

A phenomenological inquiry into the lived experience of social support for Black South African women living with HIV

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Declaration

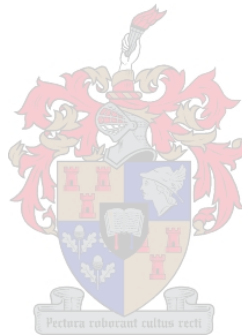
I, the undersigned, hereby declare that the work contained in this thesis is my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

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Date



ABSTRACT:

The HIV/AIDS pandemic is steadily growing throughout the world. Global estimates have revealed that forty million people are living with HIV/AIDS. Approximately 5.3 millions South Africans have been indicated to be living with the illness and within South Africa HIV/AIDS is having catastrophic effect. The burden of the HIV/AIDS epidemic has not fallen evenly. In South Africa, African women have borne the brunt of the illness. This study presents a focus on developing more effective ways of caring and therefore impacting the health of Black South African women living with HIV.

Social support understood broadly as different aspects of relationships in which needs are met and individuals feel cared for, loved and valued (Cobb, cited in Friedland, McColl, & Renwick, 1996) was indicated as having a powerful impact on health. For this reason social support was considered crucial in the development of effective strategies of care.

Studies examining the role of social support in the management of chronic illness such as HIV/AIDS underscore the ability of social support to provide a sense of health within illness. From within a South African context, however, a gap in social support research has been apparent. Although frameworks for understanding social support as a broad concept were available, social support research failed to provide adequate foundations for understanding social support in terms that could implicate strategic intervention and contribute to the development of more effective strategies of care.

The aim of this study was to develop a deeper understanding of the lived experience of social support for a sample of nine Black South African women living with HIV. The study was conducted qualitatively within a phenomenological paradigm. A phenomenological paradigm encouraged

participants, through in-depth interviewing, to provide information based on their own lived experiences of social support. The interviews were then transcribed and analysed using rigorous data analysis methods. Initial findings were presented to the sample and then developed further. Final findings were written up as rich descriptions of the lived experience of social support for the sample.

Fourteen themes emerged as comprising constituent aspects of social support. Descriptions of the fourteen themes, including health care professionals, partners, family/children, support groups, meeting others needs, story telling, Memory Box Project, media and books, organisations within the community, activities, the community, being involved in research and spirituality, provide rich understandings of the interpersonal relationships constituting the lived experience of social support for the sample. A polarity was identified in the lived experience of social support. Interactions had the potential to be satisfactory and supportive as well as non-supportive. The research findings are discussed within a greater theoretical body of knowledge and considered in light of three contexts considered influential in impacting the lived experience of social support.

The study assisted in the development of a culturally contextual understanding of the lived experience of social support. This understanding has implications for effective intervention strategies seeking to purposefully care for those living with HIV in South Africa

OPSOMMING:

Die MIV/vigs-pandemie neem wêreldwyd steeds toe. Internasionale beramings dui daarop dat sowat 40 miljoen mense tans met MIV/vigs saamleef. Altesame 5,3 miljoen Suid-Afrikaners ly na raming aan die siekte en dit het 'n katastrofiese uitwerking. Wat bevolkingsgroepe betref, is die siekte egter nie eweredig versprei nie. In Suid-Afrika is dit die swart bevolkingsgroep, en in die besonder die swart vrou, wat die meeste deur die siekte geaffekteer word. Hierdie studie fokus op die potensiële ontwikkeling van doeltreffender versorgingsmetodes wat dan ook die lewensgehalte sou kon verbeter van swart Suid-Afrikaanse vroue met MIV/vigs.

Sosiale steun het 'n sterk invloed op gesondheid. Hierdie steun verwys na die verskillende aspekte van verhoudings wat geaffekteerde individue vervuld, versorg en gelief laat voel (Cobb soos aangehaal in Friedland, McColl, & Renwick, 1996). Daarom word sosiale steun as belangrik beskou in die ontwikkeling van doeltreffende versorgingstrategieë.

Verskeie studies oor die rol van sosiale steun in die bestuur van chroniese siektes soos MIV/vigs, bevestig dat sosiale steun 'n deurslaggewende rol speel in die vestiging van 'n gevoel van gesondheid binne 'n siektetoestand. Binne die Suid-Afrikaanse konteks blyk daar egter 'n gebrek aan navorsing te wees wat betref die rol van sosiale steun. Hoewel daar wel werk beskikbaar is wat die rol van sosiale steun as 'n breë konsep verklaar, bied navorsing op hierdie gebied nog nie 'n geskikte grondslag vir 'n beter begrip van sosiale steun wat betref strategiese intervensie en die bydrae wat dit kan lewer tot doeltreffender versorgingstrategieë nie.

Die doel van hierdie studie was om 'n groter begrip te ontwikkel vir sosiale steun soos beleef deur 'n steekproef van nege swart Suid-Afrikaanse vroue met MIV. Dit studie is kwalitatief uitgevoer vanuit 'n fenomenologiese paradigma. Deur die voer van diepte-onderhoude binne hierdie fenomenologiese paradigma is deelnemers aangemoedig om inligting te verskaf oor hulle eie ervaring van sosiale steun. Die onderhoude is vervolgens getranskribeer en geanaliseer deur middel van streng data-analise-metodes. Daar is terugvoering oor die aanvanklike bevindinge gegee aan die vroue in die steekproef en die data is hierna nog verder ontwikkel. Die finale bevindinge is in die studie weergegee as 'n omvangryke beskrywing van die steekproef se deurleefde ervaring van sosiale steun.

Veertien temas is geïdentifiseer wat kernaspekte van sosiale steun omvat. Hierdie temas sluit onder meer in gesondheidsorgwerkers, metgeselle, familie/gesinne/kinders, steungroepe, behoeftevoorsiening, die vertel van stories, die "Memory Box"-projek, die media en boeke, gemeenskapsorganisasies, aktiwiteite, die gemeenskap, betrokkenheid by navorsing, en geesteslewe. 'n Beskrywing van die veertien temas het bygedra tot 'n veel groter begrip van die interpersoonlike verhoudings wat deel uitgemaak het van die deelnemers se beleefde ervaring van sosiale steun.

Daar is egter 'n polariteit geïdentifiseer ten opsigte van hierdie beleefde ervaring van sosiale steun. Dit het geblyk dat interaksie potensieel bevredigend en ondersteunend van aard kan wees, maar ook afbrekend. Die navorsingsresultate is verder bespreek binne 'n uitgebreide teoretiese kennisraamwerk en is beskou in die lig van drie kontekste wat as belangrik geag word betreffende die invloed daarvan op die beleefde ervaring van sosiale steun.

Hierdie studie het bygedra tot die ontwikkeling van groter begrip binne kulturele konteks vir die beleefde ervaring van sosiale steun. Hierdie begrip is belangrik vir doeltreffende intervensie.



**...If there is one thing I feel I have learned in my adult life lived
inside an unreliable body, it is that care not cure will keep us
floating in the ocean (Weingarten, 2000)**



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To the participants of this study, for the invaluable contribution of your lives shared with me. Without you this study would have been impossible.

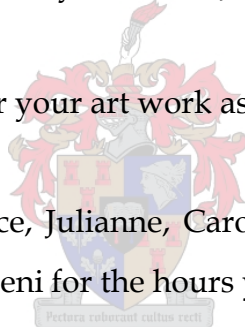
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CHAPTER ONE: INTRODUCTION

1.1 Introduction

Over twenty years ago the Acquired Immune Deficiency Syndrome (AIDS) was first documented in the United States (Gottlieb, 1983) and more than 15 years ago the Human Immunodeficiency Virus (HIV) was linked to and identified as causing AIDS (Piot & Seck, 2001). Since then HIV/AIDS cases have been documented all over the world (Shisana & Simbayi, 2002). Global estimates of the HIV/AIDS pandemic have revealed that more than 60 million people worldwide have lived with HIV/AIDS and 20 million have died of the disease (UNAIDS, 2003). A global summary of the HIV/AIDS pandemic in December 2003 revealed that approximately 40 million people were living with HIV/AIDS (UNAIDS, 2003).

In South Africa the pandemic is having a catastrophic effect. In the latest available UN statistics it was noted that HIV/AIDS was a crisis in Sub-Saharan Africa, being the worst affected region in the world (UNAIDS, 2003). In South Africa the pandemic is still in its earliest stages and its prevalence is climbing (UNAIDS, 2003). The Department of Health - National HIV and Syphilis Antenatal Sero-Prevalence Survey conducted in 2002 revealed that 5.3 million South Africans are living with HIV/AIDS making HIV/AIDS a major public health concern within South Africa (Department of Health, 2003).

In response to the pandemic there has been a surge of HIV/AIDS initiatives. These include educational efforts, preventative measures, Voluntary Counselling and Testing (VCT) and the roll out of the Prevention of Mother-To-Child Transmission (PMTCT) programme in antenatal clinics and hospitals. Specialised help has also been made available to individuals living infected and affected by

HIV/AIDS (UNAIDS, 2002). The development of antiretroviral drugs (ARV's) is another of the HIV/AIDS initiatives. ARV's suppress or prevent the replication of HIV in white blood cells, resulting in increased survival periods for people living with HIV/AIDS (Piot & Seck, 2001).

Presently cures for HIV/AIDS and methods of prevention and control are being sought. The South African Minister of Health acknowledged the importance of developing effective strategies to manage the illness, facilitate adjustment, enhance wellbeing, improve the quality of life and purposefully care for the millions in this country living with HIV/AIDS (Department of Health, 2003).

The burden of HIV/AIDS has not fallen evenly; the disease has hit the poor and marginalised hardest (Walker & Gilbert, 2002). More specifically, the United Nations AIDS epidemic update of December 2003 exposed that of the millions living with HIV/AIDS in South Africa, African women bear the brunt of the illness (UNAIDS, 2003). At the opening of the Second African Conference of the Social Aspects of HIV/AIDS research, hosted in Cape Town (May 2004), Dr. Kaseje asserted "The women of Africa are most vulnerable to the disease" (Women of Africa most vulnerable to vicious cycle of HIV/AIDS. Retrieved June 28, 2004 from www.hrsc.za).

Women and girls are increasingly at risk of becoming HIV positive due to biological vulnerabilities as well as unequal gender relations and other factors (De Bruyn, 1992). Young African women are considered "most susceptible to infection, have the highest rate of infection, get the most inadequate and inferior access to treatment, take the most responsibility for caring for the sick and dying and have the shortest survival rates" (Walker & Gilbert, 2002, p.75). For this reason the current study presents a focus on this vulnerable portion of the South African population referred to in this study as *Black South African women*. Black

South African women as a term was chosen over the terms, *non-white* or *African* to describe the group on which the present study focuses. Non-white implies an opposition to whiteness as well as a range of possible other groups (Ross, 1995). African includes other racial categories such as *Coloured*, *Indian* or *Black* (Walker & Gilbert, 2002b). Hence in this study Black refers specifically to Xhosa speaking African women. In South Africa there is still an awareness of groups being colour-coded (Cummins, 2002). For this reason this crude but necessary label is used throughout the study to describe the group on which the present study focuses.

1.2 Rationale for the present study

Developing more effective ways of positively impacting the health of Black South African women living with HIV/AIDS was the starting point for the present study. *Social support* defined very broadly as including different aspects of relationships in which needs are met and individuals feel cared for, loved and valued (Cobb, cited in Friedland et al., 1996) was identified as having a powerful impact on health and, therefore, considered crucial in the development of effective strategies of care.

An editorial review on *Social Support and Health* by Green (1993) provided a basis for understanding the positive impact of social support on *wellbeing*, *quality of life* and *health*. Research displayed the positive impact of social support on wellbeing understood as physical, psychological, social and spiritual wellness (Bergholte et al., 2001; Louw, 1994). Research further provided evidence of the positive impact of social support on quality of life, defined as the adequacy of instrumental, tangible, informational, and emotional support. Quality of life refers to a subjective sense of meaning and purpose in life (Bastardo & Kimberlin, 2000; McDowell & Newell, 1987). Finally, the impact of social support on health generally was evident (Green, 1994).

In the management of chronic illnesses such as HIV/AIDS social support has been indicated to provide a sense of *health within illness* enabling individuals to manage their illness (Green, 1993; Jones & Meleis, 1993; Pierret, 2000). Although health has been described as “a state of complete physical, mental and social wellbeing” (in Taylor, 2001, p. 792) this definition is unrealistic with the advent of HIV/AIDS. A utopian state of health is impossible in the face of chronic illness (Taylor, 2001). Thus the concept of “health within illness” is a relevant way of conceptualising health for people living with HIV/AIDS (Moch, in Jones & Meleis, 1993, p.3). Health in this study is defined as “a multidimensional human state or condition and is not necessarily disease free” (Simmons, in Taylor, 2001, p.793). Considered broadly, it incorporates both quality of life and wellbeing. It is also understood as having a number of dimensions including physical, psychological, intellectual, emotional, social, spiritual and occupational aspects (Seedhouse, 1986). Social support was identified as an influential factor on the health of individuals living with HIV/AIDS. This determined that social support should not be ignored in considering strategic intervention into the lives of Black South African women living with HIV (Bastardo & Kimberlin, 2000; Baumeister, Cantanese, & Twenge, 2002; Bergholte et al., 2001; Broachhead et al., 1983; Friedland et al., 1996; Green, 1993; Green, 1994; Koopman et al., 2000; Leserman et al., 2000; Mady, 1996; Matthews, Robinson, & Witek, 2001; Walker, 2002).

Research has provided broad frameworks for understanding the concept of social support (Barrera, Ramsay, & Sandler, 1981; Caplan, 1974; Cobb, 1976; Cohen & Syme, 1985; Cohen & Wills, 1985; Friedland et al., 1996; Green, 1993; House & Kahn, 1985; House, Landis, & Umberson, 1988; Sarason & Sarason, 1983). However, a gap in social support research was apparent. Although frameworks for understanding social support as a broad concept have been developed, social support studies have been criticised for their “theoretical poverty” (Green, 1993, p.90). Particularly from within a South African context,

social support research lacked adequate foundations for understanding social support. Furthermore, social support research within South Africa failed to provide an understanding of social support that could lead to a utilising of the tool of social support in strategic intervention (Kelly & Parker, 2001).

Broachhead et al. (1983) suggested the need for in-depth inquiry into the concept of social support to define it within the context of gender, culture and race. This was particularly necessary from within a South African context. In order to utilise the tool of social support to effectively intervene into the lives of Black South African women living with HIV, inquiry into the concept of social support would be necessary. Social support needed to be defined within the context of gender, culture and race. It was critical that the essence of social support be explored and understood. This could lay the foundation for further efforts made to care and positively impact the health of Black South African women living with HIV. In turn, this would enable intervention strategies to be rooted in informed understandings of social support.

Evidence of the severity with which women have been affected by HIV/AIDS has led to an increase of research focusing on women and HIV (Lawless, Kippax, & Crawford, 1996). However, indications of a paucity of research eliciting information aiding strategies of care and promotion of health were evident (Lawless, Kippax, & Crawford, 1996). Kelly and Parker (2001) commented on the lack of research that “seeks to inform the development of well-honed and effective responses”. They (Kelly & Parker, 2001, p.20) also explained how “(m)uch of the research that exists provides little adequate foundation for developing effective responses”.

This study’s purpose therefore is to deepen understandings of the lived experience of social support for Black South African women living with HIV. The

study seeks to lay foundations of understanding regarding social support that will inform the development of more effective responses thereby implicating strategies of care.

To accomplish these purposes, specific focus will be given to Black South African women's worlds as they describe them, and their lived experiences of social support within those worlds. The study will explore the powerful concept of social support in order to construct a definition of participants' experiences of social support.

The study will be conducted qualitatively within a phenomenological paradigm. A phenomenological paradigm will encourage participants to provide information based on their own lived experience of social support. This, in turn, will inform the development of deepened understandings of the concept of social support. Deepened understandings of social support will have implications for the development of more effective care strategies.



1.3 Broad aims of the study

The current study seeks to review the literature addressing HIV/AIDS as well as issues surrounding women and HIV. Theoretical frameworks for understanding the relationship between social support and health will be explored. Contemporary research displaying how social support positively impacts on quality of life, wellbeing and, therefore, health in general will be highlighted.

The study also seeks to create a space for Black women from a South African context, whose voices have been relatively unheard, to tell their stories (Allen, 2003). Inquiry will be made into the day-to-day lived experiences of social support examining participants' experiences and perceptions of social support.

The study aims to construct a definition of the lived experience of social support as it pertains to the sample and to consider it in light of a greater body of knowledge. Finally, based on the results of the study, implications of deepened understandings of the lived social support will be considered. Implications will be discussed specifically as they pertain to health care professionals, educators and support group facilitators, impacting their strategies of care. Limitations of the study will be considered and recommendations made for future researchers and further research.

