peers. The findings show the increased desire to learn about the disease in order to survive. It also shows that there was growth - from the observer who is not infected, to the patient, the survivor, and to the experts. The participants' knowledge about HIV increased in relation to their knowledge of their own HIV status. This links to what Mezirow (1991) referred to as a "disorienting dilemma". Although it was a once-off study, the participants presented different stages of growth that are linked to their HIV status. This confirms the findings of Baumgartner's (2002) study which linked transformative learning to meaning-making, meaning schemes and action.

### **5.3.2 How did the People Respond to the Knowledge Acquired?**

The findings show that the participants responded to the knowledge they acquired on HIV and AIDS differently at each stage of acquisition of knowledge. Initially the information received instilled fear of the disease in people, causing fear of those infected, hand in hand with a false sense of safety and denial that HIV can happen to us or people close to us. HIV was a disease far from us. At testing both the knowledge about being ill and the already existing knowledge about the disease caused different forms of fear. The fear experienced was not only of the disease within us, but also the fear of people knowing, rejection and death. There was also stigma towards self, those infected, and self blame; these hindered some from seeking further support. It is clear that we all took a step forward to apply the knowledge about being HIV positive, to search for more knowledge in order to survive. The participants' knowledge had widened after finding out that they were HIV positive and, as they learnt more, they came to understand the disease better.

### **5.3.3 What Factors Influenced their Responses to Knowledge Acquired?**

The data also showed that having knowledge does not always guarantee safety, for sometimes there are factors that are beyond our control. Without the right support system – such as lack of cooperation from one’s partner - it is very difficult to implement the knowledge received. The data show that all the research participants had sufficient knowledge about HIV as a disease, and knowledge about caring for themselves to manage HIV and to support others. However, because of internal and external factors, they were not able to effectively implement some of the knowledge they possessed in their daily lives, particularly their sexual lives. This finding raises questions for me regarding Freire’s adult learning concepts, particularly the “praxis” (Freire, 1972) which states that transformative learning should result in action which acts as an indicator of internal paradigm shift. From the findings it is clear that knowledge acquisition does not equal knowledge implementation (external action – *ABC approaches*). Does this mean learning has not taken place? Doesn’t the desire to take action, however powerless the person may be, count as or rather indicate the learning?

#### **5.3.3.1 Intersectionality: Gender, Power and Culture and “ABC approach”**

One of the study participants refers to HIV and AIDS as a social disease. This is mainly due to the mode in which the disease is transmitted from one person to another. HIV is mainly transmitted through sexual contact with persons infected, and most of the campaign has been focused on the “*ABC approach*” (Abstain, be faithful and condomise). Except for one participant who was not sure on how she was infected, all the other participants indicated that they were infected with HIV through sexual contact, though not all were sure from whom or when it happened. The data clearly showed that factors linked to gender, power and culture played a great part in driving the disease in the lives of the study participants; they feed into each other to undermine all the educational efforts to curb the disease, contributing to failure in changing risky behaviour in the lives of the participants.

## **“Abstain”**

Most of the participants in the study stated that it is difficult to abstain from sexual intercourse once one has started. Nonetheless, some study participants have made decisions at some point of their lives to abstain from sex for a number of reasons. These included the following: i) The fear of being re-infected, or transmitting the virus to others, ii) The strong need to live or survive has given some women strength to abstain sexually in their relationship.

## **“Faithfulness”**

All the study participants stated that unfaithfulness in their relationships and marriages remained a significant problem; all the culture/races presented in the study were concerned about this fact. The data indicated that it is the men who tend to be unfaithful, getting involved in multiple sexual relationships, though there was also data indicating that women can be unfaithful. This was a particularly interesting finding as it contradicts the fact that in most situations women have been perceived as the innocent victims (Gray, 2009; Dubai, 2010; Inungu & Karl, 2006). Some of the women’s behavior reported in this study might be linked to findings from the studies carried out by Goodman & Falloot (1998) and Cunningham *et al* (1994) regarding women who have been exposed to childhood sexual and physical abuse,. These correlate with high risk behaviors, for most of the women in the study acknowledge having been sexually assaulted at some stage in their lives. What is not apparent is when or how often.

A number of factors were cited for unfaithfulness, particularly amongst men. The cultural and societal expectation, homophobic complexities and peer pressure force men to prove their manhood to other men (his peers). This is a similar finding to Campbell’s (2003) study on mine workers which showed that these pressures put on men by society rendered them vulnerable. Multi-partner sexual relationships seem to be acceptable for men in the cultures of the study participants. There seemed to be a double standard in the cultural tolerance regarding the issue of unfaithfulness and sexual behaviour, where it is okay for men but not women. This factor puts women at higher risk of getting infected with HIV and makes it hard for the men to be positive

influences on their children. The data above confirm the study done by Karim (2005) that indicates there are dominant ideologies in our cultures which define what is viewed as acceptable for women and men in the society. “[T]hese double standards for men and women in acceptable sexual behavior seriously challenge HIV prevention efforts targeted at promoting monogamy and fidelity” (Karim, 2005, p.253).

Other factors cited that indirectly contribute to unfaithfulness included: i) the general immorality that is taking place in our communities, within families and in media which seems to be accepted in our societies and adds to the pressure. ii) Family backgrounds: broken family structures and functions play a great role in how one grows up, learns, regard others and behaves as an adult. This particular finding is similar to the TAI study (2005) which raised the issues of male role models at home, the issues of the role of a father figure, and how this can impact on the future behaviour of young men. Yet it is much broader in sense that the study findings regarding families force us to first look directly into our families and homes for solutions to HIV. This highlights the need to repair the family structure and to re-establish the family’s role. The data points to the reality of family breakdown, as well as indicating what it should represent in this HIV era.

### **“Condomise”**

Despite the evidence and the knowledge the study participants had about condoms, most still do not use condoms consistently because of issues related to cultural, gender and power issues. In the study some men referred to condoms as a hindrance and thus chose not to use them for the felt that condoms spoil their sexual moods. The issue of trust as “power” in a stable relationship: a wo/man demanding the use of a condom would indicate lack of trust in partner; on the other hand the data showed that sometimes the introduction of condoms in a relationship could be taken as a sign of being unfaithful; closely linked to trust are insecurities and denial about possibilities of contracting HIV in a stable relationship.

Different cultural/racial groups use condoms for different reasons, in this study, the Indian participant highlighted the fact that the Indian culture does not accept pregnancy out marriage; the role of condoms for contraceptive purposes, and not HIV prevention results in unprotected sex during the period when a woman is safe from



conception resulting to HIV transmission. Also there was a question about condom quality, particularly government condoms, which resulted in some men refusing to use condoms.

The terms and conditions of a relationship and one cultural/religious beliefs lives in may impact on whether or not a person uses the condoms. For example, a marriage relationship might mean no barriers, openness, wholeness... in other words it equals no condoms, marriage is supposed to be based on trust and faithfulness, of which the data proves otherwise. Linked to the *habitus* are the cultural and gender roles which position women as lesser beings and men as more powerful, thus a woman's suggestions in most matters do not count including introducing condoms in a relationship.

Money has become a powerful tool of control, even in condom negotiation in marriage and relationships, the high levels of poverty and unemployment rates strip women of their power to negotiate safer sex, positioning many women as vulnerable. According to the FGD a number of women said they were afraid of introducing the use of condoms in the middle of a relationship that has been ongoing due to fear of: i) Disclosing their HIV status, ii) Losing their partner once their partner knows their status, iii) abuse or murder if the partner was to know their status and iv) losing financial support.

### **5.3.3.2 “ABC Approach” – Support systems**

While “ABC approach” should be effective theoretically, the realities in which the research participants live sometimes make it difficult for them to implement this approach. One of the male participants stated that, “*It requires practice, determination and strategies on how to control self, but it is not easy.*” This practice, determination, strategies and self-control require support from family, partners, peers and community.

Most of the participants have disclosed their HIV positive status to their families, friends, support group and other key service providers where they access to medical and other forms of social support. HIV impacts on us emotionally, spiritually and

physically. Most of the struggle is emotional, which if not dealt with manifests physically leaving us vulnerable to disease and other negative impacts in our lives. Therefore there are different psycho-social and economic forms of support we require. The data presents some of the needs in our daily lives, these include: financial support, medication, knowledge, counselling and most importantly a person to lean on. Different people play different roles of support in our lives. Without a multi-support network system it is so easy for a person to give up on life. Unfortunately the people who we may want to seek support from may be the same people who will strip the support from us. Unfortunately in this study mostly women went for testing first before their partners; such a situation places a woman in vulnerable position.

People living with HIV in this study require continuous support from different disciplines to enable them to effectively implement the knowledge acquired in their lives and in the lives of those affected in their lives. While they share similar experiences and the same disease, they experience it uniquely and as individuals. HIV is a very personal illness, touching on our intimate, social and at times public lives. By the time a person comes to know their HIV positive status, they already have pre-existing knowledge, lifestyles, norms, relationships and lists of problems. One has to make sense of how to fit HIV into their lives. The big dilemma is who to tell first, why and how will they react. Disclosure is the key to the next steps - to access any form of support, change of behaviour and change of lifestyle. Thus each individual needs a personal arena to process the new knowledge, consider new plans and make decisions that affect all the areas of their lives.