1.4 Outlining areas of research

Three areas of research are pertinent for the current study. Firstly, the broader context of HIV /AIDS needs to be delineated. This will include developing an understanding of HIV, its impact and the vulnerability of Black South African women to HIV. Secondly, previous social support research and links between social support and health need examination. Previously established frameworks for understanding social support will be explored. In addition, the powerful impact of social support on the health of those living with HIV will also be investigated, as well as the limitations of social support research. Finally, phenomenology will be described and an understanding developed of the phenomenological research paradigm employed to explore the lived experience of social support.

1.5 Content analysis

The introductory chapter presents the context and rationale for the present study providing an understanding of the broad aims of the study as well as an outline of the areas of research.

CHAPTER TWO:

In this chapter an understanding of HIV and its prevalence in Southern Africa is

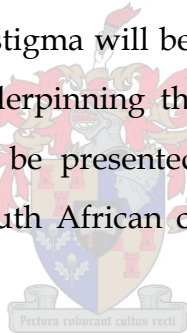
developed. The vulnerability of women is addressed by looking at the realities faced generally by Black South African women.

CHAPTER THREE:

Frameworks for understanding the link between psychological factors and health are explored. This is done by considering contributions from the field of psychoneuroimmunology. A model of stress and coping that highlights the importance of social support is also presented. In this chapter social support, as a broad concept, is investigated.

CHAPTER FOUR:

The need of individuals living with HIV for social support will be reviewed in this chapter. HIV/AIDS related stigma will be highlighted because of its impact on social support. Research underpinning the assumption that social support powerfully impacts health will be presented. The paucity of social support research, particularly from a South African context, is explored providing the rationale for the present study.



CHAPTER FIVE:

Phenomenology, as the methodology of choice for the present study, is introduced, defended and critiqued. Procedures for data collection, ethical issues, limitations of phenomenological research and a discussion on quality and rigour in the study will be presented.

CHAPTER SIX:

In this chapter, the research findings summarised in fourteen themes emerging from the data are presented. A diagrammatical illustration of the world of interpersonal relationships constituting the lived experience of social support for the sample is provided.

CHAPTER SEVEN:

Research results are discussed and interpersonal relationships examined. Results are linked into a greater theoretical world of knowledge and considered in light of three contexts, namely socio-cultural context, temporal context and situational contexts.

CHAPTER EIGHT:

Findings of the study are presented and implications of the study discussed. Implications of the study are addressed to health care professionals, educators and support group facilitators. Recommendations for future research are suggested and implications for future research considered. Comment is made regarding the limitations of the study and recommendations for future studies are made. Finally, the present study will be summarised.



CHAPTER TWO: UNDERSTANDING HIV/AIDS - THE BIGGER PICTURE

This chapter focuses on the physical aspects of the HIV illness, mapping out the course and progression of the illness as it manifests itself in the human body. The progressively debilitating nature of HIV/AIDS demonstrates the need of individuals living with HIV/AIDS for social support. The prevalence of HIV in South Africa will be addressed. Social, economic, sexual and biological vulnerabilities of Black South African women to being infected with HIV will be highlighted providing an understanding of why effective strategies of care need to be developed.

2.1 What is HIV/AIDS

HIV is a disease affecting the immune system, which is the body's defense against infections. The immune system produces cells called antibodies to fight off or kill infections. The immune system comprises a complex system of blood proteins and white blood cells (formed in the bone marrow called phagocytes and two types of lymphocytes, T cells - CD4 cells and B cells). This complex system works together to repel attacks by invading organisms. HIV infects and eventually destroys these cells in the immune system leaving the body defenseless against infections. Individuals infected with HIV become open to opportunistic infections (Van Dyk, 2001). Opportunistic infections are infections that do not usually cause disease in a healthy individual's body. The infections, however, exploit the opportunity presented by an HIV positive person's weakened immune system and attack the body eventually resulting in AIDS and death (Van Dyk, 2001).

The progressively debilitating nature of HIV/AIDS provides insight into the need of individuals living with HIV/AIDS to have available, social support.

Social support assists in aiding in the acceptance of an HIV diagnosis, improving quality of life and helping in times of crisis. Social support enables management of both the illness and daily life, as the body becomes progressively weaker (Pierret, 2000).

2.2 Stages of HIV/AIDS

The course and progression of HIV/AIDS has been theoretically split into a number of phases determined by the amount of HIV in an individual's blood - called a viral load (Van Dyk, 2001). A viral load can be elicited by conducting a CD4 count. A normal CD4 count should be greater than 600 and is typically between 1000 and 1500. The CD4 count of an individual with AIDS is below 200, sometimes even dropping as low as one. An increasing viral load is usually associated with a decreasing CD4 count (Van Dyk, 2001).

2.2.1 Stage one: Acute sero-conversion illness

This phase begins when, through exposure to HIV, an HIV negative person becomes HIV positive. This phase can last from four weeks to eight weeks. During this time the HIV is rapidly replicating making the person's viral load very high. Flu-like symptoms or glandular fever-like illness may present themselves (Van Dyk, 2001).

2.2.2 Stage two: Asymptomatic latent phase

The second phase has been called the silent phase because an infected person displays no symptoms suggesting s/he is HIV positive. The HIV, nevertheless, remains active in the body and continues to damage the immune system. This phase can last for a very long time from months to 16 years. During this time individuals are seemingly well, and possibly unaware that they are HIV positive. Contrary to misconceptions about the transmission of the virus during this stage, those exposed to bodily fluid and blood of the HIV infected individual are at risk

of becoming HIV positive themselves (Van Dyk, 2001).

2.2.3 Stage three: Minor symptomatic phase

During the third phase minor symptoms of HIV begin to manifest. This stage begins when individuals experience mild swelling of the lymph nodes, fevers, shingles, skin rashes, oral ulcerations, recurrent upper respiratory tract infections, weight loss, fatigue and a range of other symptoms (Van Dyk, 2001).

2.2.4 Stage four: Major symptomatic phase

In this phase opportunistic diseases begin to appear as the immune system weakens. The CD4 count becomes very low and the viral load extremely high. A host of symptoms plague the individual and s/he may become bed ridden. Often at this stage individuals will be admitted to hospital where they may find out for the first time that they are HIV positive (Personal communication, R. Badenhaust, May, 2003; Van Dyk, 2001).

2.2.5 Stage Five: AIDS, the severe symptomatic phase

In the final stage, the symptoms of HIV become acute. The immune system has deteriorated to a point where, unable to defend the body against infection, severe, untreatable conditions begin to manifest. Once at the AIDS stage, an individual will usually die within two years. The progression of HIV to the AIDS stage may be accelerated depending on which opportunistic diseases present themselves. Antiretroviral drugs, however, may extend the individual's life (Van Dyk, 2001).

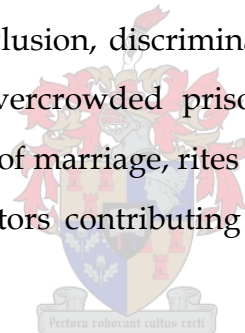
2.3 Prevalence in South Africa

The latest available statistics revealed that in South Africa at the end of 2002 one in nine South Africans was living with HIV/AIDS (UNAIDS, 2003). Based on the National Antenatal Survey conducted by the Department of Health (2003), 5.3

million South Africans were estimated to be HIV positive (UNAIDS, 2003). Results of the National Antenatal Survey further revealed that in South Africa every region, together with all race and age groups were affected by HIV/AIDS. Kwazulu Natal had the highest HIV prevalence rate with Gauteng having the second highest rate. The Free State, Mpumalanga, North West, Eastern Cape, Limpopo and the Northern Cape followed. The Western Cape had the lowest HIV prevalence rates (Department of Health, 2003). These results confirmed the results of the Nelson Mandela Household survey (Shisana & Simbayi, 2002).

2.3.1 Behavioral research results in South Africa

Behavioural research conducted in South Africa has suggested that numerous factors contribute to the rapid spread of HIV/AIDS. These include unsafe sexual behaviours, stigma, denial, exclusion, discrimination and gender related issues. Migration, incarceration in overcrowded prisons, poverty, male and female circumcision or initiation, rites of marriage, rites of death and indigenous healing practices were all cited as factors contributing to its rapid spread (Shisana & Simbayi, 2002).



2.3.2 HIV/AIDS and vulnerability

The vast majority of people becoming infected with HIV have been found to be vulnerable segments of the population. These segments included children, youth, prisoners, refugees, migrant workers, ethnic minorities, the military, the poor, and women (Shisana & Simbayi, 2002). African women and young girls were described as being particularly vulnerable to contracting HIV, reflecting continuing gender inequalities, and a biological vulnerability to infection (UNAIDS, 2003).

2.4 Women and HIV/AIDS

An overwhelming majority of those living with HIV in South Africa are women.

Results of the National Antenatal Survey displayed that at the end of 2002 almost three million women between the ages of 15 and 49 years were infected with HIV. UNAIDS (2003) suggested that African women were more likely to be infected with HIV than men. Several factors could play into this. In South Africa, there exist great social inequalities and societal imbalances. These disparities determine that Black South African women are the most susceptible to infection (Walker & Gilbert, 2002b). In an attempt to explain the vulnerability of Black South African women to HIV, some inequalities and imbalances are discussed below. Social, economic, sexual and biological realities that Black South African women face will be addressed.

2.4.1 Social realities

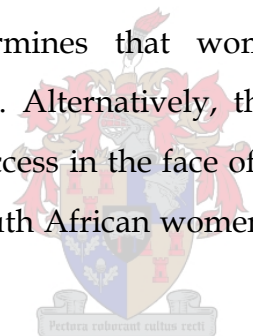
African society generally is patriarchal - the male dominates while the female is subordinate. Social norms define acceptable behaviour, relationship characteristics and role responsibilities. In South Africa research has demonstrated how these social norms translate into gender power imbalance. This imbalance increases the vulnerability of Black South African women to becoming HIV positive (Jewkes, Levin, & Kekana, 2003).

- The cultural norm that men need sex and have a right to get it means many women are “monogamous partners to non-monogamous men” (Haour-Knipe & Aggleton, 1998, p.264).
- Risk taking sexual conquest that is a part of defining manhood, creates vulnerability in men but greatly increases the risk of women becoming HIV positive (Jewkes et al., 2003).
- Women experience lack of power and control over decision-making. This “imbalance in power reduces the female voice in the negotiation of sex” (Macphail & Campbell, 2001, p.1623). Additionally, women have little or no control over their lives sexually, making them at risk for contracting HIV (Macphail & Campbell, 2001).

2.4.2 Economic realities

According to Walker and Gilbert (2002a), many Black South African women live in socio-economically depressed communities, where poverty is endemic. Traditionally these women have had less education than men leading to high unemployment amongst women for example in South Africa in 1995, 23% of Black South African women who were older than 25 had no education. Over a quarter had not passed grade five and 31% of women who had studied had dropped out as a result of falling pregnant. Results of the 2001 census in South Africa reveal that the present situation reflects extremely high unemployment rates among Black South African women deeming these women economically vulnerable (Stats SA, 2004; Walker & Gilbert, 2002a, p.77).

Economic vulnerability determines that women are dependent on their husbands/partners for money. Alternatively, they make attempts to fend for themselves often with little success in the face of poverty and lack of education. This has led to many Black South African women lacking both power and social status (Strebel, 1995).



Economic dependency, lack of power and social status, increase women's vulnerability to HIV on several levels:

- Women are more likely to exchange sex for money or favours. Where poverty exists, women may be driven to prostitution, "(s)exual exchanges with men have become a valuable source of income" (Strebel, 1995, p.3).
- Women are less likely to succeed in negotiating preventative means. Additionally they are less likely to leave relationships they perceive as risky (Gupta, 2000).
- Women are often not in a position to negotiate safer sexual practices because they fear violence and abandonment if they do (Gupta, 2000).
- Lack of material resources leads to malnutrition, stress and susceptibility

to tuberculosis. This is compounded by women being unable to access health care, leading to reduced immunity which combined with other factors, increases the risk of HIV infection (Strebel, 1995).

- Unemployment and lack of education results in minimal exposure to AIDS education thus further increasing the risk of HIV infection (Streubel, 1995).

These economic realities have made it common practice in South Africa that school girls who fear asking their parents for “extra fees if they fail a year are vulnerable to sexual harassment and exploitation by their teachers in exchange for marks” (Neihaus, cited in Jewkes et al., 2000 p.126). “Sugar daddies” offer school girls money in return for sex increasing the likelihood that young girls will be at risk for contracting HIV (Van Dyk, 2001, p.21).

2.4.3 Sexual realities

In South Africa research on sexuality has revealed a tradition of silence and virginity for unmarried Black South African girls. This increases their risk of being infected with HIV. This tradition of silence and virginity condemns pre-marital sexual activity creating a barrier to young women adopting preventative sexual practices. Silence leads young women to fear asking for information regarding safer sex and contraception from clinics and chemists not wanting to be negatively labeled as displaying “unbridled promiscuity” (Vaughan, cited in Strebel, 1995, p.14). This tradition has also heightened parental fear of providing daughters with information regarding sex in case premature sexual activity is encouraged (Jewkes et al., 2003). The myth that should a HIV positive man sleep with a virgin he will be cleansed from infection, further puts young virgins at high risk of rape and being infected with HIV (Leclerc-Madlala, 2002).

Within intimate sexual relationships a similar culture of silence and submission

has been identified. Good women are expected to fulfill their partners' needs and wishes, satisfy their male partner's urge for sexual pleasure, and remain ignorant about sex. Good women are also expected to be passive in sexual interactions (Jewkes et al., 2003). This increases vulnerability to HIV on two levels:

- Difficulty is experienced in being proactive in negotiating safer sex because women do not talk about sex with their husband or partner for fear of appearing promiscuous (Varga, 1997).
- Negotiating safer sex is difficult because of concerns regarding men's sexual pleasure (Wood, in Jewkes et al., 2003).

2.4.4 Biological realities

As well as being socially, economically and sexually vulnerable, women have a biological vulnerability to becoming infected with HIV.

- Women are particularly vulnerable to heterosexual transmission of HIV, due to exposure to seminal fluids during sexual intercourse (Strebel, 1995).
- Menstration makes women more vulnerable to contracting HIV. Sexually transmissible infections (STI's) are readily acquired during this time. However, these remain undetected resulting in inefficient treatment that in turn increases the risk of HIV infection (Strebel, 1995).
- As a result of the accepted practice within South Africa of Black South African men having other lovers with whom they have sexual intercourse, many women have STI's (Haour-Knipe & Aggleton, 1998). Accessing services for STI's is thought to be highly stigmatising. Consequently many women do not seek treatment. In the presence of STI's the risk of contracting HIV is greatly increased (Gupta, 2000).

In summary, this complex mix of social, economic, sexual and biological vulnerabilities Black South African women generally face, has resulted in many

living with HIV. This is reflected in the review of the prevalence of HIV in women in South Africa. On top of these every day realities, women contracting HIV experience marginalisation as they become the recipients of rejection, isolation, stigmatisation and are ostracised as a result of the social unacceptability of HIV (Orr & Patient, 2004).

Black South African women living with HIV are in need of social support aiding the management of the illness (Pierret, 2000). The impact of social support on health indicates that receiving social support is a crucial (Callaghan, Chung, Lam, Molassiotis, & Twinn, 2002). A dilemma, however, exists. The social unacceptability of a HIV diagnosis may lead to discrimination and stigmatisation. This determines that at the time when social support is most needed, least may be experienced (Callaghan et al., 2002).

For this reason a deepened understanding of social support must be elicited. Adequate foundations must be laid for understanding social support within the context of gender, culture and race. These foundations can inform those developing HIV/AIDS management strategies, determining that more effective forms of care be provided for individuals living with HIV, positively impacting health.

In beginning to understand social support, some theoretical frameworks will be developed. In the following chapter contributions from the field of psychoneuroimmunology will be addressed. These will display the link between psychological factors and health. A model of stress and coping, introducing the importance of social support, will be presented. Furthermore, a framework will be established for understanding the concept of social support.

CHAPTER THREE: UNDERSTANDING SOCIAL SUPPORT AND HEALTH

In this chapter a link will be presented between psychological factors and health by considering contributions from the field of psychoneuroimmunology. A model proposed by Lazarus and Folkman (1984a) will be examined to provide an understanding of the relationship between stress, coping and social support. This will later be translated into the relationship between HIV illness stressors and social support. A framework for understanding the concept of social support will be presented. Limitations of previous social support research will also be addressed.

3.1 Psychoneuroimmunology

Research conducted over the past twenty five years in the field of psychoneuroimmunology has provided evidence for understanding the role of psychological factors in physical illness (Ader, 2001). The concept of a neuroendocrine response to the psychological factor of stress was introduced in the 1940s by Seyle (1946). Since then, studies with both humans and animals have provided evidence that behavioural and psychological factors have a profound impact on immune functioning and health (Ader, 2001).

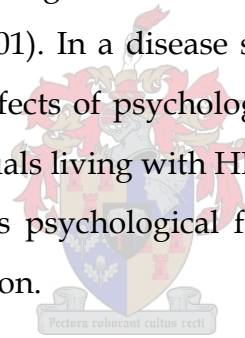
Cohen and Herbert (1996) provide a summary of key findings in the field of psychoneuroimmunology:

- Bi-directional pathways connecting the brain and the immune system provide a foundation for understanding neural, endocrine, psychological and behavioural effects on immunity (Ader, 2001; Cohen & Herbert, 1996; Kelly, Hertzman, & Daniels, 1997).
- Biological pathways have been discovered through which psychological characteristics and states yielded physical changes.

- The immune system and disease susceptibility have been found to be altered through psychological intervention.
- Psychological states such as depression, anxiety, psychological distress or, conversely, social support, and an optimistic view are able to alter one's ability to resist infection.

These findings generate plausible explanations for understanding how psychological factors influence the immune system and mediate disease (Ader, 2001). These findings are also important in considering effective care strategies impacting the health of Black South African women living with HIV.

The immune system cannot be regarded as functioning independently of other systems in the body (Ader, 2001). In a disease such as HIV where the immune system is compromised, the effects of psychological factors (for example, stress and social support) on individuals living with HIV cannot be ignored. The effects of stress and social support as psychological factors impacting health will be examined in the following section.



3.2. Stress

Stressful events are believed to alter immunity. When demands imposed by events exceed the ability to cope, “(a) psychological stress response composed of negative cognitive and emotional states is elicited. It is these responses that are thought to influence immune function through their effects on behavioural coping and neuroendocrine response” (Cohen & Herbert 1996, p. 119).

3.2.1 *Stress and coping*

To understand the impact of stress on health, a model developed by Lazarus and Folkman (1984a) will be examined. In this model, stress is seen as a relationship between individuals and their personal environment that challenges them to

mobilise coping resources. If individuals cognitively appraise their environment as demanding or exceeding personal coping resources, the result is stress. Adaptive coping occurs when the individual faced with a stress-producing situation is able to cope effectively so as to resolve the stressor. They do this by managing or altering stress producing situations and regulating emotional responses. Coping has been defined as “(c)ognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984b, p.141). The ability to employ adaptive coping positively impacts health. Conversely, individuals unable to employ adaptive coping may become overwhelmed by stress. This, in turn, negatively impacts on health.

The effects of stress on individuals were investigated by Glaser and Kiecolt-Glaser (in Cohen & Herbert, 1996) who studied the impact of stress on immune function. First year medical students’ psychological stress levels and immune responses were assessed just before a vacation, and again during a series of important exams. Students reported more stress during exams and indicators of immune levels decreased. These results demonstrated increased stress to be associated with immune change (Cohen & Herbert, 1996).

3.3 Social support

Taking the model proposed by Lazarus and Folkman (1984a) further, social support has been identified as enabling the employment of adaptive coping strategies. Buffering the negative effects of stress, social support enables management of stress producing situations and regulation of emotional response, minimising stress and positively impacting health. Research has shown social support to be associated with wellbeing, the absence of distress and better health outcomes (Cobb, 1976; Cohen & Wills, 1985; Friedland et al., 1996; Gore, 1978; Green, 1993; Nuckolls, Cassel, & Kaplan, 1972; Ridder & Schreurs, 1997).

Individuals cope better with life's stresses and stressful conditions when social support is available to them and they are integrated into a social network perceived to be positively supportive. Social support, therefore, has been identified as playing a central role in insulating individuals from stressors and maintaining health (Cohen & Syme, 1985).

Adapting the model (Lazarus & Folkman, 1984a) into a context of HIV allows an examination of the positive impact of social support on the health of individuals living with HIV. For individuals living with HIV, social support is of utmost importance in insulating them from HIV illness stressors, in contributing to host resistance and in maintaining health. Social support buffers the negative stressors of HIV strengthening the immune system, thereby positively impacting health (Matthews et al., 2001). Alternatively, poor social support has been associated with a more rapid progression from HIV to AIDS (Matthews et al., 2001). Thus an understanding of the powerful concept of social support, as an effective tool enabling the management of HIV/AIDS, thereby, promoting health, needs further investigation.



3.4 Introduction to the context of social support

For almost three decades, social support has been of interest to researchers because of its potential to positively influence health outcomes in a variety of situations (Cobb 1976). Caplan (1974) first investigated support systems and community health. The term social support has become popularised since. Social support is generally understood as the various forms of aid and assistance individuals feel are available to them (Barrera et al., 1981; Cohen & Wills, 1985; Friedland et al., 1996).

3.5 Defining the concept of social support

In its simplest form, social support is defined as being cared for, loved, valued, esteemed and able to count on others should the need arise (Cobb, cited in Freidland et al., 1996, p.16). Social support has been described by Cobb (in Barrera et al., 1981) as the information enabling individuals to believe they are part of a larger network. Members of this larger network include kin and non-kin, professional and non-professional relationships. These relationships provide various forms of assistance in response to the needs of individuals.

3.6 A framework for understanding social support

Social support has been referred to as an “omnibus term”, relating to different aspects of social relationships. Green (1993, p.90) summarised various research suggesting a conceptual framework for understanding social support.

- Firstly, social support refers to the existence, quantity and type of interpersonal relationships (social network/sources of support.)
- Secondly, social support is about how interpersonal relationships function on a psychological, tangible, informational and emotional level (interactional content).
- Thirdly, social support is influenced by how individuals perceive the quality and adequacy of support.

i) Social network

Social support is made up from a social network. Social network is derived from major areas of life and the structures that exist within those major areas that create space for interpersonal interactions. These include work, school, church, family, friends, community involvement, leisure interests, sport, etc. (Hirsch, 1983). The quality of interpersonal interactions within major areas of life affects levels of personal satisfaction impacting on health (Hirsch, 1983).

Henry (in Sarason & Sarason, 1983) referred to a social network as a personal community that individuals make up by expressing and embedding themselves in major areas of life. An individual's personal community reflects the nature of his or her life, interests, priorities, obligations, love and disappointments. In creating and maintaining a particular personal community, individuals implicitly choose, from among feasible alternatives, how to achieve meaningful participation in culture and society. Whether individuals are successful in establishing a satisfactory personal community has important bearing on health (Henry, in Sarason & Sarason, 1983).

ii) Interactional content

Interpersonal relationships within a social network are potential positive support, if the interactional content meets individuals' needs on one or more of the following levels (House & Kahn, 1985), by providing:

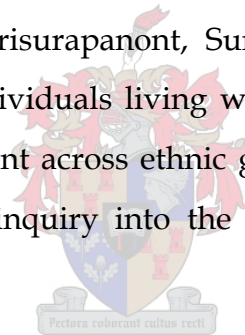
- Instrumental support: for example, receiving advice regarding a particular problem.
- Tangible support: for example, receiving material assistance.
- Informational support: for example, receiving information and advice on certain issues.
- Emotional support: for example, receiving reassurance or experiencing emotional connectedness.

iii) Perception of the quality and adequacy of social support.

Individuals perceiving the quality of their social support to be adequate or satisfactory experience high levels of positive supportive interactions within their social network. In turn, high levels of personal satisfaction are experienced. Individuals more personally satisfied are considered healthier than individuals experiencing low levels of supportive interactions (Hirsch, 1983).

3.7 Limitations of the framework of social support

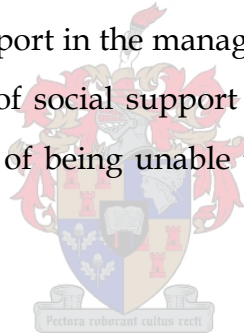
The above goes some way to propose a conceptual framework for understanding social support and the health promoting effect of social support. However, it has been suggested that much needs to be learned about the complexity of social support, and its practical applicability (Friedland et al., 1996). Within a South African context the paucity of social support research impacting prevention and care efforts has been noted as has the need for frameworks of social support leading to the development of effective health management programmes (Kelly & Parker, 2001). Green (1993, p.90) commented on “the theoretical poverty of social support studies” suggesting the need for an in-depth inquiry into the concept defining it within a context of gender, culture and race. Broachhead et al. (1983) highlighted the problem of the socio-economic, gender and cultural variation in social support. Srisurapanont, Sungworn and Jarusurasin (2001) observed in their study of individuals living with HIV in Thailand, that social support appeared to be different across ethnic groups. The need, therefore, has been identified for a deeper inquiry into the concept of social support as it pertains to specific groups.



The present study responds to the limitations of previous social support research. The present study aims at understanding the lived experience of social support for a group of Black South African women living with HIV. The conceptual framework of social support will be translated into a working definition. Understandings the experience of social support will enable practical applicability of the concept. Reflection on the emerging definition of the concept of social support will have implications for strategic intervention. Furthermore, foundations for future social support research, within a specific South Africa context will have been laid.

In summary, this chapter has presented the link between psychological factors and health. Contributions of the field of psychoneuroimmunology have been considered. A model of stress and coping introduced the importance of social support and its potential to positively impact health. A conceptual framework for understanding social support was explored and limitations of previous social support research have been highlighted. How the present study responds to the limitations has been mentioned.

In the ensuing chapter, the context of HIV will be linked to the model proposed by Lazarus and Folkman (1984a). Specific illness stressors for individuals living with HIV will be described. The powerful impact of social support as a buffer against the negative effects of HIV stressors will be examined. Selected studies observing the role of social support in the management of HIV will be presented. Specific aspects of the impact of social support on individuals living with HIV along with some of the effects of being unable to access social support, will be highlighted.



CHAPTER FOUR: UNDERSTANDING THE IMPACT OF SOCIAL SUPPORT

In the following chapter literature demonstrating the impact of social support on the health of individuals living with HIV will be presented. Two specific stressors related to HIV will be highlighted, these being stigma and disclosure. HIV/AIDS related stigma will be addressed in some detail because of its impact on social support. The buffering role of social support against the negative effects of HIV illness stressors will be illustrated by examining a number of selected studies. These were chosen for their capacity to highlight the impact of social support on specific aspects of the health of individuals living with HIV. A discussion centering on a gap in social support literature from a South African context will provide further rationale for the present study.

4.1 Illness as a stressor

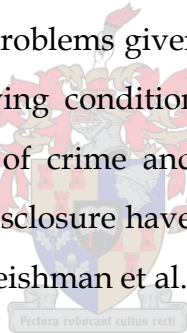
Lazarus and Folkman's (1984a) model of stress and coping provides insight into the effect of stress on coping and health, displaying the power of social support to buffer the negative effects of stress. Research has suggested that in conditions of chronic illness or disability stressful events become particularly prevalent (Friedland et al., 1996; Olley, Gxamza, Seedat, & Stein, 2003). A chronic illness diagnosis itself is a stressor. On top of that the various sequel of illness or disability such as changed roles, changed income, the risk of becoming unemployed or already being unemployed and changed relationships, etc., become additional stressors or "chronic strains" (Avison & Turner, cited in Friedland et al., 1996, p.16).

4.2 HIV stressors

The stressors at work in individuals living with the chronic illness of HIV/AIDS have been found to be immense (Avison & Turner, cited in Friedland et al., 1996;

Olley et al., 2003). The burden of receiving an HIV diagnosis and the illness trajectory of HIV leads to a weakening of the body. HIV infection involves recurrent symptoms such as night sweats, nausea, swollen lymph nodes and other symptoms. These present HIV illness stressors to individuals infected with the virus (Fleishman et al., 2000). On top of physical illness stressors, HIV has been found to generate fear, misunderstanding, misinformation and discrimination. Isolation, loss of status and roles, unemployment, lack of financial resources, disfigurement and the need to change patterns of physical intimacy all place individuals living with HIV at high risk of psychological problems (Olley et al., 2003).

Particularly within a South African context, Black women living with HIV may be at high risk of psychological problems given the realities already discussed in section 2.4, namely, stressful living conditions, high unemployment, poverty, inadequate housing, high rates of crime and domestic violence (Olley et al., 2003). In addition, stigma and disclosure have been described as major stressors for those diagnosed with HIV (Fleishman et al., 2000; Orr & Patient, 2004).



4.2.1 Stigma and disclosure

Stigma, defined as “a construction of deviation from some ideal or expectation” (Alonzo & Reynolds, 1995, p.304), has been described as marginalising and excluding individuals from groups because of an acquired attribute such as an HIV positive diagnosis (Taylor, 2001).

Throughout the world an HIV positive diagnosis carries a stigma (Orr & Patient, 2004). Stigmatisation resulting from HIV has been considered a result of physical deformity and or blemishes of individual character with the latter being of greatest concern. Cultural, sexual, religious and legal influences that dictate sexual practices, preferences, sexual desires, the number and type of sexual

partners, the use of birth control, the use of condoms and the use of drugs, link individuals who are HIV positive to undesirable sexual behaviour and a sexual moral domain that views pre-marital/extra-marital sex as 'sin' blemishing the character of an individual (Goffman, 1990; Lie & Biswalo, 1996).

Herek (1999) suggests that stigma has been strongly connected to HIV/AIDS for a number of reasons. Contracting HIV has been perceived to be the bearers' responsibility. HIV as an illness is perceived as having been contracted through voluntary and avoidable behaviours that are immoral. Herek (1999) continues by saying that stigma has also been strongly connected to HIV because of its unalterable or degenerative nature. The fact that HIV/AIDS has been constructed as a fatal disease determines that it has been inextricably linked to death (Herek, 1999). Orr and Patient refer to this as "stigma creating belief number 1: AIDS equals death. You are going to die. Resources are scarce. Therefore I cannot afford to invest time and resources in you" (2004, p.10). Stigma has also been associated to HIV/AIDS because HIV/AIDS have been perceived to be highly contagious even in conditions of casual contact (Herek, 1999). Finally, Herek (1999) highlights that full blown AIDS has been a condition that is very apparent to others evoking distress and stigma from observers.

A number of different types of stigma are attached to HIV/AIDS. *Societal stigma* is a result of spoken or unspoken expectations of community members to withdraw themselves from those members living with HIV/AIDS due to the above mentioned reasons (Weingarten in Blom, 2003). *Self stigmatisation* results from individuals living with HIV internalising societal stigma or subtly buying into stigmatised notions of people living with HIV which may lead to self loathing, self blame and self destructive behaviour (Herek, 1990; Klitzman, 1997; Personal communication, T. Shefer, November, 2004). *Courtesy stigma* is the stigmatisation loved ones of individuals living with HIV may experience as they

too often face discrimination because of their association with a person living with HIV/AIDS (Goffman, in Herek, 1999).

Stigma has major implications for social support. Being HIV positive determines that social support is needed to enable coping with mounting HIV illness stressors. However, as a result of the social unacceptability of an HIV diagnosis at the time social support is most needed, least may be experienced. Disclosure is experienced as too difficult and too risky (Callaghan et al., 2002) Fear of the stigma attached to HIV/AIDS and discrimination, therefore, constitute major barriers to accessing adequate care, support and treatment (UNAIDS, 2003).

HIV/AIDS and stigma have been well documented. Studies encapsulating the experience of HIV/AIDS and stigma in India, Hong Kong and South Africa will be examined. The Ugandan experience will also be highlighted.

In India, where a strong patriarchal society exists, Bharat and Aggleton (1999) reported how women diagnosed as HIV positive experienced marginalisation and discrimination, sometimes being severed from their families and considered dead.

In Hong Kong, a study was conducted (Callaghan et al., 2002) investigating perceived needs to elicit physical, psychosocial, health behaviour and informational needs of individuals living with HIV. Results of the study revealed that stigma, denial and exclusion were major sources of concern. Participants described feeling unable to disclose their status and having no one to talk to about their illness or worries (Callaghan et al., 2002).

In South Africa, research revealed the main fears for women diagnosed HIV positive to be fear of stigma, denial, exclusion and discrimination at a

community, family and health personnel level (Shisana & Simbayi, 2002). Accounts of serious physical abuse within South Africa further highlight the problem of stigma in this country (Personal communication, R. Badenhaurst, June, 2003; McNeil, 1998).

Stigma is a social construction that profoundly impacts the life experiences of individuals living with HIV (Taylor, 2001). In South Africa the social, economic and sexual realities discussed earlier dictate that many Black South African women live within a context in which they are socially disadvantaged. They live in poverty, lack education, have poor access to health care, lack employment as well as power and control over decision-making (Walker & Gilbert, 2002b). Within these conditions, the fear of stigmatisation, being discriminated against, being morally degraded and labeled socially unacceptable is heightened determining that many diagnosed HIV positive, live in silence and isolation (Lie & Biswalo, 1996). Fears centre on inevitable discrimination, negative social reactions, loss of employment, rejection from the family, expulsion from housing, isolation, avoidance and negative judgment should one's HIV status be revealed (Olley et al., 2003).

South African researchers Orr and Patient (2004) suggest that the stigmatisation of people living with HIV is a major obstacle to dealing with HIV/AIDS effectively. They posit that primarily stigma prevents South Africans living with HIV/AIDS from accessing resources and from seeking very necessary forms of support (Orr & Patient, 2004).