### **5.3.3.3 Gender Violence**

The study shows how gender violence contributes to the spread of HIV. It has a negative impact on the "*ABC Approach*". Most of the women mentioned that they have experienced some form of sexual abuse at some point in their lives, which then stripped them of the power to abstain from sex, being faithful or practice, negotiate or demand safer sex. The silence surrounding sex and sexual abuse results in most of the women not accessing the right form of support. Gender violence is not only perpetrated by men, in some cases it is carried out by our own families, directly or indirectly. According to the data, women have been socialized to embrace the abuse,

thus sending their daughters back to an abusive relationship. Linked to gender violence is substance abuse (alcohol and drugs), which according to the data can interfere with the intentions to abstain from sex, practice safer sex and being faithful. Gender violence impacts on both “*ABC approaches*” and support systems necessary to implement knowledge acquired.

#### **5.4 Key Findings**

The findings of this study show that HIV remains a considerable all round threat to our communities and that the negative intersection of gender, power and culture remains key to the problems related to the receptivity of HIV and AIDS education in the communities of persons infected with HIV. The literature showed that HIV is still on the increase in Pietermaritzburg-uMgungundlovu district. The study findings support the concerns I raised in chapter one. Therefore, the following conclusions are drawn in relation to these concerns. Also they concentrate on HIV positive people because the study is focused on HIV and AIDS education provided for this particular group.

- From the data collected it is clear that all the study participants had sufficient knowledge about HIV transmission and prevention. Their knowledge has grown from one stage to another - from being bystanders who heard about AIDS, to being observers watching it happening to someone else, to being patients. Most of them have grown to become experts and implementers in different roles.
- It also showed that learning can happen through different processes, consciously or unconsciously and anywhere when one considered the different stages of the study participants. Furthermore, data shows the growth of knowledge to enable us to survive.
- The data clearly demonstrates that possessing knowledge does not necessarily mean that the person will implement it. Knowledge related particularly to the HIV prevention requires all the players to be willing participants in the implementation process and if one fails, it all fails. The data has presented a number of factors linked to our culture, gender expectations and power, factors which also compromise these processes.

- The data also showed that although we are willing to learn and we possess the knowledge about the “*ABC approaches*”, these approaches are not realistic in our lives. There is a need for proper support systems to be put into place to support the implementation.
- The data demonstrates that there is a need for effective yet efficient multi-disciplinary educational approaches and support systems networks to support persons infected with HIV, so that they are able to apply their knowledge, where necessary in their lives.
- The learning process and environment in which the study participants learnt had a definite impact on the receptivity, reception and implementation.
- From the data collected it is clear that there are factors which are beyond the participants’ control, related to gender, power and the cultures of the study participants. These influenced their reception and receptivity to the knowledge acquired concerning HIV prevention.
- The data showed a clear power imbalance amongst men and women as a result of the culture and habitat in which the participants live. These imbalances are worsened by socio-economic status amongst the women. It also indicates that women with monetary power have a better chance of negotiating safer sex and reducing the risks of being infected with HIV.
- The data also indicated that cultural and gender inequities which promote casual sex and multi sexual relationships by men positions at women at more risk of getting infected by HIV. Unfortunately these risk behaviors place men in a risky space, for the fear and lack of power in a relationship silences the infected woman (she fails to apply the knowledge she possesses). Therefore programme developers and implementer need to review how to effectively approach the gender/power factor.

### **5.5 Recommendations and implecations for HIV strategies**

The data presented in this chapter shows complex situations in which knowledge about HIV and AIDS has been acquired and is also expected to be applied by the study participants. We cannot ignore the fact that HIV is a social disease. Therefore the learning process has to be a continuous one, informed by the progression of the

disease in our lives, the social, economic and political challenges and changes around us, and by the ongoing scientific developments.

Key principle informing all recommendations: is the central active meaningful role of HIV positive people in issues which affect them – interventions, counselling etc. There is a need for strong and meaningful voices of persons living with HIV in the solution process.

a. Effective Support System for the people living with HIV;

- Continuous, effective yet sufficient support from different disciplines (educational, psycho-social, economical, spiritual etc) in order to be able implement “ABC approaches” and the general HIV and AIDS management in their daily lives.
- To be put in the centre of the HIV responses. However farfetched and difficult it may seem (considering the millions infected), we know our challenges and our issues. As individuals, each experience HIV uniquely thus the response should be individually focused.
- There is a need to balance the HIV prevention education approaches. More support should be provided to HIV positive persons so that they can prevent infecting the next person, if a drop is desired in the HIV prevalence rates.
- Need for safer spaces to explore the challenges we face and also share and support each other in our attempts to implement the knowledge we learn.

b. Collaborations

- Government, policy makers, program developers and implementers need to draw people with HIV around the decision-making table as equals, so that they become part of the solution, not just the patients. By putting us in the centre, involving us and consulting us, together we can prevent millions of people from getting infected.
- Need for consistent and sufficient support for HIV positive people’s initiatives that prove effective in slowing the implementation of HIV

prevention (particularly support groups). For people living with HIV are more open in such space thus strengthening such spaces will create safer learning space.

- Establishment of stronger, respectful, equal, transparent working relationships between key stakeholders and the support groups of people living with HIV to ensure effective responses. In so doing establish shared databases for people living with HIV which will foster proper focused effective, efficient, fair distribution and monitoring of resources and, support which in return might contribute to the expansion of the enabling learning space.

### c. Power

- There is the need to see deeper political will in practice. Words without sufficient resources (human, financial and infrastructural) will not achieve change. Lack of resources foster lack of quality committed services for people living with HIV (Education included).
- Women's rights which are in existence on paper need be implemented in real life by both men and women. There is need for systems to be put in place which will allow these rights. Unless people start to recognize that HIV can affect anyone, the disease will continue to spread and lead to tragic consequences.
- Life skills are required to equip us to be able to handle the complex challenges thrown at us daily, to learn new ways, and to let go of bad cultures that promote high risk behavior. I use "us" here collectively to mean those infected and not infected, for we are all affected by HIV.
- Economic empowerment for women living with HIV should be given priority as part of the responses to HIV and AIDS. This will reduce dependency on men in abusive relationships, thus reducing risks of HIV transmission. As stated earlier monetary power seems give women a stronger footing from which to negotiate safer sex.

#### d. Gender

- There is a clear need for dialogue between men and women to facilitate: i) real understanding of the differences between them, ii) possible ways of complimenting this difference without feeling disempowered or de-rolled and iii) identification of their combined strengths in addressing HIV. These dialogues should focus on issues related to gender, power, culture and sexuality.
- Education on its own cannot succeed, as enough has been said about men and pressures that make them behave in certain ways. If these pressures can be used positively, they can prove vital in changing and reducing sexual risk behaviors amongst the men, thus reducing the transmission of HIV. With proper support, men can be a force for change in other men's lives.
- I would like to urge more women to break the silence surrounding HIV and sexuality. There is a need for resources to support women's dialogue, and safe spaces to allow such openness. This silence drives the disease, oppressing women and children, leaving all (perpetrators and victims) vulnerable to HIV and other ills of our society and systems. The Zulu refer to a woman as *Imbokotho* – the rock, which forms the foundation of our community. If the rock is broken, then the community will be broken. There is a need to heal and strengthen the woman.

To address the educational gaps identified and informed by the study participants' voices and the literature reviewed in this study, I would recommend the following models to be used in future in implanting HIV and AIDS programmes of which the education forms one of its components.

#### **Models Developed from Study**

The models that follow are drawn and suggested from the findings of this study. They are related to the experience of one support group (Springs of Hope) but might be applicable to other support groups. They are tentative models that would require

further testing and refinement to show their effects in improving knowledge implementation for people living with HIV. The models are:

- HIV and AIDS Management Education Support Systems Networks Model
- Support Group as an Enabling Learning Environment
- The HIV Positive Person – Knowledge Reception, Receptivity and Implementation Model
- Factors that impact on reception and implementation of HIV and AIDS Education

These are related in the sense that they present different environments in which knowledge can be accessed and applied. They address the issues of how the environment can impact on the person, as well as HIV and AIDS education reception, receptivity and implementation.

On the next Page the HIV and AIDS management education support system networks model.



**Model 1 (Figure 4)**

**HIV and AIDS Management Education Support Systems Networks Model**

The diagram presents a model which consists of three circles. The bigger outer circle represents the community and all the stakeholders that impact on the daily life of an HIV positive person. The same stakeholders are also somehow linked to the support group, due to the work they are doing to support the people infected by HIV. The medium circle placed inside the bigger circle represents the support group for people living with HIV – in this case *Springs of Hope Support Group*. The smallest of the circles represents the person living with HIV, positioned between both circles to present

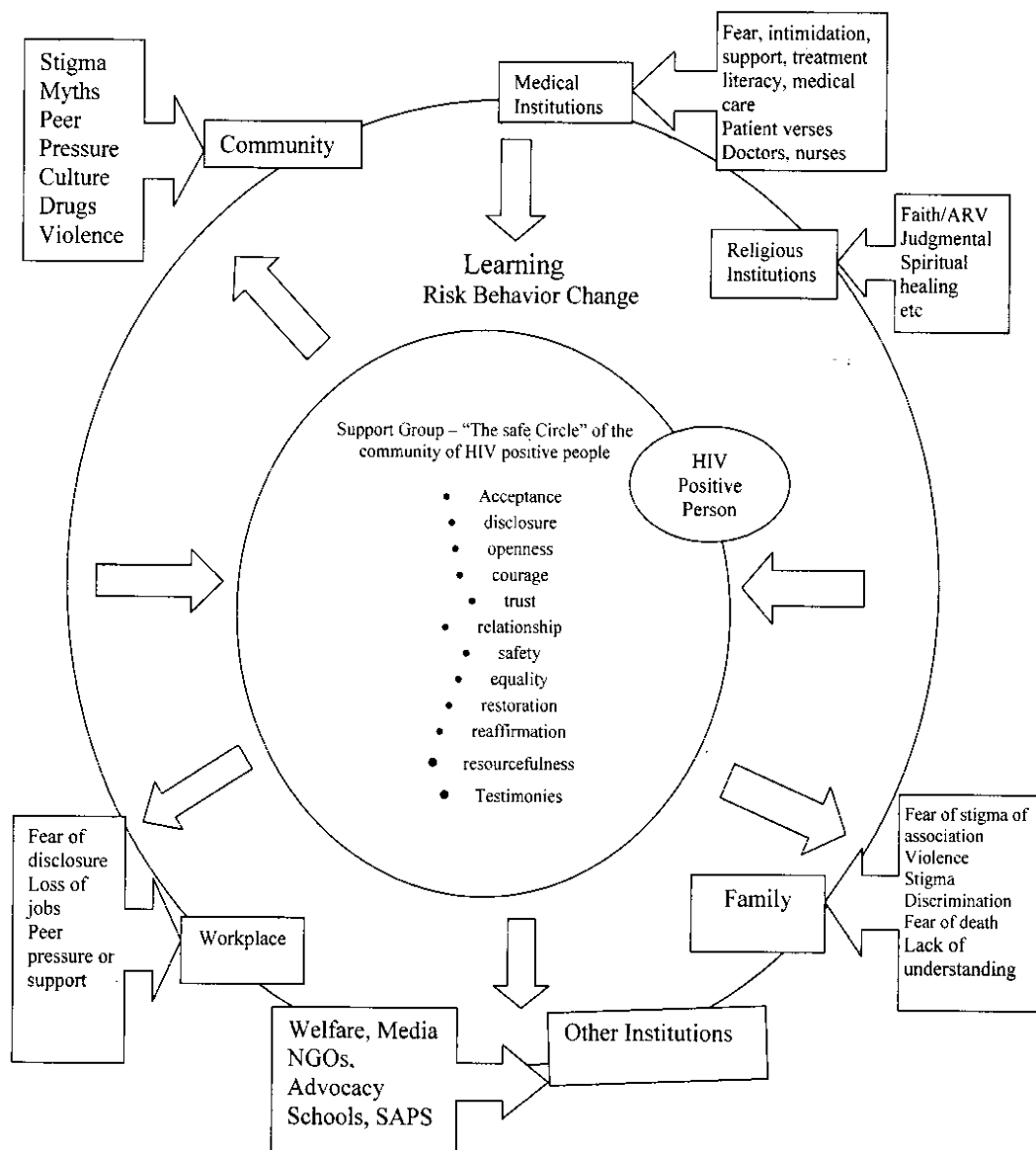


Figure 4: HIV and AIDS Management Education Support Systems Networks Model

My discussion on this particular model focuses on the inner medium sized circle and how it relates to the outer circle and how the both impact on the person living with HIV who exists in both circles. The model characterizes the support group as the “*safe circle*” of/for the community of people living with HIV. It places the support group in the centre and other stakeholders that play a part - positively or negatively - in the lives of a person living with HIV, on the outer circle. The person infected with HIV is placed on the inner circle, but is also partly on the outside to indicate the importance of both worlds.

The arrows pointing in and out indicate;

- The knowledge the person comes in with and takes out
- The knowledge the support group sources from outside to equip members, and draws from the group to empower the stakeholders
- Other forces that impact on the individual and community of persons infected with HIV and our impacts on the outside circle

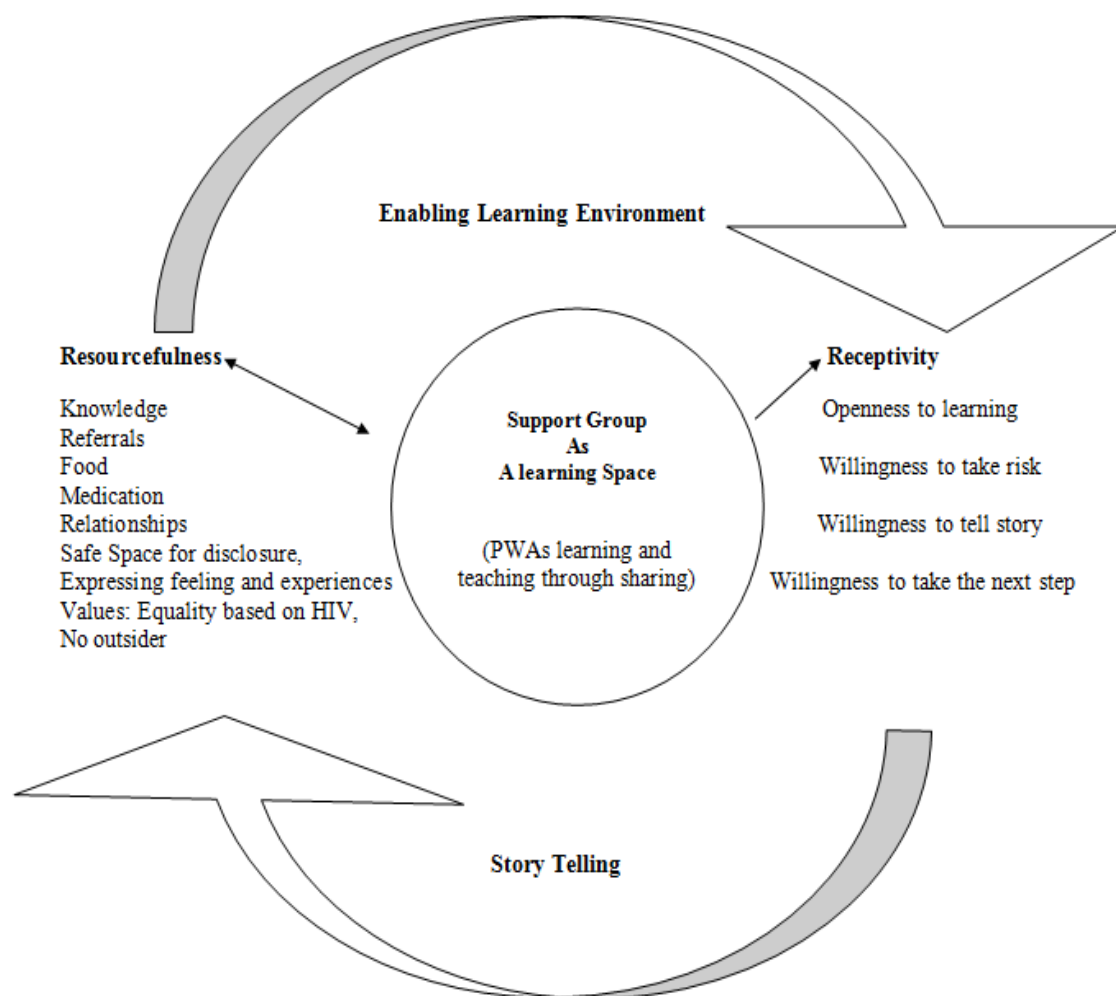
The circles also indicate the need for connections with the entire range of different stakeholders to effectively support the individual coming into and going out of the safe circle. There is also a need to strengthen the safe circle. The three circles have to co-relate if we aim to successfully implement HIV programs. The people living with HIV need the support and services of all around them to acquire and implement knowledge, yet they also need to open up to do so. There is need to establish stronger, respectful, equal, transparent working relationships between the stakeholders and the support group for such a model to be successful. Unfortunately at the moment these links hardly exist. Support groups provide an enabling learning environment to persons living with HIV.

The next figure presents a model demonstrating Support groups as an enabling learning environment for people infected by HIV.

**Model 2 (Figure 5)**

**Support Group as an Enabling Learning Environment**

The model demonstrates the learning environment. It attempts to demonstrate how the environment provided within *Springs of Hope* support group allows for the reception, receptivity and possible implementation of HIV education. The data presented the fact that the support group has a major role in the education, the reception, receptivity and implementation of the knowledge acquired about HIV and AIDS.



**Figure 5: Support Group as an Enabling Learning Environment**

The model represents the support groups as a learning space where persons living with HIV and AIDS learn and teach each other through sharing of their stories. The

stories combined with mini HIV management workshops at each meeting are aimed to equip the person, correcting misconceptions. Generally support groups provide: an enabling learning environment for the community of people living with HIV; a safe space for them to learn new ways to implement new knowledge learnt. The safe space is created through: confidentiality; equality as all being HIV positive; a non-judgmental environment- we all fall, but we have learn to rise; not allowing outsiders (HIV negative persons, unless they are they to equip); and the location of the support group

The data presented the support group as a resourceful learning space, not only to the person infected with HIV, but also to the lives of the others in their lives – including their communities. On the other hand, for the learning to happen, the person must be willing and open to the process. The person must take the risk of disclosing their status to the group and sharing their story, however difficult or shameful they may perceive it to be. It is in that openness that learning takes place, for one is then able to reflect on what is shared. The person has to take the next step to implement change in their lives. The learning is an ongoing process that acknowledges that in some cases it is not easy to implement the HIV management techniques. Moreover, we are not the same; we all come from different context and backgrounds, therefore we are not able to apply the knowledge in the same way.