In contrast, in Uganda, a study evaluating counselling, medical and social services of The AIDS Support Organisation (TASO) revealed that people's attitudes, knowledge and lifestyles displayed an acceptance of HIV (Kaleeba & Kallibala, 1997). This could be attributed to the National AIDS Control

Programme set up in 1986 following the first reported AIDS cases in Uganda. Together with TASO the National AIDS Control Programme has radically changed Ugandan mindset about HIV/AIDS. This has resulted in 90 percent of individuals revealing their status and a high level of acceptance of people living with HIV/AIDS by the family and the community (Kaleeba & Kallibala, 1997). As already displayed, this is not the experience reported generally. However, the Ugandan study provides hope that the stigma surrounding HIV/AIDS can lessen and may not always be such a harsh reality for those diagnosed HIV positive.

The illness stressors of an HIV diagnosis have been found to lead to emotional distress. Kelly, Raphael and Statham (1996) reported that emotional distress was higher in HIV positive individuals than among patients with other life-threatening illnesses. Stigma undermines and devalues individuals living with HIV, generating shame and insecurity (UNAIDS, 2003). Consequently an HIV diagnosis has been associated with alienation, loneliness, depression, suicidal ideation, guilt, fear of social isolation, questioning and an evaluation of one's entire existence - the purpose of life that has just been cut short (Green, 1993).

4.3 The impact of HIV stressors

Tsasis (2000) described living with HIV as a complex phenomenon, an experience of confronting loss, fluctuating emotions, making changes and gaining control of an altered life style. As a result, individuals diagnosed with HIV struggle with resolving personal dilemmas and finding meaning in life. They are constantly reminded of losses through limitations and illness complications.

Individuals living with HIV tend to mobilise all their strength to cope. However, coping in the face of such adversity is difficult. Stress mounts as short comings

and an inability to manage alone become a reality. Tension increases, leading to fear and a sense that coping is impossible (Louw, 1994).

Stressors for individuals living with HIV have been described as becoming overwhelming, threatening wellbeing, quality of life, overall health and exacerbating medical problems (Catania, Coates, Kyung-Hee, & Turner 1992; Hedge, 1990).

4.4 Social support and chronic illness

According to Feldman (in Tsasis, 2000), in chronic illness individuals need to come to terms with the reality that their chronic condition is their state of being. Feldman (in Tsasis, 2000, p.555) purports that chronic illness involves individuals “(d)iscarding false hope and destructive hopelessness and restructuring their environment in which they must now function.” It involves accepting the self and creating meaning and purpose that transcends “the limitations imposed by illness” (Feldman, quoted in Tsasis, 2000, p. 555). This is only possible if social support, aiding in performing such tasks and buffering the negative effects of HIV illness stressors, is available.

Studies observing the role of social support in the management of long term and chronic illnesses have consistently found social support to provide invaluable psychological resources. These psychological resources help the sufferer to cope with illness and promote health (Green, 1993). A strong link between social support, psychological wellbeing and a lower incidence of physical illness has been noted (Cobb, 1976; Cohen & Wills, 1985). Social support, in the form of aid and assistance supplied by family members, friends, neighbours and others, positively impacts health (Barrera et al., 1981). On the other hand, perceptions of non-supportiveness have been associated with increased psychosocial, situational stressors and poor health outcomes (Tsasis, 2000).

4.5 Social support and HIV/AIDS

Literature supports the link between social support and the health of individuals living with HIV/AIDS. Studies have indicated that social support reduces HIV illness stressors playing a significant role in coping with HIV (Bastardo & Kimberlin, 2000; Baumeister, Nuss, & Twenge, 2002; Bergholte et al., 2001; Broachehead et al., 1983; Callaghan et al., 2002; Friedland et al., 1996; Green, 1993; Green, 1994; Koopman et al., 2000; Leserman et al., 2000; Mady, 1996; Matthews et al., 2001; Pakenham, Dadds, & Terry, 1994; Walker, 2002).

In the ensuing section studies focusing on the impact of social support on various aspects of health are presented. The studies demonstrate how social support positively impacts quality of life and coping, gives a sense of hope and wellbeing, minimises psychological distress and improves immune functioning. The studies also provide insight into the effects of being unable to access social support. Unhelpful aspects of social support will be highlighted. Key findings of the studies will be noted and, in some cases, limitations discussed.

4.6 The impact of social support on individuals living with HIV, a review

4.6.1 Social support indicates higher perceptions of quality of life

A study conducted in Venezuela (Bastardo & Kimberlin, 2000) hypothesised that social support could affect health outcomes through its effects on the immune system, wellbeing and quality of life. This hypothesis was explored using a cross-sectional design. One hundred individuals living with HIV were tested with quality of life measures, a symptom scale measure and social support measures. Using quantitative data analysis methods, results showed significant positive association between social support and quality of life in both the psychological and physiological domains of participants' lives. Social support was shown to be

indicative of higher perceptions of quality of life, enabling participants to be healthier and live more positively with HIV (Bastardo & Kimberlin, 2000).

4.6.2 Social support reduces stress response to HIV and improves coping

In a study displaying the link between social support and wellbeing (Koopman et al., 2000) the relationship between coping, social support and stress was examined in 140 HIV positive participants (80 men and 67 women). The study evaluated psychosocial factors associated with perceived stress among individuals living with HIV/AIDS. The study aimed at identifying factors contributing to a high prevalence of emotional distress. Participants were examined in ongoing randomised clinical trials of group therapy. Results of the study suggested that coping strategies were important contributors to perceived stress for participants. Moreover, results displayed the importance of social support in minimising the stress experienced by individuals living with HIV. The protective effect of social support was noted and seen to operate by both contributing to ability to cope with stressors and by reducing stress response to stressors. The simple perception that adequate social support existed emerged as having a buffering effect. According to Koopman et al. (2000) and Lazarus and Folkman (1984), social support is critical in reducing response to stressors, therefore essential to the health of individuals living with HIV, because it facilitates the adoption of adaptive coping strategies. The results of the study revealed the main factor associated with emotional distress to be low perceived social support (Koopman et al., 2000).

Some limitations were noted in the study: The self report methods, cultural limitations of the findings whereby the population sample was largely white, urban, heterosexual individuals or individuals living in large cities. Nonetheless, the study challenged the acceptance of the key findings: That ability to employ coping strategies was an important contributor to perceived stress for

individuals living with HIV and perceptions of social support a crucial factor, in impacting levels of emotional distress and health for individuals living with HIV (Koopman et al., 2000).

4.6.3 Social support empowers and evokes a sense of hope

In examining the link between social support and health, Heckman et al. (in Walker, 2002) noted the tendency of research to focus on urban samples, and thus focused on women living in rural areas. The focus on rural areas ensued as a result of the awareness of the alarming increase in HIV infection in rural areas. Heckman et al. (in Walker, 2002) found that women infected with HIV living in rural areas who felt they had social support available to them, had a stronger sense of hope. These women were identified as doing well and being more empowered, compared to women living with HIV in rural areas, without access to social support. Women unable to access social support were defined as lower functioning and less resilient in coping with illness. Heckman et al. (in Walker, 2002) concluded that women living with HIV/AIDS needed to access social support because it was crucial in boosting coping skills, providing support and nurturance, thereby positively impacting health.

4.6.4 Social support heightens perceptions of wellbeing

Bergholte et al. (2001) studied the effects of the intervention of a small support group into the lives of sixteen individuals living with HIV. A pretest-posttest, no-control group design approach was adopted. The study showed that the support group intervention increased perceptions of social support. This produced higher perceptions of wellbeing enabling individuals to engage in more adaptive coping skills, planful problem solving, confrontive coping and future optimism that led to higher perceptions of wellbeing.

Participants also recounted experiencing less illness stressors associated with AIDS-related loss and health concerns. In addition, at a three month follow-up assessment, participants reported that they experienced less psychological distress, were less depressed and experienced less grief reaction. Although the study dealt with an aspect of individuals' social support network (namely support groups), results verified the importance of social support in the lives of individuals living with HIV/AIDS.

4.6.5 Social support decreases psychological distress and uncertainty in illness while increasing immune functioning

Callaghan et al. (2002) conducted a study in Hong Kong in which 46 individuals were recruited from an outpatient clinic of a large hospital. Individuals participated in a comparative study, assessing the effectiveness of Cognitive Behavioral Therapy (CBT) and Peer Support Counselling group therapy (PSC) in relation to improving mood, quality of life and decreasing uncertainty in illness, compared to the group receiving no-treatment. Individuals were randomly assigned to the CBT group, PSC group or the no-treatment group (who for ethical reasons were offered crisis intervention and individual counselling; no one required it). Each of the two treatment groups had twelve sessions of two hours and was measured pre-intervention, post-intervention and three months post-intervention on levels of quality of life, profile of mood states and uncertainty of illness.

Results displayed that treatment groups had higher quality of life scores and experienced a significant decrease in distress and uncertainty in illness compared with the no-treatment group. At completion of the programme, individuals of the treatment groups reported regret that they would lose an aspect of their social support network that had proved invaluable. The study revealed that supportive groups and social support decreased psychological distress and

improved the quality of life of individuals living with HIV. This was attributed to the role social support played in decreasing uncertainty in illness (Callaghan et al., 2002).

Following on from the above study, Pakenham et al. (1994) argued that social support was associated with higher CD4 cell counts along with self reports of less HIV related symptoms in individuals living with HIV. The Callaghan et al. study (2002) substantiated the argument, as results displayed the positive effect of support groups on the CD4 count of participants. The CD4 count of individuals in the treatment groups increased at the end of the intervention. In comparison there were no changes in the CD4 count of the no-treatment group. Both Pakenham et al. (1994) and Callaghan et al. (2002) studies have demonstrated the health promoting physiological impacts of experiencing an improved quality of life as a result of accessing social support.

The link, therefore, between social support and health has been displayed. This link provides evidence of the stress buffering hypothesis of social support (Cohen & Wills, 1985). Social support is able to provide protection against the effects of stressful events and situations (Cohen & Wills, 1985; Koopman et al., 2000). Further studies (Hays & Magee, 1994; Leserman et al., 2000; Wheeler, 1999) display the positive impact of social support on health, by considering the effects of an inability to access social support.

4.6.6 Weak social support negatively impacts health increasing the speed of progression of HIV to AIDS

In a five and a half year study of 96 gay men infected with HIV, the disease progression of HIV and the influences on disease progression were explored in the lives of participants. Exploration took place by examining the association of stressful life events, social support, depression, anger, serum cortisol and

lymphocyte subsets with changes in multiple measures of HIV disease progression (Leserman et al., 2000). Leserman et al. (2000) suggested the probability of HIV progressing more rapidly was two to three times higher for men living with HIV who had more than average stress and less than average social support, compared to those below the median on stress and above the median on social support. In addition stressful life events and limited social support were associated with a more rapid progression of HIV to AIDS. These results confirmed the strong link between social support and health for individuals living with HIV/ AIDS (Leserman et al., 2000).

4.6.7 Weak social support increases stress

Wheeler (1999) conducted a two year study with 82 men living with HIV. He argued that stressful events and weak social support sped up the progression of HIV to AIDS. Every six months participants' disease status and conditions of life were measured using checklists and interviews. Results demonstrated the link between weak social support, severe stress, depression and low measures of immune system function. Participants experiencing high stress had weak social support and a more rapid progression from HIV to AIDS.

These studies clearly indicate the significant impact of social support on the health of individuals living with HIV. Although no data were available correlating the exact rate of progression of HIV with social support, survival time for individuals living with HIV has been shown to be extended by a supportive environment and supportive interactions, thus endorsing social support (Green, 1994).

4.6.8 Unhelpful behaviours

In considering the impact of social support on health, Hays and Magee (1994) suggested that some behaviours perceived as helpful and supportive by the

support giver may be the opposite. Certain behaviours were hypothesised to have a detrimental effect on health outcomes for individuals living with HIV. Awareness of the negative impact of specific behaviours and their effect on health outcomes were examined in a study conducted by Hays and Magee (1994).

Twenty five gay men living with HIV were interviewed regarding their social support networks. Helpful and unhelpful behaviours of loved ones were identified by participants (Hays & Magee, 1994). Results revealed that unhelpful behaviours included, Being treated in a patronising or over-protective manner; caregivers, acting in a pessimistic manner, and avoiding intimate interaction and expression of feeling, in an attempt to be treat the individual living with HIV as if nothing was wrong; criticism or judgment regarding how the individual living with HIV was coping with their illness in an attempt on the part of care givers to give advice about the way they should be living; caregivers expressing doubt regarding medical care in an effort to better care for the individual living with HIV was also experienced as unhelpful behaviour; caregivers' behaving as if they were embarrassed or ashamed of the individual's status was unhelpful, as was caregivers being rude and insensitive about the individual living with HIV without realising it. Finally, breaking confidentiality in an effort to provide more friends for individuals living with HIV, for example, inviting friends over without asking if that is what the individual living with HIV would like, was expressed as unhelpful behaviour.

Participants expressed that these behaviours made them feel more unwell, unhealthy and less likely to access social support that would be beneficial (Hays & Magee, 1994). The generalisability of the findings of this study was limited by the small sample. Furthermore, participants were predominantly white, middle class and gay men. Nonetheless, the importance of developing an understanding

that the experience of receiving social support has both positive and negative components was highlighted. Hays and Magee (1994) suggested that, although considerable evidence displays the positive impact of social support on health, unhelpful support had detrimental effects on health (Hays & Magee, 1994). Exploration of this polarity in social support is necessary.

4.7 The present study and social support research

The present study has reviewed the literature related to the link between social support and health, to date. However, the researcher notes that from a South African context there are limited accessible academic publications of social support research. This could be partly attributed to the lack of intricate and detailed understandings of social support from within a South African context.

This present study will focus on examining social support from within a South African context. This is necessary for two reasons: Firstly, because of the prevalence of the AIDS pandemic in this country and particularly in the Black South African community. Secondly, this focus is necessary because of the evidence of the positive impact of social support on the health of individuals living with HIV.

This study aims to search for deeper understandings of the lived experience of social support from within the socio-cultural and situational contexts of Black South African women living with HIV. Exploring the concept of social support as Black South African women themselves describe it will provide foundations of understanding surrounding the lived experience of social support. Furthermore, it will provide a definition of social support. Informed understanding of the lived experience of social support will assist in laying groundwork for the utilisation of the tool of social support in the development of more effective care strategies.

In order to fulfill the aims of the study, the lived experience of social support for nine Black South African women living with HIV will be explored. Face to face interviews will provide these women with an opportunity to tell their stories, describe their lived experiences and share their feelings. The data generated from the interviews will elicit rich understandings of social support and provide an in-depth understanding of the lived experience of social support that takes into consideration gender, culture, race, life experience and situational contexts.

This chapter, in summary, has presented the illness stressors of HIV and engaged with HIV/AIDS related stigma. The positive effect of social support on the health of individuals living with HIV has been demonstrated. The studies reviewed have highlighted the impact of social support on various aspects of health. An understanding was provided of the impact of being unable to access social support as well as awareness that not all aspects of the experience of receiving social support are health promoting. Limited accessible social support research within a South African context was noted providing rationale for the current study and the need for a deepened understanding of social support. In the next chapter, the research design and methodology of the study will be presented.

CHAPTER FIVE: RESEARCH METHODOLOGY

In this chapter the research methodology employed in the study is presented. Justification is provided for the chosen qualitative research design. Sampling is discussed and the participants making up the sample are introduced. Ethical issues, collection, management and analysis of data as well as an examination of the limitations, quality and trustworthiness of the study will be presented.

5.1 Research design

The purpose of this study was to gain an understanding of the lived experience of social support for nine Black South African women living with HIV. Hence, the study focuses on the perspectives of the women, and their day-to-day lived experiences of social support. In designing the study, information was gathered regarding the broader context of HIV/AIDS, specifically as it pertains to Black South African women. The relationship between social support and health was examined providing rationale for the need for in-depth understandings of the lived experience of social support. Finally, the research question was constructed, which stands as “What is the lived experience of social support for Black South African women living with HIV?”

On examining possible research methodologies, the main concern was to choose a methodology that would provide a framework within which the research question could be meaningfully addressed. A qualitative research approach was chosen, seeming more appropriate than a quantitative approach. Although data derivation and reduction strategies based on quantification are often viewed as most viable for achieving knowledge and generalisability of that knowledge, “the transformation of phenomena into quantitative data is not a guarantee of knowledge” (Crawford & Valsiner, 2002, p.95).

Morse and Richards (2002, p.27) identify five conditions under which a qualitative research paradigm should be utilised. These guided the selection of such a paradigm. A qualitative research paradigm should be employed where there is a concern to:

- Understand an area in which little is known or previously offered understandings appear inadequate and a desire exists to see the subject a new.
- Make sense of complex situations.
- Learn from individuals regarding the way a phenomenon is experienced, the meanings put on it, and how the experience is interpreted.
- Construct a theory or a theoretical framework reflecting reality.
- Understand phenomena deeply and in detail.