On the next page the “HIV Positive Person: Knowledge Reception, Receptivity and Implementation” model is presented.

### Model 3 (Figure 6)

#### HIV Positive Person: Knowledge Reception, Receptivity and Implementation

The model presents the person living with HIV as a learner, together with the factors that impact on the person's learning. We learnt earlier that having knowledge does not automatically equal the implementation of knowledge in our lives.

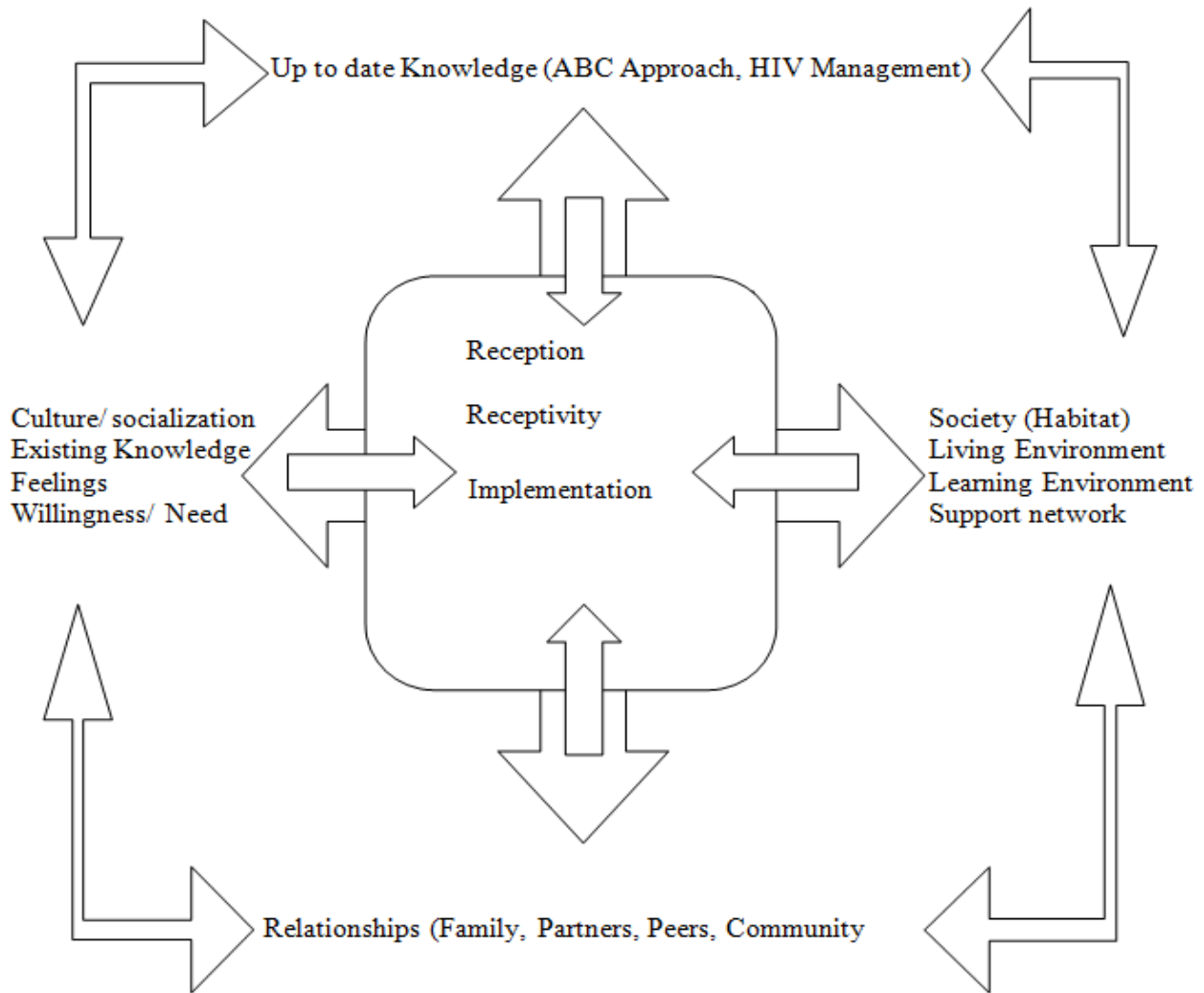


Figure 6: HIV Positive Person: Knowledge Reception, Receptivity and Implementation

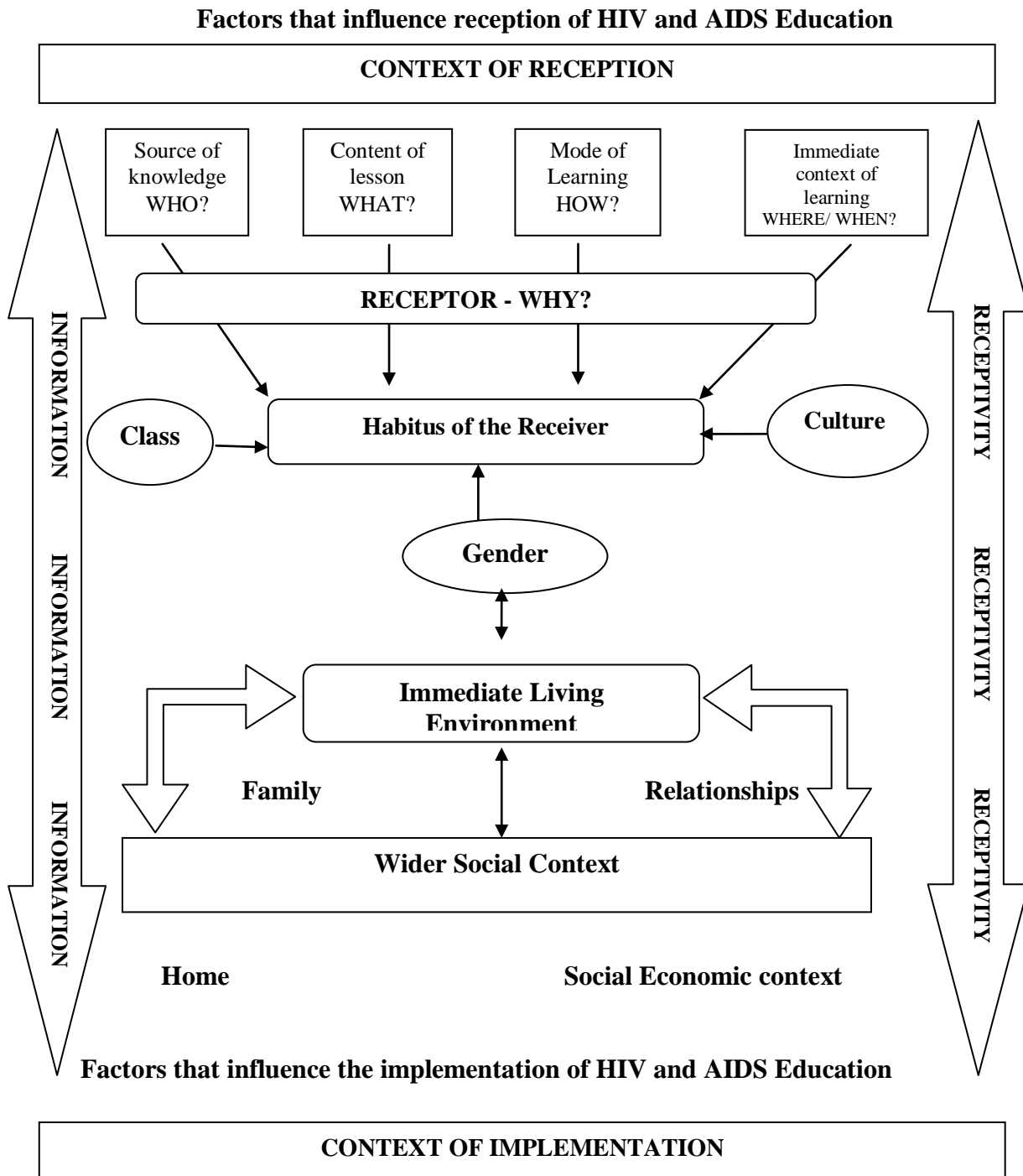
The model recognized the person's prior knowledge, acknowledging that this knowledge can impact on the receptivity and implementation of knowledge received by the person infected with HIV. The arrows that are pointing to the person living with HIV and towards the outside indicate the areas where learning takes place, as well as the areas where the person attempts to implement the knowledge acquired. There are outside forces and inside forces that have implications for how the knowledge is processed and implemented by the person living with HIV. The factors presented on the outside with right-angled arrows connecting them have influence each other. For example the information about "*ABC approach*" can influence the ways in which people have been doing things (*habitus*) or relationships. These influences can be positive if approached positively and with openminds.

The model summarizes the complex dynamics involved in learning to change our lifestyles, particularly cultural and sexual lifestyles. These are already surrounded by cultural, power and gender issues in our families, communities and relationships, as demonstrated in the other models.

On the next page I present a model on factors that influence the reception and implementation of HIV and AIDS education by HIV positive people.

**Model 4 (Figure 7)**

**Factors that Impact on Reception and Implementation of HIV and AIDS Education**



**Figure 7: Factors that Impact on Reception and Implementation of HIV and AIDS Education**

Figure 7 presents a summary drawn from the data on factors that influence reception of HIV and AIDS education in persons living with HIV. At the top of the diagram, factors that influence the reception are presented; first they are presented broadly and later broken into more details. The broad factor is the context of reception, which includes,

- i) The source of knowledge - who is conveying the message (doctor, counselor, fellow person living with HIV).
- ii) The content of the knowledge being passed to people (treatment, positive living, ABC approaches, HIV consequences).
- iii) How is the knowledge being passed to the people (methods, language, educators' attitudes to the topic, rapport).
- iv) The immediate context in which the knowledge is being conveyed (who is present, safe environment, doctors room, location, public, support group, counselling).
- v) The receiver of knowledge (needs, whether the person is there willingly or not, expectations, purpose for learning, role or position of mind). Throughout it is important to consider and be aware of the receiver of knowledge.

This brings us to the next level of consideration of factors that influence knowledge reception and implementation - the receivers' habitus. What kind of environment have they grown up in and what has it taught the person? Issues of culture, gender and class will have a great impact on the reception and implementation of knowledge.

The next level of influence would be the immediate living environment in which the person might have to implement the acquired knowledge (home, partner, children, parents, the social economic status etc). How does the person relate to these people? Has the person disclosed their status to these people? Does the knowledge require that the person discloses their status? Is this a supportive environment or discriminative one? Are there already other existing problems that already put strain on relations? Again at this level the issues of the people's perceptions on gender, class and cultural practices have great impact.

The next factor that impacts the reception and implementation of knowledge is the wider social context. How does the community view issues of HIV, sexuality,



condoms? Who are these people and how are they affected by the HIV factor. What are the myths etc.? The arrows connecting the wider social context and immediate context attempt to capture the influence society has on families. On the other hand, an influential family can make an impact on society. All of these impact on the individual who has been presented through out the different models in this chapter.

On both sides of the diagram I have drawn two arrows. One presents the knowledge the person already possesses, and continues to receive from all other levels of implementation (TV, clinic, partner, paper, cultural beliefs, religion etc). This knowledge can be useful in the reception and implementation of knowledge, yet on the other hand it can counter effect the process.

The other arrow presents receptivity; that which is going on within the person (intellectually and emotionally). Throughout the process, there is something happening (fear, anger, shame, grief, denial, realization, acceptance, frustrations, powerlessness etc). All the different factors mentioned have effects on a person's receptivity, which will determine the reception and implementation of the knowledge presented.

This model can be very useful in program development and implementation, for sound knowledge does not necessarily translate into reception and implementation. Neither does reception necessarily translate into implementation. The receptivity seems to determine whether the person living with HIV will implement the knowledge.

## **5.6 Recommendations for Future Studies**

Arising from the experiences and findings of this study, I suggest three areas for future studies related to HIV and AIDS education:

- There is the need for future macro studies similar to this study, with a focus on the role of HIV and AIDS support groups as institutional sites for HIV and AIDS management education, to ensure future support and respectful equal partnerships.

- Since the implementation of free ARVs programmes in South Africa, there is an assumption that we are past the HIV problem yet new challenges come up every day in our lives. More studies need to focus on the realities of the daily lives of people living with HIV so that we can draw on good practice and strengthen this “community”.
- Future studies should also explore new ways to approach the “Gender, Power and Culture” intersection, possibly through participatory studies that involve persons infected with HIV.

## 5.7 Conclusion

The study aimed to investigate HIV education in uMgungundlovu, perspectives of HIV positive people on HIV education, and factors that affect the implementation of the knowledge they acquire. Although this study echoes a lot of what has already been said before regarding HIV, it brings to light very specific insight into the realities of people living with HIV and their perception towards HIV and AIDS education.

It is clear that the study participants have knowledge about HIV, yet they require support to be able to effectively apply the knowledge in their live. The demand and burden for learning placed on an HIV positive individual (who has the potential to transmit HIV to the next person) are far more over whelming than “ABC”. In order to achieve the positive prevention, which starts with the HIV infected person, there is a need to put into consideration the individual’s context so that we can facilitator proper support system where necessary. There is an urgent need for all of us to regroup in transparent, respectful relationships to one another, and to work together to support people living with HIV so that they are able to contain the disease in their lives.

However hopeless the picture seems I chose to stay positive and end on a positive note, the Zulu sayings; ‘*Umntu umuntu ngabantu*’ (a person is a person through other people) and ‘*izandla ziyagezana*’ (hands wash each other) clearly shows that we cannot do this on our own, we need each other as humanity. We need to put our differences aside, men and women, infected and affected, support groups and other stake holders to make a difference. Education without other forms of support cannot result in any change, particularly in this era of HIV.

## KEY REFERENCES RELATATED TO THE AREA OF RESEARCH

- AIDS Foundation. (2005). HIV and AIDS in South Africa, Current Situation. Retrieved 21<sup>st</sup> October 2007, from <http://www.aids.org.za>
- amfAR. (2008, March). *Women and HIV/AIDS Fact Sheet 2*. amfAR. Retrieved 10 December 2010, from <http://thehill.com/images/stories/whitepapers/pdf/WomenFS.pdf>
- AVERT. (2007). AIDS Education – Why and How?, Retrieve 20 October 2007, from <http://www.avert.org/education.htm>
- AVERT. (2010). HIV and AIDS stigma and discrimination. Retrieved 10 September 2010, from <http://www.avert.org/hiv-aids-stigma.htm>
- Baumgartner, L. M. (2002). Living And Learning With HIV/AIDS: Transformational Tales Continued. *Adult Education Quaterly*, 53 (1), 44-59.
- Bloor, M., Franland, J., Thomas, M. & Robson, K. (2001). *Focus Groups in Social Reseach*. London: Sage
- Boonzaier, F. & Rey, C. (2004). Woman abuse: The construction of gender in women and men's narratives of violence. *South African Journal of Psychology*, 34 (3), 443 – 463.
- Borg, W. R. (1963). *Educational research: an introduction*. New York: Longman.
- Brown, D. (14 June 2010). African women begin test of vaginal ring intended to kill HIV virus. *The Washington Post*. Retrieved 23 November 2010, from <http://www.washingtonpost.com/wp-dyn/content/article/2010/06/14/AR2010061405577.html>
- Campbell, C. (2003). *'Letting them Die' Why HIV/AIDS Prevention Programmes Fail*. Wetton: Double Storey Books.
- CDC. (1996). Universal Precaution for Prevention of Transmission of HIV and Other Bloodborne Infections. *Department of Health and Human Science*.

Retrieved 01 December 2010, from

[http://www.cdc.gov/ncidod/dhqp/bp\\_universal\\_precautions.html](http://www.cdc.gov/ncidod/dhqp/bp_universal_precautions.html)

CDC. (2008, February). Male Circumcision and Risk for HIV Transmission and Other Health Conditions: Implications for the United States. *Department of Health and Human Science*. Retrieved 23 November 2010, from

<http://www.cdc.gov/hiv/resources/factsheets/print/circumcision.htm>

Cohen, L., Manion, L. & Morrisson, K. (2007). *Research Methods in Education* (6th Ed) Abingdon : Routledge

Cunningham, R. M., Stiffman, A. R., Dore, P. & Earl, F. (1994). The association of physical and sexual abuse with HIV risk behaviors in adolescence and young adulthood: Implications for public health. *Child Abuse and Neglect*. 18 (3) 233-245. Retrieved 16 September 2010, from

[www.sciencedirect.com/science/journal/01452134](http://www.sciencedirect.com/science/journal/01452134)

Denison, J. (1996). *Behavior Change Theories and Models. A summary of four Major Theories*. Retrieved 15 November 2003, from

<http://www.hst.org.za/update/42/research.htm>

Department of Health, (2010). National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa, 2009: *Pretoria*: National Department of Health. Retrieved 16

November 2010, from <http://www.health->

[e.org.za/documents/85d3dad6136e8ca9d02cceb7f4a36145.pdf](http://www.health-e.org.za/documents/85d3dad6136e8ca9d02cceb7f4a36145.pdf)

Department of Health: KwaZulu-Natal. (2009, 8 October). Department of Health Explains High HIV Statistics in Umgungundlovu and the Province. Retrieved 10 May 2010, from

<http://www.kznhealth.gov.za/mediarelease/2009/hivstats.htm>

Dibua, U. (2010, 25<sup>th</sup> June). Socio-Economic and Socio-Cultural Predisposing Risk Factors to HIV/AIDS: Case Study of Some Locations in Eastern Nigeria. *The Internet Journal of Tropical Medicine*. 6 (2) Retrieved 16 September

2010, from

[http://www.ispub.com/journal/the\\_internet\\_journal\\_of\\_tropical\\_medicine/volume\\_6\\_number\\_2\\_42/article\\_printable/socio-economic-and-socio-cultural-predisposing-risk-factors-to-hiv-aids-case-study-of-some-locations-in-eastern-nigeria.html](http://www.ispub.com/journal/the_internet_journal_of_tropical_medicine/volume_6_number_2_42/article_printable/socio-economic-and-socio-cultural-predisposing-risk-factors-to-hiv-aids-case-study-of-some-locations-in-eastern-nigeria.html)

Diener, E., & Crandall, R. (1978). *Ethics in social and behavioral research*. Chicago, IL: University of Chicago Press.