Within a qualitative research paradigm, traditionally qualitative research has provided three major methods from which to choose (Marshall & Rossman, 1989). Morse & Richards (2002, p. 7) suggest that “(a)lthough no one method is intrinsically superior to others, each method serves a different purpose.” The researcher aimed to link method and purpose.

Marshall and Rossman (1989) provide a summary of three traditions of qualitative research:

- **Ethnography:** Traditionally employed in addressing observational research questions, ethnography is considered the oldest form of qualitative research. Ethnography is useful in describing detailed features of a culture, a way of life, or groups.
- **Phenomenology:** Addresses questions regarding lived experiences and provides a framework for questions of meaning or essences of phenomena.

- Grounded theory: Focuses on generating theory and the reality negotiated between people, which is always changing and constantly evolving. Grounded theory best answers process questions regarding changing experience over time, stages or phases (Morse & Richards, 2002).

5.2 Phenomenology and postmodern paradigms

Given the purpose of this study, the most appropriate method was derived from within a phenomenological genre. As early as 1765, *phenomenology* was used as a term in philosophy. Phenomenology was first defined by Hegel as, “(k)nowledge as it appears to consciousness, the science of describing what one perceives, senses and knows in one’s immediate awareness and experience” (in Kockelmans, 1967, p.24). Husserl considered the founder of phenomenological research, took that further asserting that any phenomenon could represent a starting point for investigation (Moustakas, 1994). Husserl was concerned with the “discovery of meanings and essences” (in Moustakas, 1994, p.27).

Phenomenology is placed within an interpretive paradigm. “The interpretive research paradigm views the world as being constructed, interpreted and experienced by people in their interactions with each other and their wider social systems” (Allen, 2003, p.40). Within this paradigm explorations and interpretations of various aspects of individual experience embedded in a social and cultural context can take place. This is not the only paradigm that offers opportunity to engage with the experience of individuals. A narrative, social constructionist paradigm also affords this opportunity.

Within a narrative, social constructionist paradigm “the main premise is that beliefs, values, institutions, customs, labels, laws, divisions of labour and the like that make up our social realities are constructed by the members of a culture as they interact with one another from generation to generation and day to day.

Societies therefore construct the lenses through which their members interpret the world” (Freedman & Combs, 1996, p.16). The interpretive paradigm and narrative, social constructionist paradigm offer methods useful for exploring and interpreting aspects of individual reality. They become part, along with other paradigms, such as feminism, of a post modern worldview concerned with how the world is constructed, experienced and understood (Mason, 1996; Personal communication, D. Foster, November, 2004).

5.3 Phenomenological research

Phenomenological research begins in the *life world*. The life world is defined as the world as it is experienced immediately, not as it is conceptualised or theorised (Robertson-Malt, 1999). Phenomenological research is a distinctive method for understanding the world of everyday life or the life world (Robertson-Malt, 1999). Rose (1990) describes how phenomenology seeks to develop deeper understandings of the human experience, endeavouring to capture aspects of the world as they are immediately experienced. Thereby, phenomenology assists in coming to deeper understandings of the nature of everyday experience, and ultimately deeper understandings of what it means to be human (Rose, 1990, p.59).

Van Manen (1984) summarised phenomenological research suggesting that phenomenological research provides a framework for:

- Inquiring into the nature of a phenomenon.
- Gaining deeper understandings and insight into an aspect of human experience and what makes that experience what it is.
- Mindful wondering of what it means to live life and search for a fuller understanding of what it means to be human.
- Describing an aspect of life in language that takes one back to the phenomenon as it is experienced.

Oiler (in Allen, 2003) summarised the phenomenological perspective as research methodology in which:

- Phenomena are the focus and are described as they are subjectively experienced.
- Phenomenological study explores individual reality that is understood as being subjective and unique.
- Reality is explored from individual perspective.
- The researcher is key in the phenomenological research process and needs to take measures to ensure that his/her experiences and assumptions do not impact on the research process.
- Results are qualitative expressions and rich descriptions allowing for a more full understanding of a particular experience or phenomenon as it is experienced.
- Context is valued and findings are described only within the context in which the phenomenon occurred.

Phenomenological research was therefore considered appropriate for developing an understanding of the lived experience of social support for Black South African women living with HIV. It was further selected as it would facilitate the emergence of rich, thick descriptions of social support from participants own perspectives as they experienced it within the context of everyday life.

5.4 The process of inquiry

Van Manen (1984, p.2) provides four steps in pursuing phenomenological research. These were used to guide the process of inquiry. Table 5.4 provides a summary of the process.

Table 5.4 Four steps in pursuing phenomenological research.

Step	Aspect of the process of inquiry	Area of research in which the step was applied
Step 1	Firstly, the researcher must turn to a phenomenon, in which they are genuinely interested, which “commits them to the world.”	* Preparation of the researcher. * Sampling of participants * Ethical considerations
Step 2	Secondly, investigation of the experience must occur as the phenomenon is lived, rather than as it is conceptualised.	* Data Collection
Step 3	Thirdly, a reflection on essential themes characterising the phenomenon must take place.	* Data Analysis
Step 4	Finally, phenomenon must be described through the art of writing.	* Presentation of the data * Results and Discussion

5.5 Preparation of the researcher

Over the five years that the researcher has been studying psychology, a deep concern for women’s mental health, especially the mental health of women living with HIV has been developed. In engaging literature written about Black South African women living with HIV/AIDS as well as interacting with women living with HIV, a desire was stirred to develop practical ways to more effectively care for, thereby impacting the health of Black South African women living with HIV.

In orientating to the phenomenon, the researcher attended workshops and courses that would enable her to develop the personal skills necessary for caring for women living with HIV. These workshops were facilitated by the Western Cape AIDS Training Information and Counselling Centre (ATICC). These workshops aimed at educating health care professionals and lay counsellors in issues regarding HIV/AIDS and STI’s. The researcher also underwent an HIV test to better understand the emotions around being tested and receiving an HIV diagnosis.

In addition, the researcher began work as a HIV counsellor and an AIDS ward carer at False Bay Hospital (FBH) in Fish Hoek. FBH is a government hospital, primarily servicing the South Peninsula (Muizenberg to Cape Point). While working at the hospital, a deep compassion emerged for Black South African women living with HIV and dying of AIDS. As part of orientating to the phenomenon, the researcher became involved in the life world of Black South African women living with HIV. The researcher endeavoured to understand their experience of being HIV positive and their lived experience of social support. Personal involvement with Black South African women living with HIV led to an increased motivation to develop more effective strategies to care for these women.

In day to day living, the impact of social support on Black South African women living with HIV was recognised. For instance, the researcher sat with a woman as she died of AIDS. She listened to her story of isolation and loneliness. Having told no one that she was HIV positive, except her employers who banned her from their home, she lay continuously ruminating about her fear of family reactions. She felt a desire to be a good mother and have her children at her side. However, she died convinced she had failed as a mother and was unfulfilled as a person (Personal communication, anonymous, May, 2003). The need for foundations for understanding the lived experience of social support within a South African context became increasingly pressing. Such understandings could implicate strategic intervention aiming to care for Black South African women living with HIV, therefore impacting their health.

In beginning to understand social support and HIV, the role of individuals living with HIV, counsellors, specialist doctors and nurses was crucial. Becoming immersed in the literature surrounding HIV, including understanding the course and progression of HIV to AIDS, social support, and the experiences of women

living with HIV etc., also facilitated a growing understanding of the importance of social support for individuals living with HIV.

5.6 Sampling of participants

The period of employment at False Bay Hospital became the researcher's immersion into the phenomenon. During this time access to the sample was also gained. The study was initially discussed with HIV counsellors as well as specialist doctors and nurses in the field. One counsellor from the hospital provided information regarding her involvement in facilitating a support group being run independently of the hospital, in Masiphumelele. Subsequently, the support group leader was approached and informed regarding the aims of the study as well as the type of participants being sought. Independent of the researcher the support group leader, who would later be used as a translator, conversed with select individuals in the support group to explore their interest in being involved in the study. These individuals were identified for their potential to elicit valuable information regarding social support. The individuals were also identified according to the criteria for inclusion. Criteria for inclusion were the following:

- HIV positive diagnosis
- Female
- Between the ages of 15 and 49
- Black South African women living in Cape Town, in townships at the time of the study.
- Willing to fill out the general information sheet, be interviewed by the researcher about the phenomenon and participate in a follow-up interview.

To this end, purposeful sampling was employed to recruit the participants. Purposeful sampling involves identifying individuals who will generate rich

descriptions of the phenomenon (Colazzi, 1978). Individuals who were identified were approached and their interest in being involved in the study was explored. Those individuals, who were interested, were introduced to the researcher.

The support group leader accompanied the researcher in visiting interested women in their homes at an arranged time. The purpose of this visit was for the researcher to meet potential participants and inform them in more depth regarding the study. During these meetings the women were presented with a research package, consisting of a standard letter (*Appendix A*), informed consent form (*Appendix B*), and a general information sheet (*Appendix C*). The standard letter explained the nature of the study and invited the women to participate in the study. Upon agreeing to participate in the study, the women signed the informed consent form. The general information sheet required participants to fill out their demographic information. Nine of the women agreed that they would like to be a part of the study.

5.7 Introducing the sample

The sample was homogenous in that all the participants were Black South African Xhosa-speaking women who were HIV positive and living in townships, specifically Masiphumelele and Vrygrond. The women were from similar socio-cultural contexts. These socio-cultural contexts include the various realities addressed in section 2.4, all of which were assumed to have a profound effect on the lived experience of being HIV positive, and, therefore the lived experience of social support. Participants were all attending support groups at the time of the study and had been patients at False Bay Hospital or Masiphumelele clinic at some stage during their HIV illness.

Participants were between the ages of 15-44 with two being between the ages of 20-25, two between 25-29, one between the ages of 30-34, two between the ages of

35-39 and two between the ages of 40-44. None of the participants were in the age group 44-49.

The median educational level of the sample was grade eight. Four out of nine participants had no other form of training; only four participants were employed at the time of the study. Reported income ranged between one hundred rands and two thousand rands - 3 participants stated that their monthly income was between one hundred rands and five hundred rands; 3 indicated between five hundred and one thousand rands, and 1 participant was earning between one thousand six hundred rands and two thousand rands. Two participants said that there was no one in their home who earned an income.

All of the participants had been involved with partners from whom they had contracted HIV. Although six participants were married, only one was living with her husband. Seven of the participants were mothers.

All of the participants had found out about their HIV status by being diagnosed at a hospital or clinic as part of VCT or the MTCT programme. Two participants were at stage one of HIV, four at stage two and three were at stage three. The nine participants provided the researcher with invaluable information regarding their lived experience of social support as Black South African women living with HIV. As their stories are the source and essence of the study, the individual participants and their contexts are introduced in the ensuing section

A look at some specific demographic information participants provided will assist an understanding of the life world of participants. To protect the identity of the participants, each is referred to by their code name. Tables 5.7.1 - 5.7.9 provide a brief introduction to each participant.

Table 5.7.1 Participant one

Code name	N
Age category	35-39
Description	Appeared healthy and attractive, with a bright vibrant personality, confident and unashamed of her HIV status. She said that today she is, "the fighter of her life" and just living with HIV.
Born in	Butterworth, Transkei
Educational level	Grade 11
Other training	None
Employment	Employed by Memory Box Project and as domestic worker.
Monthly income	R1-R500
Residential status	Masiphumelele with her two daughters, in a shack
Family	Lived in Masiphumelele and Khayelitsha her father is deceased, her mother was still alive. N has four brothers and two sisters, and is the oldest.
Marital status	Single
Children	Two daughters, 19 and nine. One son, 21.
Diagnosed HIV positive	2001
Discovery of HIV	N attended the clinic because she was sick; she was diagnosed with a Sexually Transmissible Infection and encouraged to have an HIV test.
Reaction	N was shocked, angry and felt alone. At first she told nobody but eventually disclosed to her family.
Response of those she disclosed to	Her family responded in a number of ways, from being very rejecting to caring and accepting.
Stage, Symptoms and medication	Stage three, TB and Pneumonia, none.

Table 5.7.2 Participant two

Code name	L
Age category	35-39
Description	Appeared young and healthy, her athletic-looking body added to her fit appearance, she was confident and contented about her status. L expressed an involvement with the Treatment Action Campaign (TAC) that guided the way she spoke; she promoted the TAC at every opportunity.
Born in	Eastern Cape
Educational level	Grade Six
Other training	Trained by Love Life.
Employment	Employed by Memory Box Project and voluntary work with Love Life.
Monthly income	R1-R500
Residential status	Masiphumelele, with her friend in a small shack in the wetlands.
Family	Mother is living in Butterworth and father in Khayelitsha her parents are divorced. She has one brother and two sisters. She is the oldest.
Marital status	Long term relationship described as good.
Children	None
Diagnosed HIV positive	2003
Discovery of HIV	L attended the clinic for a HIV test, as she was working with people who were HIV positive and wanted to know her status.
Reaction	Initially L didn't feel bad about being diagnosed with HIV. She knew a lot about HIV and that it was a disease "for all people."
Response of those she disclosed to	Her friend gave her advice and helped her. When she first disclosed her status to her family she said they "welcomed her" but after a time they changed. Her boyfriend was very sad when she disclosed to him, he told her it was his fault.
Stage, symptoms and mediation	Stage one, headaches, none.

Table 5.7.3 Participant three

Code name	NM
Age category	20-25
Description	Appeared healthy, shy and reluctant to speak at first, over the interview she relaxed and was open about her status and experiences.
Born in	Zimbabwe
Educational level	Grade Six
Other training	Gardening
Employment	Unemployed. NM said that she just sits at home with her certificate.
Monthly income	None. No income earners in their home
Residential status	Masiphumelele, with her father, mother and four sisters, behind a kiosk.
Family	Father, mother and four sisters live in Masiphumelele. NM is the second born
Marital status	Married but divorced. Husband lived in Zimbabwe. She is presently involved with a boyfriend who is from Zimbabwe.
Children	Two children who do not live with her.
Diagnosed HIV positive	2003
Discovery of HIV	Boyfriend was sick, had an HIV test and was diagnosed positive. NM. went for an HIV test and found out that she, too, was positive.
Reaction	She longed to tell her family her status but was scared of their reaction, because she feared they would reject her as she had been married and divorced
Response of those she disclosed to	Her boyfriend and the support group knew that she was HIV positive. She had tried to tell her sister, but her sister wouldn't accept it.
Stage, symptoms and medication	Stage one, STI, none.

Table 5.7.4 Participant four

Code name	C
Age category	40-44
Description	Beautiful full figured African woman who seemed brave but emotionally tired. She cried throughout the interview. She was gentle and sensitive and explained how she struggled through the process of accepting HIV.
Born in	Ngcobo
Educational level	Grade ten
Other training	None
Employment	Unemployed
Monthly income	R500-R1000 rand. A disability grant makes up her monthly income.
Residential status	Masiphumelele with her three children and youngest sister, in a shack.
Family	Family lived in Ngcobo, C had one brother and two sisters. She was the oldest and her family was dependent on her.
Marital status	Married but separated.
Children	Three children: 21, 16 and nine
Diagnosed HIV positive	2000
Discovery of HIV	C went for a HIV test because she had an STI.
Reaction	Initially she felt shocked about being HIV positive.
Response of those she disclosed to	C felt unable to disclose her status, because her family was not staying in Masiphumelele, she wondered who to trust. After a year she disclosed her status to a friend. Before the interview she went to the Eastern Cape and disclosed to her brother. Her brother told her she shouldn't tell anyone, she should just keep her status to herself. She found this extremely hurtful.
Stage, symptoms and medication	Stage two of HIV, STI, none.

Table 5.7.5 Participant five

Code name	NU
Age category	20-25
Description	NU was the youngest of the sample group. NU discovered her sister was HIV positive shortly before the interview, the news elicited shock; she always thought her sister would look after her, now the possibility existed that she would have to look after her sister and her sister's children. NU expressed this was very painful, she was tearful throughout the interview.
Born in	Ngcobo
Educational level	Grade Eight
Other training	None
Employment	Unemployed
Monthly income	R500-R1000. Dependant on a disability grant.
Residential status	Masiphumelele, with her boyfriend, at the back of her sister's shack.
Family	Family lives in Ngcobo. One brother and two sisters.
Marital status	Single, living with boyfriend.
Children	None
Diagnosed HIV positive	2003
Discovery of HIV	NU was raped when she was 17 and was diagnosed HIV positive shortly there after; a second test confirmed her HIV positive result.
Reaction	She didn't believe that it was true she said in her heart "I am negative."
Response of those she disclosed to	She was scared of telling anyone she was positive she was worried they wouldn't love her. She disclosed to her Aunty and sister. Her Aunty and sister she described as treating her "like parents." She didn't want her mother to know because her mother was very sick.
Stage, symptoms and medication	Stage three, bad skin problems and headaches, none.

Table 5.7.6 Participant six

Code name	F
Age category	30-34
Description	Warm, talkative, happy, positive, strong and not scared of HIV. She said she was living with the virus-not dying.
Born in	Guguletu
Educational level	Grade 11
Other training	Business skills and counselling skills.
Employment	Employed as a lay counselor at a government hospital.
Monthly income bracket	R1600 - R2000
Residential status	Vrygrond, with her boyfriend, and two her children, in a shack.
Family	Lives in Gugeletu and Khayelitsha. She has three sisters and is the youngest.
Marital status	Married but separated. She has been living with a boyfriend for three months.
Children	Three children, thirteen, six and four.
Diagnosed HIV positive	2000
Discovery of HIV	F was very sick and was encouraged by the doctors to have an HIV test.
Reaction	Initially F was scared and wished that she could kill her husband for what he had done to her.
Response of those she disclosed to	People generally responded to her in a supportive way, she is unafraid to disclose her status but knows that the community is full of discrimination and judgment.
Stage, Symptoms and medication	Stage three, TB and Pneumonia, taking Bactrim to keep her immune system strong.

Table 5.7.7 Participant seven

Code name	NP
Age category	25-29
Description	A beautiful woman who looked happy and content. NP had a radiance she attributed to her new born baby being recently diagnosed HIV negative. Her husband had also recently permitted her to attend a support group.
Born in	Eastern Cape
Educational level	None
Other training	None
Employment	Unemployed
Monthly income bracket:	None. There are no income earners in their home. NP and her husband are dependent on Living Hope to give them food parcels.
Residential status	Masiphumelele, with her husband, in a small shack.
Family	Lives in the Eastern Cape.
Marital status	Married
Children	Four children
Diagnosed HIV positive	2003
Discovery of HIV	During her last pregnancy NP attended the ante-natal clinic. She was referred to the MTCT clinic and had an HIV test. She discovered that she was HIV positive.
Reaction	Her immediate concern was for her unborn child. She was very distressed she thought about the child she was carrying, "would that child live?"
Response of those she disclosed to	NP disclosed her status to her husband who said she must never tell anyone in the community. He forbade her from talking about HIV to anyone. Recently he allowed her to begin attending the support group at Living Hope and this helped her to accept her HIV status.
Stage, symptoms and medication	Stage two, none, none.

Table 5.7.8 Participant eight

Code name	OLIVIA
Age category	25-29
Description	OLIVIA had a big bright smile, which epitomised the kind of person she presented herself as. She was unashamed of people knowing about her status and had a positive attitude.
Born in	Eastern Cape
Educational level	Grade Nine
Other training	None
Employment	Employed by Memory Box Project.
Monthly income bracket:	R1-R500
Residential status	Masiphumelele, alone at the back of her brother's shack.
Family	Her family lives in the Eastern Cape. OLIVIA has three brothers and three sisters.
Marital status	Married but staying alone.
Children	One child
Diagnosed HIV positive	2000
Discovery of HIV	When OLIVIA lived in the Eastern Cape she became very sick and unable to walk. The doctor at the clinic recommended that she have an HIV test. She was diagnosed HIV positive.
Reaction	Initially she felt extremely sad.
Response of those she disclosed to	The doctor at the hospital disclosed her status in front of her family, she expressed this was very painful. Her family, lost hope because they didn't know anything about HIV, they just thought that she was going to die.
Stage, symptoms and medication	Stage two, OLIVIA moved down to Cape Town to receive better health care.

Table 5.7.9 Participant nine

Code name	DELI
Age category	40-44
Description	A big beautiful African woman wearing full tradition outfit was the way DELI presented herself at the interview. She was soft spoken and a little nervous but relaxed over the course of the interview and was very open. DELI appeared to be strong but her story was one of pain and sadness.
Born in	Butterworth
Educational level	Grade eight
Other training	None
Employment	Unemployed
Monthly income	R500 - R1000 rand. She is dependent on a grant for financial support.
Residential status	Masiphumelele with her three children, in a shack.
Family	Family lives in Butterworth. DELI has one brother and one sister.
Marital status	Married but separated
Children	Three children: one son age 11, and two daughters age 18 and five.
Diagnosed HIV positive	1996
Discovery of HIV	She went for a HIV test because her child was sick. The doctor was unable to diagnose the child and asked if they could do an HIV test. DELI and her child were diagnosed HIV positive.
Reaction	Initially she was shocked and saddened thinking her child was going to die.
Response of those she disclosed to	DELI disclosed her status to her husband and from then her husband wanted nothing to do with her and he moved to Gauteng. DELI's pain regarding her husband's reaction was evident and for four years she remained silent. The first person she told about being HIV positive was her sister; she was encouraging and reassured her that she was not the only one with HIV in South Africa.
Stage, symptoms and medication	Stage two, skin problems, none.

5.8 Ethical considerations

Morse and Richards (2002, p. 205) identify the following ethical principles regarding participants' rights:

- The right to be informed of the purpose of the study as well as what is expected during the research process. The amount of participation and time required. What information will be obtained and who will have access to it. Finally what the information will be used for.
- The right to confidentiality and anonymity.
- The right to ask questions of the researcher.
- The right to refuse to answer questions the researcher may ask, without negative ramifications.
- The right to withdraw from the study at any time without negative ramifications.

The study adhered to these ethical specifications. The researcher met each participant personally and spoke with them about the research, informing them of the purpose of the study. A letter was presented explaining the aims of the study and what would be expected from participants. Xhosa was the first language of all of the participants therefore a translator was present during the initial meetings. The translator read through the letter with participants who were unable to fluently read and understand English. Participants were given time to ask questions. The letter informed participants of the amount of participation and the time required. Participation entailed, completing one general information sheet, one interview with the researcher and one follow up session. In the follow up session participants were informed that they would be asked to respond to the results of the first round of analysis. Participants' responses would verify the interpretation, credibility and validity of results. Participants were informed that each session would be between 30 and 90 minutes, would be taped and then transcribed.

Participants were also informed that the interview material would be used for its informational value, to more deeply understand the lived experience of social support. Participants were made aware that findings would be presented in the form of a paper handed in for examination. Participants were further informed that there was a possibility of the material being used in the future to positively impact care strategies for women living with HIV/AIDS within a South African context. Confidentiality and anonymity was guaranteed. Participants were informed they would be given a code name to ensure their privacy. To further ensure privacy, only the research team constituting the research supervisor, the researcher, a translator and a transcriber would have direct access to the transcribed interview. Only the researcher had access to the code connecting participants with the transcribed interview.

The study posed no risk to participants physically. Due to the sensitive nature and complexities of being HIV positive as well as the emotions that may have been evoked during the interview, counselling was made available to participants should this have been warranted. None of the participants requested or required counselling or debriefing following the interviews.

Participants were informed that they held the right to withdraw from the study at any time without negative ramifications. Should they withdraw from the study, participants were informed that they would be given all material they had contributed to the study up to the time of withdrawal. Participants were made aware that the researcher's gratitude to them for participating in the study, would be displayed tangibly. A food parcel would be given at the end of the first interview. Participants had opportunity to request a bound copy of the study, upon its completion. Permission to conduct the research was obtained from the University of Stellenbosch (*Appendix D*). Approval was granted from the Full Gospel Church, in Fish Hoek, to use their premises to conduct the interviews and

use the sound equipment to record the interviews (*Appendix E*). The participants were not directly linked to a single hospital or agency from which permission to interview its members could be requested. Participants were therefore responsible to provide informed consent for themselves. Informed consent was obtained from all participants before the commencement of the first interview.

Participants were individually asked if they would feel comfortable being interviewed in English. For participants who felt they would be unable to communicate their lived experience of social support comfortably in English, a translator was provided. Swartz (1997) suggests that in conditions where there exists a language barrier, it should be seen as fundamentally unethical not to have an interpreter present. Permission to have a third person present (the translator) was obtained verbally from six participants. The interpretation process was structured in such a way that questions asked by the researcher of the participant, were translated into Xhosa. When participants responded to the question, interpretation of the responses followed. This was a taxing process for both researcher and translator and several interviews scheduled for the same day, were rescheduled. Rescheduling was necessary due to the unexpected energy required to conduct the interview as well as have it translated in a focused manner.

5.9 Data Collection

Data collection was conducted using in-depth interviewing. Participants were asked to describe in-depth their lived experience of social support. At the root of in-depth interviewing lies an interest in understanding some aspect of another persons experience and how they make sense of that experience (Seidman, 1998).

Interviewing allowed participants space to tell their stories. It was their personal stories that would inform the research question. In-depth interviewing as a

“basic mode of inquiry” (Seidman, 1998, p.1) would construct the appropriate data for the phenomenological inquiry into the lived experience of social support for the sample of Black South African women living with HIV. It would allow space for interaction which would lead to an uncovering of the meaning and essences of the lived experience of social support for participants.

The art of in-depth interviewing needed to be grasped. To this end, the researcher met with colleagues experienced in in-depth interviewing. During these meetings issues of interviewing were discussed (Personal communication, L Wilbraham, June, 2003). The researcher was also attentive to guidelines provided by Seidman (1998). These guidelines included listening on three levels: firstly, to what the participant is saying, secondly, to what participant is trying to say and, thirdly, to the participant’s nonverbal voice. Seidman (1998, p 63-77) also proposes interviewers talk less and follow-up on what participants are saying, ask questions when it is unclear what participants are trying to express; ask to hear more about a subject and explore different aspects of the subject without being intrusive. He heeds interviewers to avoid asking leading questions and ask open ended questions; avoid interruptions and keep participants focused by asking them to share experiences to illustrate what they are saying (Seidman, 1998). Finally, he recommends exploring laughter, following hunches and being tolerant of silence (Seidman, 1998, p. 63-77).

Interviewing was both a means of data collection and a type of relationship (Mishler 1986). Qualities the researcher needed for this relationship were sensitivity, empathy, focus, and active listening. This required the researcher to remain focused throughout the duration of the interview. It also required the researcher to guide the participant in addressing the research question. The researcher was to be tolerant of the way the participant led the interview, their opinions and stories.

In interviews the researcher is the research instrument. To avoid bias, the researcher needs to come to the interview with “(o)penness to whatever meanings should emerge” (Hycner, 1985, p. 280).

Openness was attained by suspending or *bracketing* beliefs about the phenomenon. Bracketing is understood as explicating understandings, biases, assumptions, presuppositions and theories exposing them to consciousness in order to become aware of their existence. With an awareness of their existence the data is more able to emerge true to itself. Bracketing involves suspending, “subjective meanings and interpretations of the phenomenon” thereby “entering into the world of the unique individual who was interviewed” (Hycner, 1985, p.280). Bracketing was a crucial aspect of phenomenological research; it enabled the researcher to attain openness. It was a process that assisted the researcher in opening herself up to the lived experience of social support, with its textures and meanings as described by participants.

Although no “supposition less” space exists, remaining true to social support as described by participants was crucial. To meet this demand both during the interviewing phase and analysis phase, the researcher sought to become more consciously aware of her assumptions and suppositions (Hycner, 1985). The researcher wrote assumptions and suppositions down and dialogued with a colleague about held assumptions (Personal communication, C. Allen, September, 2003; Personal communication, A.A. Smyth, September, 2003). Dialoguing led to a growing awareness of further assumptions. Self reflexivity was also engaged and the researcher was aware of what she brought to the interview by way of subjectivities such as gender, age, physical appearance, educational background, life experiences etc. Self reflexivity also led the researcher to an awareness that her inability to communicate with participants in their language determined that she embodied to participants, a culture and

identity that would influence the relationships developed with participants and possibly participants' communication of the lived experience of social support (Swartz, 1997).

The in-depth interviews were conducted at the Full Gospel Church, Fish Hoek in an office. Interviews dates and times had been set up during the first meeting and transportation for participants from their homes to the church and home again had been organised. A church office was chosen as it was considered neutral ground. The sound system at the church was convenient for recording purposes and less intrusive than having a tape recorder sitting on a table. One small microphone placed on a table in the centre picked up the interview, recording it directly into a sound box in the next room.

Interviews commenced by informing the participant briefly about the interview. The participant was asked to try and express how she perceived and described her lived experience of social support as a woman living with HIV. The participant began by talking about herself, which created an atmosphere of comfortable trust. During this initial time the participant, researcher and translator were able to relax and rapport was established. The researcher requested that the participant talk about her experience of being diagnosed HIV positive and what feelings were generated, along with thoughts about the diagnosis, what people stood out and what incidences or things were intimately connected with her HIV diagnosis. As the participant conversed with the researcher about these experiences, the lived experience of social support as a Black South African women living with HIV was articulated. The interview was concluded when the participant informed the interviewer that she felt she had shared all that was significant with reference to her lived experience of social support.

5.10 Data analysis

A fear is expressed by phenomenological theorists and researchers that should analysis become too focused on specific steps, quality may be lost. Unlike other methodologies, phenomenology cannot be reduced to a “cookbook set of instructions it is more an approach, an attitude, an investigation posture with a certain set of goals” (Keen, in Hycner, 1985 p.279).

To analyse the rich wealth of data generated by the in-depth interviews, however, it was necessary that the researcher, being inexperienced in phenomenological analysis, follow a set of guidelines. These guidelines were provided by Hycner (1985) and Giorgi (1975) who felt a need existed to provide guidelines to researchers who did not have enough philosophical background to know what “being true to the phenomenon” meant in relation to concrete research methods (Hycner, 1985, p.280). Practical guidance from Allen (Personal communication, November, 2003) was also critical.

To demonstrate the steps of the analytical process followed, a portion from interview one with N will be utilised. The portion is presented below in its original form as it was transcribed word for word from the audio tape.

The day the doctor told me I'm HIV I decided to tell my family, so I go back to my home to my step-mother and my sister and brothers, and I sit down and told them. But the things were changed because they told me and my children to go away and they chased me away from home. Um, sitting around with my children, even now there's nobody visiting us, I'm just staying with my children only, but my step-mother and my sister also they are in Masiphumelele, but there's no one come and visiting us. So it was so bad to me, because I was thinking about my children's future, because I was not working on that time.

5.10.1 Transcribing the data

To begin the process of analysis, portions of the interviews with participants who utilised the skills of the translator, were listened to by a Xhosa and English speaking colleague. This colleague validated that the translation was accurate. Interviews were then transcribed word for word from the audiotapes. The researcher transcribed one of the interviews herself to familiarise herself, with the process. The rest were transcribed professionally. In interviews in which a translator was utilised, only the English translation was transcribed.

5.10.2 Bracketing

To analyse the interviews with complete openness to what ever meanings emerged, the researcher engaged in bracketing. This involved extensive writing of the researcher's meanings and interpretations regarding social support. Writing facilitated the bracketing of assumptions and ideas in order that the researcher could consciously step into the world participants were describing. The discipline of bracketing assumptions was continued throughout the analytical process. This determined that the researcher's personal thoughts and understandings remained constantly in check as she monitored her own processes. It was impossible for the researcher to remain in a completely neutral position especially as listening to many of the participants stories was painful and evoked strong emotions. However meeting with the research supervisor and another phenomenological researcher, provided opportunity to talk around the issues of emotional investment in the research process as well as explicate further assumptions (Personal communication, C. Allen, November, 2003). Having transcribed the interviews and engaged in bracketing, the world of the participant could be entered and data could be allowed to speak for itself.

5.10.3 *Gaining a sense of the whole*

In order to gain a sense of the interview in its entirety, the researcher listened to the entire audio taped interview, while reading the transcript at the same time. This was important because “(o)nce the researcher has bracketed his/her interpretations and meanings as much as possible, s/he will want to get a sense of the whole interview, a gestalt” (Giorgi, 1975, p.87). Reading and listening to the interview as a whole, provided a context in which meanings could begin to emerge. The researcher listened to the interview for a second time, jotting down personal thoughts.