Domrose, C. (2003, 20 November). Africa's Silent Killer: Scattered gains in the battle against AIDS helps nurses carry on their work in the face of formidable challenges. *NurseWeek*. Retrieved 2<sup>nd</sup> December 2010, from <http://www.nurseweek.com/news/features/03-11/africaAIDS.asp>

Drennan, M. (1998). *Reproductive Health: New Perspectives on Men's Participation*. *Population Reports*, Series J, No. 46. Baltimore, Johns Hopkins School of Public Health, Population Information Program, Baltimore. Retrieved 16 November, 2010, from [http://info.k4health.org/pr/j46/j46chap2\\_1.shtml](http://info.k4health.org/pr/j46/j46chap2_1.shtml)

Dunkle, L. K., Jewkes, R. K., Brown, C., Gray, G. E., McIntyre, J. A., & Harlow, S. D. (2004). Gender-Based Violence, Relationship Power, and Risk of HIV Infection in Women Attending Antenatal Clinics In South Africa. *The Lancet*. 363 (1) 1415-21

Dunkle, L. K., Jewkes, R. K., Nduna, M., Levin, J., Jama, N., Khuzwayo, N., Koss, M. P., & Duvvury, N. (2006). Perpetration of partner violence and HIV risk behaviour among young men in the rural Eastern Cape, South Africa. *AIDS*. 20 (16) 2107-2114

Floods, M. (2003). Lads in Latex? Why young heterosexual men do not use condoms. *Impact, London-based journal of the National AIDS Trust*. 4, (10-11) Retrieved 04 April, 2007, from <http://www.xyonline.net/Ladsinlatex.shtml>

- Gaskell, J. & McLaren, A.T. (Eds). (1987). *Women and education: A Canadian perspective*. Calgary, AB: Detselig.
- Gibbs, A. (1997). Focus Groups. *Social Research updates*. Issue 19. University of Surrey. Retrieved 15 November 2010, from <http://sru.soc.surrey.ac.uk/SRU19.html>
- Goodman, L. A. and Fallot, R. D. (1998) HIV Risk Behaviours in Poor Urban Women With Serious Mental Disorders; Association with childhood physical and sexual abuse: *American Journal of Orthopsychiatry*. 68 (1) 73- 83
- Gordon, S. F. (2009). *Discursive Constructions of Gender-based violence and Safe Sex Practices among Female Residence Students at UKZN, Submitted in fulfilment of the requirements for the degree of Masters by Dissertation in the School of Psychology, Faculty of Humanities, Development and Social Science*. University of KwaZulu-Natal, Durban
- Gouws, E. & Karim. Q. A. (2005). HIV Infection in South Africa: The Evolving Epidemic. In Karim, S. S. A. & Karim, Q, A. (ed) *HIV/AIDS in South Africa*. New York: Cambridge University Press. pp.48 - 66
- Gray, D. (2009, September). The Relationship Between The Spread Of HIV/AIDS and Inequality in Africa. Retrieved 16 September 2010, from <http://www.e-ir.info/?p=2319>
- Human Rights Watch. (1995, 23 November). [Human Rights Watch Finds Mixed Government Response to High Rates of Rape and Domestic Abuse of Women in South Africa](http://www.hrw.org/en/news/1995/11/23/human-rights-watch-finds-mixed-government-response-high-rates-rape-and-domestic-abus). New York: *Human Right Watch*. Retrieved 17 November 2010, from <http://www.hrw.org/en/news/1995/11/23/human-rights-watch-finds-mixed-government-response-high-rates-rape-and-domestic-abus>
- Iiffe, J. (2005). *The African AIDS Epidemic: A History*. Athens: Ohio University Press.

- Innes, O. R. (2006, October). Sociocultural Aspects of HIV/AIDS. *HIV/Aids - The South African culture*. Health24. Retrieved 17<sup>th</sup> October 2007, from <http://www.health24.com>
- Inungu, J., & Karl, S. (2006). Understanding the Scourge of HIV/AIDS in Sub-Saharan Africa: Factors fuelling the spread of HIV/AIDS in Africa. *Medscape General Medicine*. 8(4). Retrieved 16 September, 2010, from <http://www.medscape.com/viewarticle/>
- Jackson, H. (2002). *AIDS AFRICA- Continent in Crisis*: Harare: SafAIDS
- John, V. & Rule, P. (2008). Unbinding the Other in the Context of HIV/AIDS and Education. *Journal of Education*. 43, 79-99
- Kalichman, S.C., Simbayi, L.C. Cain, D., Cherry, N., Henda, N. and Cloete, A. (2007). Sexual assault, sexual risks and gender attitudes in a community sample of South African men. *AIDS Care*. 19 (1), 20-27
- Kalichman, S.C., Simbayi, L.C., Kaufman M., Chauncey, D.C.C., Jooste, S. & Mathiti, V. (2005), Gender attitudes, sexual violence and HIV/AIDS risks among men and women in Cape Town, South Africa, *Journal of Sex Research*. Retrieved 04 April, 2007, from, <http://www.finarticles.com/p/articles/mi>.
- Kanabus, A. & Fredriksson, J. (2007, 26 June). History of AIDS 1981 to 1986. *The history of AIDS up to 1986*. Retrieved 24<sup>th</sup> October 2007 from <http://www.avert.org/historyi.htm>
- Karim, S. S. A. (2005). Introduction. In Karim, S. S. A. & Karim, Q. A. (ed) *HIV/AIDS in South Africa*. New York: Cambridge University Press. pp.31–36.
- Karim, Q. A., (2005)
- Ki-Moon, B. op-ed. (2008, 6 August). The Stigma Factor. *Washington Times*, p2. Retrieved 16 September 2010, from <http://www.washingtontimes.com/news/2008/aug/06/the-stigma-factor/?page2>

- Knudsen, S.V. (2006). Intersectionality – A theoretical inspiration in the analysis of minority cultures and identities in textbooks. In E. Bruillard et al. (eds.). *Caught in the web or lost in the textbook*. (pp. 61-76). Caen: Stef, IARTEM, Iufm.
- Krug, E. G., Dahlberg, L. L., Mercy, J. A., Zwi, A. B. & Lorenzo, R. (2002). World Report on Violence and Health. *World Health Organization*. Geneva. Retrieved 16 November 2010, from [http://whqlibdoc.who.int/publication/2002/9241545615\\_chap4\\_eng.pdf](http://whqlibdoc.who.int/publication/2002/9241545615_chap4_eng.pdf)
- Lerlarc-Madlala, S. (2002). *Youth, HIV/AIDS and The Importance of Sexual Culture and Context*. Durban: Center for Social Science Research.
- Letherlby, G. (2003). *Feminist Research in Theory and Practice*. Buckingham: Open University Press
- Makhaye, G. (2005). HIV Infection in South Africa: The Evolving Epidemic. In Karim, S. S.A. & Karim, Q. A. (ed) *HIV/AIDS in South Africa*. New York: Cambridge University Press. pp.313- 318
- Martin, S. L., Curtis, S. (2004) Gender-based violence and HIV/AIDS: Recognising Links and Acting on Evidence. *The Lancet* 363 (9419) 1410-1411. Retrieved 16 November 2010, from <http://www.thelancet.com/search/results?searchTerm=Sandra+martin&fieldName=Authors&journalFromWhichSearchStarted=lancet>
- Merriam, S. B., and Caffarella, R. S. (1991). *Learning in adulthood d.* (1st ed.). San Francisco: Jossey-Bass Publishers
- Merriam, S. B., and Caffarella, R. S. & Baumgartner, L. M. (2007). *Learning in adulthood d.* (3rd ed.). San Francisco: Jossey-Bass Publishers
- Miles, M. B. & Huberman, A. M. (1984). *Qualitative Data Analysis: A Sourcebook of New Methods*. California: SAGE publications



- Miller, R. L. (2008). *Research Ethics: Issues and Resources*. Kearney: University of Nebraska. Retrieved 10<sup>th</sup> December, 2010, from <http://teachpsych.org/resources/e-books/ur2008/1-5%20Miller.pdf>
- Mlomo-Ndlovu, V. C., (2000), Living with HIV/AIDS: Beyond Awareness. *University of Zululand, Journal of Psychology*. 16 (9) 27 -36.
- Mouly, G. J. (1978). *Educational research: The art and science of investigation*. London: Allen & Bacon.
- Mubiru, H. (nd). *Positive Living with HIV/AIDS. Resource Manual*. Pietermaritzburg: Community Development & (AIDS) Outreach Project.
- Mwala, C. & John, C. T. (1998). *Impact of Support Groups on People Living with HIV/AIDS*. International Conference on AIDS, Geneva. <http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102229482.html> 20 November 2010
- Namwamba-Ntombela, A. (2007). *HIV and AIDS Management Workshop*. Unpublished manuscript, Pietermaritzburg
- Namwamba-Ntombela, A. (2008). *HIV and AIDS MANAGEMENT Workshop Within A Home – Home Based Care*. Unpublished Manuscript, Pietermaritzburg.
- Namwamba-Ocharo, C. N. (2009). *The Challenge of Communicating to the Youth on HIV/AIDS: A Case Study of Kenya, A communications studies research project proposal submitted in partial fulfillment of the requirement of the MA in Communication Studies, School of Journalism*. University of Nairobi
- Parker, S. (1996). *Led by the spirit: towards a practical theology, Pentecostal discernment and decision-making*. Sheffield: Sheffield academic press.
- Pattman, R. (2006). Making pupils the resources and promoting gender equality in HIV/AIDS education: *Journal of Education*. 23 (38) 89-116.