5.10.4 *Delineating Natural Meaning Units*

Upon gaining a sense of the whole interview the researcher began to read through the transcript marking with a pencil, *Natural Meaning Units* (Giorgi, 1975, p.87). Natural meaning units (NMUs) or units of general meaning are described as “those words, phrases, non-verbal or para-linguistic communications which express a unique and coherent meaning (irrespective of the research question) clearly differentiated from that which precedes and follows” (Hycner, 1985, p.282). Below is a brief example of the above process:

Interview 1 (30/10/03)
<i>The day the doctor told me I'm HIV I was decided to tell my family, so I go back to my home to my step-mother and my sister and brothers.</i>
<i>And I sit down and told them. But the things were changed.</i>
<i>Because they told me and my children to go away and they chased me away from home.</i>
<i>Um, sitting around with my children, even now there's nobody visiting us, I'm just staying with my children only, but my step-mother and my sister also they are in Masiphumelele, but there's no one come and visiting us.</i>
<i>So it was so bad to me.</i>
<i>Because I was thinking about my children's future.</i>
<i>Because I was not working on that time.</i>

The researcher numbered each NMU and rewrote it in the 3rd person. Rewriting it in the third person enabled the researcher to interact with what was being communicated. This was particularly necessary as six of the interviews had been conducted with a translator, who at times struggled to clearly express what participants were saying. A brief example of the above process follows:

Interview 1 (30/10/03)	NMU	What is she saying?
<i>The day the doctor told me I'm HIV I was decided to tell my family, so I go back to my home to my step-mother and my sister and brothers.</i>	9	The day she found out she was HIV positive from the doctor she decided to tell her family so she went back home.
<i>And I sit down and told them, but the things were changed.</i>	10	She sat down and told them she was HIV positive but things changed.
<i>Because they told me and my children to go away and they chased me away from home.</i>	11	They told her and her children to go away and they chased her out of their home.
<i>Even now, Um, sitting around with my children, even now there's nobody visiting us, I'm just (really?) staying with my children only, but my step-mother and my sister also they are in Masiphumelele, but there's no one come and visiting us.</i>	12	Even now she is sitting around with her children and none of her family is visiting her. She just stays with her children, even though her family is in Masiphumelele no one comes to visit them.
<i>So it was so bad to me.</i>	13	She feels bad about this.
<i>Because I was thinking about my children's future.</i>	14	She was thinking about her children's future.
<i>Because I was not working on that time</i>	15	She was thinking about the fact that she is not working.

5.10.5 Delineating NMUs relevant to the research question

Reading through each NMU, NMUs relevant to the research question were marked with a coloured pen. This process required a judgment call; however, where there was discrepancy the NMU was included. This inclusion standard

ensured “subjective judgments” were kept minimal (Hycner, 1985, p.284). NMUs were then reread to ensure that each illuminated some aspect of the lived experience of social support for the participant. Throughout analysis the interview was kept as a whole, this made certain that each NMU remained within the greater context of the interview.

5.10.6 Identifying essences

Once the relevant NMUs had been marked, the researcher read through each relevant NMU and wrote down the emerging essence. The researcher consulted with a colleague who acted as an independent judge, verifying the essences (Personal communication, C. Allen, November, 2003). An example of the above process follows:

Interview 1 (30/10/03)	NMU	What is she saying?	Essence
<i>The day the doctor told me I'm HIV I was decided to tell my family, so I go back to my home to my step-mother and my sister and brothers.</i>	9	The day she found out she was HIV positive from the doctor she decided to tell her family so she went back home.	Immediate desire to disclose to her family.
<i>And I sit down and told them, but the things were changed.</i>	10	She sat down and told them but things changed.	Rejection because of HIV status.
<i>Because they told me and my children to go away and they chased me away from home.</i>	11	They told her and her children to go away and they chased her out of the home.	Chased away because of HIV. (Rejection)
<i>Um, sitting around with my children, even now there's nobody visiting us, I'm just staying with my children only, but my step-mother and my sister also they in Masiphumelele, but there's no one come and visiting us.</i>	12	Even now she is sitting around with her children and no body is really visiting her. She just stays with her children, even though her family is in Masiphumelele no one comes to visit them.	None of her family will visit her. (Rejection)

Interview 1 (30/10/03)	NMU	What is she saying?	Essence
<i>So it was so bad to me.</i>	13	She feels bad about this.	Pain of rejection.
<i>Because I was thinking about my children's future.</i>	14	She was thinking about her children's future.	What about my children?
<i>Because I was not working on that time.</i>	15	She was thinking about the fact that she is not working.	Unemployment- therefore financial concern

5.10.7 Clustering related essences

With the essence of each NMU established, the researcher began to cluster together related essences. For example, in interview one, there was a number of NMUs whose essence pointed to the experience of being rejected by family. These NMUs were clustered together under the main essence of 'rejection from family because of HIV status.' The main essence was then defined and the NMUs relevant to the main essence noted. The researcher also included "memos" of her thoughts and assumptions regarding the main essence in question. Memos prevented the researcher's thoughts from interfering with the emerging meanings of the data. In this way the researcher constantly engaged in bracketing. A brief example from interview one follows: (*See Appendix F for reflection on a few essences emerging from interview one*).

Essence 4:

Main essence	Definition	NMUs
Rejection because of HIV status.	When N told her family that she was HIV positive "things were changed, her family chased her and her children away.	10, 11, 12, 13, 36, 37, 38, 39, 40, 44, 72, 73, 122, 123

Memo:

The sheer amount of NMUs in which she refers to this *“rejection because of her HIV status”* shows the profound impact that her family’s reaction has had on her life. The place she thought she could run to for help, love, acceptance and belonging becomes the place where she was treated *“funny”* she’s not welcome. When they found out that she was HIV positive, they chased her away from her home – they robbed her of *“home.”* (Home represents a place of belonging, a place where you anticipate unconditional care, love and acceptance. Your home is where you know you can go in times of need, a place where there are people that you can depend on.) When she found out she was HIV positive the first thing she wanted to do was tell her family but her expectations of them being a support and care giving accepters were shattered.

This is the one essence, that has many NMU’s, in which she refers directly to this rejection, almost saying *“this is where I thought that I would receive love and care and support and this is where I have been “looked at with no love” and thrown away. They made “funny things to her” she said they treated her like she was dirty and would make them very sick.*

It’s not only an emotional concern that N has now that her family treat her funny, it is also a physical concern, who will look after her when she is sick? *“If family won’t stand by me who will?”* Also they not only chased her away, but also her children, which brings great distress for N because who now is going to continue caring for her children when she dies?

Social support for N was linked into the assumption that family would always be there and when family is not there, or fails to fulfil the desire within each one of us for belonging, security, safety and acceptance an essential aspect of social support is missing.

When looking at the meaning and lived experience of social support for HIV positive women, there must be an acknowledgment that for many women their HIV diagnosis removes the support structures, which they assume to be in place, leaving them very vulnerable, alone and silenced by the stigma of HIV.

5.10.8 Drawing up a summary table of the main essences

A summary table with all of the main essences from the interview was then constructed. The main essences table summarised the main essences of the participants lived experience of social support. Each main essence was defined and the numbers representing the cluster of NMUs making up the main essences

recorded. An example from interview one follows in Table 5.10.8. (*See Appendix G for the completed main essences table from interview one*)

Table 5.10.8 Main essences from interview one

	Essence	Definition	NMU
1.	Acknowledging HIV status	N is HIV positive she openly speaks about her status and seems to define herself to some extent by the fact that she is HIV positive	6, 26
2.	Motherhood	Ns desire to be a good mother to her children is very linked into her own experience of being mothered- HIV has just robbed her of her ability to be the kind of mother she wished to be for her children	8, 49, 50
3.	Desire to tell her family and be supported by them	When the doctor told her she was HIV positive she decided to tell her family	9
4.	Rejection because of HIV status	When she told her family that she was HIV positive "things were changed" They chased her and her children away	10, 11, 12, 13, 36, 37, 38, 39, 40, 44, 72, 73, 122, 123
5.	Continuing care for children	Because of Ns family's reaction to her HIV status she became very worried about her children's future.	14, 38, 49, 50, 143, 144
6.	Being cared for by children	HIV causes to some extent a role reversal in the mother/child relationship. N is now cared for by her children they are the nurturers and supporters of her rather than visa versa. N has learnt to be joyful in this care that her children give her rather than perceiving herself to be neglecting her mothering responsibilities.	74, 75, 76

A composite summary was then written for the interview incorporating the main essences that had emerged from the data (*See Appendix H*).

The process described above in sections 5.10.1-5.10.8 was conducted nine times with each participant's interviews. Upon completion of the first round of analysis, follow-up interviews with participants were arranged. Follow-up interviews provided opportunity for the researcher to present to each participant the main essences emerging from her data as her lived experience of social support.

5.10.9 Follow-up interviews

During the follow-up interviews participants were asked whether they felt their lived experience of social support had been captured accurately and in totality. Hycner (1985) recommended this as an excellent experiential "validity check" (p. 291). The follow-up interview was also used to find out if there were other aspects of social support the researcher had not identified or participants had not previously mentioned. A translator was again employed for participants unable to communicate comfortably in English.

5.10.10 Adding the new data to the original analysis

With the new data from the follow-up interview on audio tape, the researcher went back to the original set of analysis. Listening through each participant's follow-up interview, new information was added to the first round of analysis. Follow-up data aided in modifying and enriching main essences. Additional essences were included where necessary. The summary tables of main essences for each participant were revisited and the composite summary for each participant finalised accordingly.

Two of the nine participants could not be contacted for a follow-up interview due to a change in location, since the initial interview. However, given the degree of confirmation that the first round of analysis yielded, the data of the two participants were included in the final data set.

5.10.11 Identifying themes/Constituent aspects of the lived experience of social support

Finally, themes common to most or all of the interviews were identified. Themes comprised main essences from participants' interviews. The themes emerged as constituent aspects of the lived experience of social support for the sample. Within the themes, variations were identified. The constituent aspects of the lived experience of social support make up the research findings presented in Chapter Six.

5.10.12 Validity check

As a validity check, themes were presented to several independent professionals; these included a nursing specialist in the field of HIV, an educator, a trainer working in the field and the research supervisor. The above mentioned individuals acted as independent judges and checked on the rigour and validity of the study. The researcher engaged in dialogue with the above mentioned professionals regarding the research findings and how findings described and captured the participants' lived experience of social support (Hycner, 1985).

5.11 Presentation of data

Accurate presentation of the data and findings in a way that captured the essence of the lived experience of social support was crucial. The phenomenological method places great emphasis on the art of language. Van Manen (1984) suggests that language must be such that it permits the reader to see the deeper intricacies or meanings of the lived experience it describes. In presenting the results, the researcher returned to the voices of the participants to describe their own experiences.

In the following chapter research findings are discussed thematically. The lived experience of social support for the sample of Black South African women living

with HIV constituted fourteen themes. The fourteen themes will be presented by drawing on participants' voices to exemplify constituent aspects of the lived experience of social support for the sample.

5.12 Quality and rigour

Guba and Lincoln (1981) discuss several issues around validity and reliability. These are used as a framework from which the quality of the study is established. Within three criteria the quality and rigour of the study will be defended. Guba and Lincoln (1981) suggest that credibility be the criterion against which the true value of qualitative research is evaluated. They (Guba & Lincoln, 1981) also suggest audit-ability be the measure of consistency in qualitative research, and finally confirm-ability be the criterion of neutrality.

5.12.1 Credibility

Credibility refers to when something can be believed, its quality regarded as acceptable and trustable (Crowther, Kavanagh, & Ashby, 1998). Credibility in the study was established by:

- Allowing results to speak for themselves: The researcher engaged in extensive writing of assumptions, ideas and beliefs as part of the analytical process. Having personal presuppositions bracketed, and having engaged in self reflexivity the data could speak for itself.
- Taking the data and findings back to the sources from which they were drawn: Upon presenting the findings to participants, they were asked to verify whether or not results were plausible (Guba & Lincoln, 1981). Participants were given opportunity to respond to results and comment on whether they felt an accurate understanding had been grasped of their lived experience of social support. In this way participants validated results and also had opportunity to add further depth and richness to the data.

- Presenting the results of the study to specialists in the field of HIV (independent judges) for their opinions on results was another way credibility was established.
- Participants, specialists in the field of HIV/AIDS, as well as the research supervisor affirmed that credibility had been established in the study. Therefore the results could be trusted and accepted as accurately reflecting the lived experience of social support for participants.

5.12.2 Audit-ability

The concept of audit-ability is the measure of consistency in qualitative research. Audit-ability refers to the ability to illuminate the trail of the research process. This increases trustworthiness that the study is reliable. The term audit-trail refers to evidence that the researcher has kept track of research events and decisions in a way that can be checked.

- Audit-ability was established in that the researcher was answerable to the research supervisor on all levels. The research supervisor walked the trail of the research process with the researcher.
- Audit-ability was established in the description of the research process, reflected in this chapter, which has tracked diligently how the research process was carried out.

5.12.3 Confirm-ability

Finally, it is asserted that confirm-ability be the criterion of neutrality in qualitative research (Guba & Lincoln, 1981). Confirm-ability displays that results are true and correct and are also firmly established in the data (Crowther et al., 1998). Confirm-ability determines that results arose directly from the sources. In the study confirm-ability was established in that there was awareness that results could be distorted by researcher bias which would compromise confirm-ability of the results.

- The researcher undertook to minimise the distortion that could occur during the interview: By ensuring participants felt comfortable and at ease; by establishing rapport and providing a translator, so that participants unable to comfortably communicate in English could speak their first language. The researcher did not asking leading questions, listened more than she talked, asked open ended questions and followed up on what participants were saying. An effort was made on the part of the researcher to understand exactly what participants were saying. Participants were given space to present information that described their lived experience of social support.
- Using a translator may be questionable and to this end, having translation validated was crucial in confirming that the participants' voices were heard rather than the translators.
- The researcher also undertook to minimise distortion during the research process by bracketing and engaging self reflexivity through extensive writing of assumptions and thoughts that could influence the analysis of the data. The researcher valued the discipline of bracketing as being crucial throughout the research process.

5.13 Issues in phenomenological research

For the following reasons the phenomenological method was considered most appropriate for addressing the research question and was esteemed above other methods for its respect of human experience:

- Phenomenological research respects the capacity of the participant, opening up the potential for a rich source of learning and practical knowledge (Robertson-Malt, 1999).
- Phenomenological research methodology allows space for participants to speak their voices: For some participants it was the first time that they

were able to express their experiences of being HIV positive and their lived experiences of social support.

- It allows for reflection on the valuable knowledge, the participant alone is recognised as having.
- It regards the participant as instrumental and valued because of the rich information their stories provided regarding the phenomenon.

Phenomenological research, however, is not without its critics. Guided by Hycner (1985, p.295-300) who tackles several issues surrounding phenomenological research, a discussion will proceed responding to some criticisms of phenomenological research particularly pertinent to this study.

A frequent criticism of phenomenological research is that the sample group is chosen for a particular quality. The sample group is therefore criticised as being unrepresentative. This, in turn, confounds results within the boundaries of the specific sample, deeming results non-generalisable. In the present study the sample group was specifically chosen. The study had a total of nine participants—all from a specific context confining findings within specific boundaries. The primary aim of the present study, however, was not to generate results that could be broadly generalisable. Rather the aim was to generate results that illuminated the phenomenon in such a way that learning about the phenomenon could take place. Results were intended to invite a consideration of the possibility that findings may pertain to other women living with HIV within similar contexts. Further more, results were intended to provide groundwork for sharpening effective intervention strategies, enhancing care of Black South African women living with HIV. For this reason, the sample needed not be large but needed to meet the inclusion criteria. As it transpired, a volume of data emerged from the nine interviews.

Two issues are raised regarding accuracy of the description of experience: Firstly, the use of language and, secondly, retrospective description of experience (Hycner, 1985).

- “Any description of an experience is already different from the experience itself,” “(l)anguage, by its nature” enhances or distils an experience. An endeavour, however, must still be made to understand the original experience (Hycner, 1985, p. 295). In the present study whether or not descriptions accurately reflected the life world was not the major concern. The major concern was to allow the lived experience of social support to emerge as participants chose to describe it.
- In retrospect experiences are often remembered and verbalised differently than if they are explained whilst the experience is occurring. However, if verbal descriptions of experience are the means of data generation and collection, retrospective viewpoint will primarily have to be relied on (Hycner, 1985, p.296). In the present study, the aim was inquiry into the lived experience of social support for the sample as they understood, perceived and described their experience. If only concurrent descriptions of experience were considered accurate, efforts to understand most experiences would be considered futile as phenomenon is usually described in retrospect. This concern, however, seems more pertinent to the recalling of distant events. Describing the phenomenon of social support required reflection on an experience participants were having on a day to day basis. For this reason social support was regarded a continuing phenomenon not one confounded to a moment. Descriptions, therefore, were not only retrospective but in a sense concurrent.

The subjective influence of the researcher is commonly criticised in phenomenological research (Hycner, 1985, p.296). In both the interviewing phase and the analysis phase this is a concern. The problem of phenomenology is not

that too much or too little is known but that assumptions predisposing a particular interpretation of the phenomenon exist. In the present study, it was acknowledged that pure objectivity was unattainable however; steps were taken by the researcher to acknowledge assumptions and explicate presuppositions.

The researcher acknowledged that as an HIV negative White South African woman issues such as power relations, social class, education, age, research aims and emotional investment in the research guided the entire research process from the conceptualisation of the research question through the interviewing and analysis phase as well as in the writing up of the results. Bearing these issues in mind an approach was engaged that sought to remain faithful to the phenomenon as it presented itself.