- Pembrey G (2007). HIV and AIDS in South Africa. Retrieved 25<sup>th</sup> October, 2007, from <http://www.avert.org/aidssouthafrica.htm>
- Plunkett, M. (2010). New Gel a Possible Breakthrough in AIDS prevention. *A Moment in Science*. 23 November 2010, from <http://indianapublicmedia.org/amomentofscience/breakthrough-aids-prevention/>
- Race, K. E., Hotch, D. F. & Parker, T. (1994). 'Rehabilitation Program Evaluation: Use of Focus Groups to Empower Clients'. *Evaluation review*. 18 (6) 730 -740
- Rule, P. (2007). Healing, Hiding and Hope(lessness), HIV/AIDS and Workplace Education in KwaZulu-Natal, South Africa. In Farrell, L. & Fenwick, T. (eds). *Educating the Global Workforce: Knowledge, Knowledge Work and Knowledge Worker*. London: Routledge. Pp 76-88
- Sapa. (2007). HIV Stats Show Wide Geographic Variation. Retrieved 21<sup>st</sup> October 2007 from , <http://www.iolhivaids.co.za>
- Sapa-AFP. (04 May, 2004). Beaten women hit hard by HIV. *Daily News*
- Skinner, D. & Mfacane, S. (2004 November). Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Journal of Social Aspects of HIV/AIDS*. 1 (3) 157 - 164
- Spirig, R. (1998). Support Groups for People Living with HIV/AIDS: A Review of Literature. *Journal of the Association of Nurses in AIDS care*. [9 \(4\)](#) 43-55. University of Washington: Nursing School. Retrieved 20<sup>th</sup> November 2010, from <http://www.sciencedirect.com/science/journal/10553290>
- Strauss, A. & Corbin, J. (1990). *Basics of Qualitative Research*. Newbury Park: Sage.

- TAC. (2003). *HIV in our lives: A book of information sheets for people living with HIV, support groups and clinics*. (3<sup>rd</sup> ed). Cape Town: Saltyprint
- TAC. (2006). *ARVs in our lives: A handbook for people living with HIV and treatment advocates in support groups clinics and communities*. Cape Town: Hansa Reprint
- The AIDS InfoNet. (2010). Microbicides. *The AIDS InfoNet – Reliable, Up-To-Date Treatment information*. Retrieved 23 November 2010, from [http://www.aidsinfonet.org/fact\\_sheets/view/159](http://www.aidsinfonet.org/fact_sheets/view/159)
- The HIV/AIDS and Media Project. (2007). HIV/AIDS Statistics. Retrieved 23rd October 2007, from <http://www.jounaids.org>
- Tsevere, M. (2000). *HIV/AIDS in TVET staff development: Behavior Change models and teaching methods for Promoting Behavioral Change in TVET Institutions*. University of Technology: Harare.
- Tuyizere, A .P. (2007). *Gender and Development; The Role of Religion and Culture*. Kampala: Makerere University, Fountain Publishers
- Ulin, P. R., Robinson, E. T., Tolley, E. E. & McNeill, E. T. (2002). *Qualitative methods: a field guide for applied research in sexual and reproductive health*. North Carolina: Family Health international.
- UNAIDS, (2007). The Greater Involvement of People Living with HIV (GIPA). Geneva: UNAIDS. Retrieved 10<sup>th</sup> October, 2010, from [http://data.unaids.org/pub/BriefingNote/2007/jc1299\\_policy\\_brief\\_gipa.pdf](http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf)
- UNAIDS. (2005). *Operational Guide on Gender and HIV/AIDS: A Right based Approach*. Amsterdam: KIP Publisher
- UNAIDS. (2009). AIDS epidemic updates. Geneva: UNAIDS. 23 November 2010 [http://data.unaids.org/pub/Report/2009/JC1700\\_Epi\\_Update\\_2009\\_en.pdf](http://data.unaids.org/pub/Report/2009/JC1700_Epi_Update_2009_en.pdf)

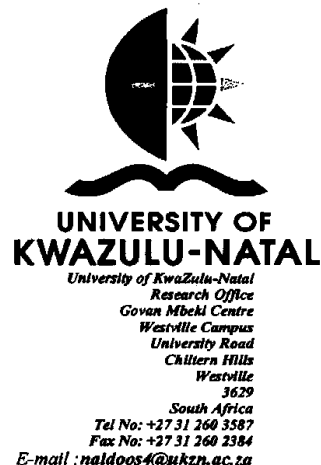
- UNAIDS. (2010). UNAIDS Report on the Global AIDS Epidemic. Geneva: UNAIDS. Retrieved 23 November 2010, from [http://www.unaids.org/globalreport/Global\\_report.htm](http://www.unaids.org/globalreport/Global_report.htm)
- UNAIDS.(2007). AIDS Epidemic Updates: Geneva: UNAIDS and WHO. Retrieved 21<sup>st</sup>October 2007, from [http://data.unaids.org/pub/epislides/2007/2007\\_epiupdate\\_en.pdf](http://data.unaids.org/pub/epislides/2007/2007_epiupdate_en.pdf)
- UNAIDS/ WHO, (2004, June). UNAIDS/WHO Policy Statements on HIV Testings. Geneva: UNAIDS/WHO. Retrieved 30 November, 2010, from [http://www.who.int/rpc/research\\_ethics/hivtestingpolicy\\_en\\_pdf.pdf](http://www.who.int/rpc/research_ethics/hivtestingpolicy_en_pdf.pdf)
- UNESCO, (2010). Culture, HIV and AIDS – Socio-cultural approaches. Paris: UNESCO. Retrieved 10 December, 2010, from [http://portal.unesco.org/en/ev.php-URL\\_ID=33649&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=33649&URL_DO=DO_TOPIC&URL_SECTION=201.html)
- UNFPA. (2005). *State of the World Populations: The Unmapped Journey, Poverty and Gender*. New York: UNFPA. Retrieved 04<sup>th</sup> October, 2007, from <http://www.unfpa.org/swp/2005/english/ch5/index.htm>
- UNPFA, (2008). *Population issues: Involving Men in Promoting Gender Equality and Women's Reproductive Health*. New York: UNPFA. Retrieved 17 November, 2010, from <http://www.unfpa.org/gender/men.htm>
- Walker, L. and Gilbert, L. (2002). South African women at risk. *African Journal of AIDS Research*. 1 (1) 75 - 85.
- Whiteside, A. and Sunter, C. (2000). *AIDS: The challenges for South Africa*. Cape Town: Human & Rousseau and TafelBerg.
- WHO /UNAIDS. (2007). New Data on Male Circumcision and HIV prevention: policy and programme implications. Geneva: WHO / UNAIDS. Retrieved 27<sup>th</sup> November, 2010, from [http://data.unaids.org/pub/Report/2007/mc\\_recommendations\\_en.pdf](http://data.unaids.org/pub/Report/2007/mc_recommendations_en.pdf)

- WHO, (2010). HIV/AIDS Male circumcisions for HIV prevention. Geneva: WHO. Retrieved 04 December, 2010, from <http://www.who.int/hiv/topics/malecircumcision/en/index.html>
- WHO. (2010). Gender Women and AIDS. Geneva: WHO. Retrieved 16 September 2010, from [http://www.who.int/gender/hiv\\_aids/en/index.html](http://www.who.int/gender/hiv_aids/en/index.html)
- Williams, B.G., Lloyd-Smith, J.O., Gouws, E., Hankins, C., Getz, W.M., Hargrove, J., Zoysa, I., Dye, C. & Auvert, B. (2006). The potential impact of male circumcision on HIV in sub-Saharan Africa. *PLoS Medicine*: 3 (7) e262. <http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.0030262>  
23 November 2010

### **PRIMARY SOURCES OF DATA**

- Interviewee 1, 2005. Interviewed by Anne Namwamba-Ntombela, Springs of Hope Support Group Project, Pietermaritzburg, 25<sup>th</sup> June.
- Interviewee 2, 2005. Interviewed by Anne Namwamba-Ntombela, Springs of Hope Support Group Project, Pietermaritzburg, 5<sup>th</sup> June.
- Interviewee 3, 2005. Interviewed by Anne Namwamba-Ntombela, Springs of Hope Support Group Project, Pietermaritzburg, 24<sup>th</sup> December.
- Interviewee 4, 2005. Interviewed by Anne Namwamba-Ntombela, Springs of Hope Support Group Project, Pietermaritzburg, 20<sup>th</sup> May.
- Interviewee 5, 2005. Interviewed by Anne Namwamba-Ntombela, Springs of Hope Support Group Project, Pietermaritzburg, 20<sup>th</sup> June.
- Interviewee 6, 2005. Interviewed by Anne Namwamba-Ntombela, Springs of Hope Support Group Project, Pietermaritzburg, 21<sup>st</sup> June.
- Namwamba-Ntombela, 2005 -07. Own Journal. Pietermaritzburg.

APPENDIX A



29 November 2010

Mrs A Namwamba-Ntombela  
School of Education and Development  
EDGEWOOD CAMPUS

Dear Mrs Namwamba-Ntombela

**PROTOCOL: Investigating HIV and AIDS Education in Pietermaritzburg-UMgungundlovu, KwaZulu-Natal: Perspectives of HIV Positive People in a support group  
ETHICAL APPROVAL NUMBER: HSS/1367/2010 M: Faculty of Education**

In response to your application dated 25 November 2010, Student Number: **971166522** the Humanities & Social Sciences Ethics Committee has considered the abovementioned application and the protocol has been given **FULL APPROVAL**.

**PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years.**

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

  
.....  
**Professor Steve Collings (Chair)**  
**HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE**

SC/sn

cc: Dr. P Rule (Supervisor)  
cc: Mr N Memela

Postal Address:  
Telephone:  
Facsimile:  
Email:  
Website: [www.ukzn.ac.za](http://www.ukzn.ac.za)  
Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

**APPENDIX B**

**Consent Form**

**Informed consent for participating in a research study done by Anne Namwamba-Ntombela a masters student at the University of KwaZulu-Natal.**

I ..... has voluntarily chosen to participate in this study. I give consent to the researcher to use the information I share during the research study (Interview or/and Focus group discussion).

The study; **Investigating HIV and AIDS Education in Pietermaritzburg - Kwazulu-Natal province: Perspectives of People infected with HIV in a support group**, focuses on HIV and AIDS education provided in Pietermaritzburg – KwaZulu-Natal, the people who are living with HIV and the factors that might affect how they implement the knowledge they acquire about HIV and AIDS with a more keen interest on how gender, power and the culture of the people impacts on the acquiring and implementation of these knowledge.

I understand that my contribution to the study might to some degree contribute to future responses, developments and implementations of HIV and AIDS education and programmes in our community and support group.

The methods in which the data will collected have been explained to me, I am comfortable with researcher using tape recorder to capture the interview session.

I agree to follow up interview if and when necessary, if the need arises.

I understand that all the information I share shall be handled confidentially and if ever I want to withdraw from the study at any stage before the publication of the study for any reason, I can do so.

I also understand that there are no payments for participating in the study, but I will receive R50.00 incentive to cover my transport expenses.

Name :  
.....

Signature :  
.....

Witness :  
.....

Signature :  
.....

Date :  
.....

## APPENDIX C

### **Semi- Structured In-depth Interview Schedule**

TOPIC: Investigating HIV And AIDS Education In Kwazulu- Natal Province:  
Perspectives Of People Infected With HIV In A Support Group.

1. Target groups: **people that are living with HIV in a support group.**
2. Methods: **Semi-structured interviews**

- 1. Introductions.**

- 2. Ethical implications of the interview.**

- 3. BIOGRAPHICAL DETAILS**

1. Age:
2. Sex:
3. Race:
4. Marital status:
5. When did you test as HIV positive?
6. Why did you decide to have an HIV test?
7. Where did you get tested?
8. Are you attending clinic? Why or why not?

- 4. SOCIO-ECONOMIC BACKGROUND**

- (a) Where do you live?
- (b) With whom do you live with?
- (c) What is your highest level of education?
- (d) How many dependants do you have?
- (e) How do you earn your income?

- 5. KNOWLEDGE ABOUT HIV/ AIDS**

- (a) When did you first here about HIV and AIDS?
- (b) From whom or where? What information did you get then?
- (c) Can you tell me how HIV is transmitted?
- (d) How and one prevent the spread of HIV?



- (e) Are you on any HIV treatment? If so please tell me about it?
- (f) How much do you know about the HIV treatment?
- (g) What forms of support do you have: at home, in community, at clinics?
- (h) Is there any form of support you feel that you lack? Why?
- (i) Before testing, do you think that you had enough knowledge about HIV and AIDS?
- (j) After testing, do you think the counselor gave you enough information to cope with the knowledge that you are HIV positive?
- (k) Presently is there any difference in your knowledge, before testing as compared to present?
- (l) Are you open about your HIV status? Please explain why or why not?

**6. HIV AND AIDS EDUCATION BEING OFFERED IN KWAZULU-NATAL**

- (a) How did you learn about HIV and AIDS?
- (b) What kind of HIV and AIDS education if have you received? (What language, level and methods were used to educate you?)
- (c) From where did you receive this education?
- (d) Did you find this education useful in your life?
- (e) Why do you say you found this education useful or not?
- (f) How was it useful to you? Or how was it not useful to you?

**7. IMPLEMENTATION OF KNOWLEDGE ACQUIRED**

- (a) Have you been able to implement the knowledge that you have?
- (b) What factors made it easy or hard for you to implement what you had learnt.
- (c) What are the lessons that you have learnt through living with HIV or AIDS?

**8. WHAT IS YOUR EXPERIENCE ON THE ISSUE OF GENDER, CULTURE AND POWER**

- (a) What kind of problems have you experienced in relation to the fact that you are:
  - A woman?

- A man?
  - A Black/Indian/Coloured?
9. **Why do you think that number of people getting infected with HIV in Kwazulu-Natal is on an increase?**
  10. **As a person living with HIV what kind of effort can make to ensure that you do not pass the virus to another person? Is this easy to implement or not?**
  11. **Do you think that something could be done differently to reduce the increase of infections in Kwazulu-Natal?**
  12. **Any other issue or comment that you feel you want to share with me?**

**APPENDIX D**

**Participants basic information form – FGD**

**Introductions**

**Ethical implications of the Focus Group Discussions**

**BIOGRAPHICAL DETAILS**

1. Age: \_\_\_\_\_ Sex : \_\_\_\_\_ Race: \_\_\_\_\_ Marital status: \_\_\_\_\_
2. When did you test as HIV positive? \_\_\_\_\_
3. Why did you decide to have an HIV test?  
\_\_\_\_\_  
\_\_\_\_\_
4. Where did you get tested? \_\_\_\_\_
5. Are you attending clinic? Why or why not?  
\_\_\_\_\_  
\_\_\_\_\_
6. Who knows about your HIV status? Please explain why?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
7. Do you have support :  
at home \_\_\_\_\_  
in community \_\_\_\_\_  
at clinics \_\_\_\_\_
8. Is there any form of support you feel that you lack?  
\_\_\_\_\_  
\_\_\_\_\_

**9. SOCIO-ECONOMIC BACKGROUND**

- a) Where do you live? \_\_\_\_\_
- b) With whom do you live with?  
\_\_\_\_\_  
\_\_\_\_\_
- c) What is your highest level of education?  
\_\_\_\_\_
- d) How many dependants do you have?  
\_\_\_\_\_  
\_\_\_\_\_
- e) How do you earn your income? \_\_\_\_\_
- f) Are you on any HIV treatment? If so please tell me about it?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## APPENDIX E

### Focus Group Discussions Questions

#### 1. KNOWLEDGE ABOUT HIV/ AIDS

- a) When did you first here about HIV and AIDS?
  - b) From whom or where?
  - c) What information did you get then?
  - d) Before testing, do you think that you had enough knowledge about HIV and AIDS?
  - e) After testing, do you think the counselor gave you enough information to cope with your HIV positive?
  - f) Presently is there any difference in you knowledge, before testing?
  - g) Can you tell me how HIV is transmitted? Prevent the spread of HIV?
  - h) How much do you know about the HIV treatment?
2. In many case people do not want to face the source of their infection, and some do not know where they picked their infection, is there any chance that you know where your picked or how you got infected?
3. Living with HIV is not as simple the books put it... what kind of challenges do you experience and where do we draw our support from?
4. Where does the support group fit in the knowledge, implementation and going on with life – what is the role of the support group?
5. HIV AND AIDS EDUCATION BEING OFFERED IN KWAZULU-NATAL

There are different ways in which we learn about HIV, how did you learn about HIV and AIDS?  
From where or whom did you receive this education?  
Did you find this education useful in your life? Why? How?

#### 6. IMPLEMENTATION OF KNOWLEDGE ACQUIRED

Have you been able to implement the knowledge that you have?  
Abstaining from sexual intercourse

Using condoms consistently  
Staying faithful to your partners  
Taking you ARVs / treatment as required  
Practicing positive living techniques

- a) What factors made it easy or hard for you to implement what you had learnt.
- b) What are the lessons that you have learnt through living with HIV or AIDS?
- c) Do these factors affect women and men differently?
- d) Does financial independence make a difference?

#### 7. What is you experience on the issue of gender, culture and power

What kind of problems have you experienced in relation to the fact that you are:

A woman

A man

A Black/India/Coloured?

8. Why do you think that number of people getting infected with HIV in Kwazulu-Natal is on an increase?
9. Do you think that something could be done differently to reduce the increase of infections in Kwazulu-Natal?
10. Any other issue or comment that you feel you want to share with me?