Even where the phenomenon emerges from the data untainted by the researcher, phenomenological research can still be limited by the researcher. The researcher's ability or inability to express the phenomenon can limit what is learned regarding the phenomenon. For this reason in describing the research findings in the present study, participants' voices were utilised.

In the same way that as much as possible was done to minimise the distortion arising from subjective influence of the researcher, in the present study an endeavour was also made to minimise the distortion arising from the language barrier. The use of a translator, however, cannot be as reliable as communication in the same language. Had the researcher been able to speak Xhosa fluently, further themes may have emerged from the data.

Replicability has been an important aspect of natural scientific research. A study must be able to be replicated achieving essentially the same results second time around (Hycner, 1985). To this end, phenomenological research does not aim to

fit into a natural scientific paradigm. The aim of phenomenological research is that the research process, data analysis and results be described in such a way that readers adopting the same viewpoint as articulated by the researcher are invited to also “see what the researcher saw, whether or not s/he agrees with it” (Giorgi, 1975, p.96). In writing up the present study, effort was made to describe the research process in such a way that this may occur.

Absence of control groups, absence of hypotheses, absence of predictions and interpretations all become criticisms of phenomenological research in light of natural scientific research. On investigating human experience these standards become superficial. The very nature of unique human experience cannot be controlled, hypothesised or predicted.

At the core of phenomenology is the very deep respect for the uniqueness of human experience and that this ever present uniqueness will always make the attempt to develop a totally comprehensiveness theory of human experience an ultimately futile one. It is the uniqueness of the human being which constantly instils novelty and unpredictability into any attempt to totally and comprehensively capture the phenomenon of human experience (Hycner, 1985, p.300).

By displaying the study’s credibility, audit-ability, and confirm-ability as well as addressing and responding to some key criticisms of phenomenological research, the trustworthiness of the study has been displayed. Therefore quality and rigour has been established in the research process.

In summary, this chapter has presented the research design of the study. Various research methodologies were explored displaying why a qualitative research paradigm was more suitable for the study. Phenomenology provided a framework in which the research question could be addressed. Ethical issues

were discussed and the research process explained in detail. The trustworthiness of the study was demonstrated by looking at quality and rigor in the research process. Finally key criticisms of phenomenological research, as they pertained to the present study were discussed.

In the following chapter the findings of the research will be presented in fourteen themes emerging from the data as constituent aspects of the lived experience of social support for participants.



CHAPTER SIX: RESEARCH FINDINGS

In this chapter, the research findings are presented in their original form as they emerged from the data as constituent aspects of the lived experience of social support. The research findings are presented in fourteen themes. Table 6.1 provides a summary of the emergent themes. Key words summarising the constituent aspect of social support being presented are highlighted. Each theme will be illustrated using quotes extracted directly from the interviews. In this way the research findings consist primarily of descriptions using participants' voices. Quotations depict the essence of the theme and describe how the theme constituted an aspect of the lived experience of social support. Quotations most accurately illuminating the theme being described appear. Effort was made to present each participant's voice throughout the research findings. In chapter seven the research findings will be discussed in more detail.

In order to understand the chapter more fully, a simple coding system enabling the quote to be accessed in the original interview material has been employed. Two coding systems will be used:

- 1). [Interview number (1-9): Natural meaning unit number] > for example, [3:107]
- 2). [Follow-up interview - with Code name] > for example, [F/UP-C]

Table 6.1 Fourteen themes constituting the lived experience of social support

	Themes	Short description of the theme
1.	<i>"I'm going to stay with the counsellors and doctors because they know me."</i>	Being cared for by health care professionals meeting physical, informational and emotional needs. Qualities defining interpersonal relationships as satisfactory or unsatisfactory will be considered.
2.	<i>"Today I'm HIV positive and it's because of the man."</i>	The role of partners will be explored. Positive and negative interpersonal relationships will be addressed.
3.	<i>"And I was thinking of the family."</i>	A discussion around family as a constituent aspect of the lived experience of social support will take place. Interpersonal relationships of a satisfactory or unsatisfactory nature will be examined.
4.	<i>"I am the mother of children."</i>	Motherhood , a role allowing room for interaction between mother and child will be discussed.
5.	<i>"...as from that day I know that I am not the only one person who is HIV positive."</i>	The importance of knowing there are others who are HIV positive will be highlighted.
6.	<i>"...come inside, sit and take your jacket off, because this is your home."</i>	The role of support groups illustrated as being "home" – a place of belonging, is considered.
7.	<i>"It's very important to share, not to keep the things inside."</i>	Story telling and sharing one's life with others as an aspect of social support will be explored.
8.	<i>"Education gives me hope in my heart that I can live."</i>	The role of both education and educators in the lived experience of social support are highlighted. Messages of hope conveyed by the media and books are addressed.
9.	<i>"...There is a lot of caring about HIV."</i>	Many organisations were cited as working to positively impact the lives of individuals who are HIV positive. The importance of these organisations will be explored.
10.	<i>"I saw that if I keep most of the time to be busy, I'm not thinking anything about HIV."</i>	Keeping busy and thinking positively was described as facilitating coping with HIV. As a constituent aspect of social support this theme will be uncovered.

Table 6.1 continued

	Themes	Short description of the theme
11.	<i>"My community...it is very important to me."</i>	Practical care of community neighbours will be reviewed.
12.	<i>"Its God who knows and I'm thankful for that."</i>	The impact of spirituality – God, prayer and the church will be addressed.
13.	<i>"...because of this interview I feel happy."</i>	The positive effect of being involved in the present study will be explored.
14.	<i>"I learn a lot when I am helping others."</i>	The importance of the extension of social support to others will be discussed.

6.1 "...I'm going to stay with the counsellors and doctors because they know me." –

Health care professionals

"I know that I can always go to the clinic, I'm going to stay with the counsellors or the doctors because they know me." [2:63-64]

Participants discovered their HIV status in clinics or hospitals. They learned of their diagnosis, either by being tested for HIV during pregnancy, as part of the PMTCT programme, or by being recommended to test for HIV because they were sick (VCT). The experience of being given an HIV positive diagnosis exacted a heavy emotional toll. This was influenced by the degree of care participants felt they received from the health care professionals working in the hospital or clinic in which they were diagnosed.

Each participant recounted interpersonal relationships with health care professionals as an aspect of their lived experience of social support. Efficient health care was defined on three levels: Firstly, by having physical needs met. Secondly, by receiving information about HIV, and, finally, by having emotional needs met.

6.1.1 The role of interpersonal relationships with doctors and nurses

“And also at the clinic they took a CD4 count. And there they said that my CD4 count is still high. And then they give that hope that I can live more than ten or five years. The information they gave me there was important because I didn’t know anything about HIV. And now I know about HIV, and I know that I must use a condom, and I know that I can live more years, because of the CD4 counts I got.” [3:23-25]

Doctors and nurses were described as playing a critical role in meeting physical, informational and emotional needs. Upon receiving an HIV positive diagnosis, participants felt that knowing that they could always go to the clinic where the doctors and nurses would provide various forms of assistance, reduced the emotional toll experienced.

“It was early last year. January I was coughing and coughing and coughing and losing the weight. And around by March, April, I was, going to the clinic and told the sisters I...I’m not feeling well at all. I’m coughing, bedwetting, always feeling tired you know; but I don’t know what’s happening to me. And they said to me I must go to False Bay for the x-ray. There I found out I’ve got TB. So I was there, for two weeks July last year sleeping there, and I was having that medication – TB medication – I was feeling very, very well. I feel very better now because as soon I got some feeling...as soon as I’m not feeling alright, I just go straight to my doctor. I’ve got my doctor there. Every Wednesdays and Fridays Doctor S, she always looking at me; if I’ve got a problem I just go straight to her and tell her I’m not feeling all right, and they give me something to help me.” [1:93-95]

Table 6.1.1 describes the characteristics of satisfactory interpersonal relationships with doctors and nurses highlighted by participants.

Table 6.1.1 Characteristics of satisfactory interpersonal relationships with doctors and nurses

Supportive behaviours of doctors and nurses	Quotes that described the aspect of support	Reference
Advisory	<i>"Told me what to do."</i>	F/UP-N
Available	<i>"Can always go to them."</i>	F/UP-C
Caring	<i>"Came to my bed and asked is there something wrong?"</i>	F/UP-F
Consoling	<i>"Told me if you have got something wrong talk about it and you will feel better."</i>	F/UP-C
Displaying physical affection	<i>"Hug me."</i>	F/UP-N
Encouraging	<i>"Encouraged me to come straight to the doctor if something is wrong."</i>	F/UP-NM
Friendly	<i>"Friendly, loving and caring."</i>	F/UP-OLIVIA
Good and Kind	<i>"So good and so kind."</i>	F/UP-F
Good listeners	<i>"Good listeners."</i>	F/UP-F
Helpful	<i>"Helpful."</i>	F/UP-OLIVIA
Helping to access further support	<i>"The doctor at the clinic, they are saying that they go to fill a grant, in case of the children."</i>	INT4-C
Knowledgeable	<i>"They give education about HIV."</i>	F/UP-F
Loving	<i>"Loving and kind."</i>	F/UP-F
Motivating	<i>"Told me you are one brave woman."</i>	F/UP-F
Supportive	<i>"So supportive of me."</i>	F/UP-NM
Taking the positive woman's symptoms seriously and treating symptoms	<i>"The clinics and doctors are very, very good. If I have the funny things on my body, I go straight to my nearest clinic and they treat me."</i>	F/UP-N

A pivotal element of the interpersonal relationship between doctors and participants was the role doctors played in assisting participants to access financial assistance. In order to access a disability grant participants explained

how they had to have a CD4 count, which only a doctor could perform. If their CD4 count was below 200, they were able to apply for a financial grant from social services.

Participants described how their doctors helped them to apply for these grants. This made them indispensable in the lived experience of social support.

“The doctor at the clinic they saying that they go to fill a grant in, to give me a grant. Now I know that at the end of the month I can give the children something to eat.” [4:107]

“The time that I had TB, they gave me the application form to get a disability grant. This has helped me because I was not working and nobody was supporting me. Also I was quite sick because when they did a CD4 count; my CD4 was very low. I was in stage...my CD 4 was 147, and I was feeling, very weak, even my weight it was 62. So that’s why ...my doctor decided to...to give me this disability grant....because they told me I must have that disability grant because of my CD 4. And that was a great help to me because I didn’t have to worry so much about money.” [1:96]

Doctors’ aid in enabling participants to access financial assistance was particularly helpful as many participants were unemployed and had no means of income. Several participants expressed their desire to have a job. They also spoke of their inability to find employment and the difficulties of being unemployed:

“What I need and want, I want something like a job because I am still young and tired of sitting around the community, I want a job” [3:128].

“Because I am not well educated, I don’t speak English. So I would like to maybe work in the factory using my hands because I can’t go to do a domestic work because I can’t hear the English.” [4:147]

“It is difficult not to work because I am always staying in the house and I have no money.” [F/UP-NU]

Being unemployed, participants spoke of dependence on their families for financial help and the relief of being able to access financial assistance.

6.1.2 The role of interpersonal relationships with lay counsellors

“The counsellor who did pre-test counsel, she said that is not the end of my life. And then when I go home I was thinking, those words that: ‘is not the end of my life’ if I cannot stand, there is no one going to stand with me in...my life. That’s why I started thinking that I must accept that I am positive.” [3:60-61]

In both PMTCT and VCT participants received pre- and post-test counselling. An HIV diagnosis was accompanied by fear and questioning. The interpersonal relationship established between the lay counsellor and participants was crucial in the lived experience of social support. The role of the counsellor was critically important, in assisting participants in coming to terms with the emotions an HIV diagnosis evoked.

“On that day I found out my results the HIV counsellor asked me the question, ‘You know that you are HIV positive?’ I’m saying that yes I know that I am HIV positive. And she asked how do you feel about HIV positive?” [7:7]

Exploration of emotion was helpful.

“What makes me feel good is that when I attend at the clinic to meet the counsellors, they are saying that, if I am positive, I am like other people who are negative. It is only that because I am positive I am going to be sick, but not now, if I can live healthily.” [5:53]

Counsellors were described as having an on going role in the lived experience of social support.

“OK. Yes, counsellors helped me a lot. If I don’t want to go the family, I...if I got a problem so I don’t want to go to the family, I can go to the counsellors to talk about my problem. Then they have got the skills to do counselling to me and refer to the appropriate resource.” [8:87-88]

Counsellors were instrumental in helping participants to access further social support in the form of support groups.

"Yes, because the counsellors they told you about support group. Like if they're checking you, you are finding HIV positive they told you must go to support group. In the support group you can share your problems." [2:134-135]

Table 6.1.2 provides a summary of the characteristics of interpersonal relationships with counsellors deemed satisfactory and supportive.

Table 6.1.2 Characteristics of satisfactory interpersonal relationships with lay counsellors

Supportive behaviours of lay counsellors	Quotes that described the aspect of support.	Reference
Advisory	<i>"I can always talk and they give advice."</i>	F/UP-OLIVIA
Available	<i>"Especially the counsellor she is always there for me."</i>	F/UP-C
Caring	<i>"I can talk to the counsellors and she comes to visit me at my house if I don't go to the clinic when I'm supposed to see the doctor."</i>	F/UP-NU
Encouraging	<i>"And the counsellor she was saying that it is better that I tell one person." [4:35]</i>	INT4-C
Giving hope	<i>"Gave me hope that it is not only me living with HIV."</i>	F/UP-NM
Helping the positive woman to be able to live positively	<i>"She was supporting me to accept to be positive and also discuss the issue with the family."</i>	F/UP-DELI
Helping to access further support	<i>"They told me about the support group."</i>	F/UP-NM
Knowledgeable and good educators	<i>"She helped me a lot and gave me a clear understanding of HIV."</i>	F/UP-DELI
Motivating	<i>"She said it is not the end of my life." [3:5]</i>	INT3-NM
Sympathetic	<i>"The counsellor is sympathetic."</i>	F/UP-NM

Participants likened receiving an HIV diagnosis to a death sentence. Almost immediately participants wondered how much time they had before they died. Health care professionals were a facet of the lived experience of social support. They were instrumental in aiding participants in coming to terms with their illness and in preparing them to disclose. Those who struggled to disclose, relied on the health care professionals, who already knew their status, and, whose relationship provided a source of strength.

“Why I want to...to decide to tell was because of the doctor there at the clinic. And the counsellor, they were saying that it is better that I tell one person, Because I was always going to the clinic if I’ve got a problem and I was crying there, and then the doctors are, saying that it’s better to tell at least one person in your family.” [4:34-36]

Interpersonal relationships with health care professionals, where physical, informational and emotional needs were being met were considered satisfactory and therefore regarded as supportive.

Within the theme of health care professionals, however, although health care professionals were indicated as a feature of social support, it emerged that not all health care professionals were considered supportive. Participants highlighted both supportive interpersonal relationships as well as non-supportive interpersonal relationships with health care professionals. One participant spoke of the unsatisfactory treatment she had received. The insensitivity of her doctor heightened her emotional distress:

“And because of...of also those feelings I’m so painful, I want to die. What is happening because I’m not walking on that time. Then the family accompanied me to see the doctor and then the doctor on that day gave me my results. He disclosed my status in front of my family because I am on the wheelchair on that time. So the family comes to fetch the results and the doctors tell straight in the family that I’m HIV positive. It definitely...it was so painful. I was crying. I want to cry even now because of those feeling. But, that

time I feel so bad. I was thinking that really I'm dying, and even the family, they lose, hope." [8:13-20]

"And, eh, I didn't have anything knowledge of HIV, so what I know, I know that I'm sick and I'm going to die any day." [8:30-31]

OLIVIA verbalised how the group of doctors at the particular hospital she attended were reported to say, "You are going to die, we don't care about you" [F/UP-OLIVIA]. She described feelings of desperation and aloneness as she ruminated over her HIV diagnosis.

Another participant relayed her struggle with non-supportive health care professionals. Upon receiving her HIV diagnosis the counsellor withheld information regarding HIV.

"That person who told me that I am HIV positive, she didn't tell me anything about HIV." [7:46]

Within the theme of health care professionals, therefore, a polarity existed. Some health care professionals provided satisfactory and supportive interpersonal relationships; others did not.

6.2 "...Today I'm HIV positive and it's because of the man."- Partners

"They are laughing at me one day when I'm talking about this at the...at the Living Hope. I said to them, 'Hey girls, I've got a problem. I hate (accented) the men!' (Laughter) They were laughing and said, 'No...maybe it's still early because of the virus. Maybe that when the times goes, you are going to be OK.'. I said, 'I don't think so.' They're laughing at me." [1:105]

"I hate men, I don't know why. I think when I am looking at men I hate them. I think it's because today I am HIV positive and it's because of the man." [1: F/UP]

One of the most difficult issues participants faced on being diagnosed as HIV positive was the question, "Where did this virus in my body come from?" Participants felt the role of partners (referring to husbands and boyfriends) in their lived experience of social support could not be ignored. The reality participants had to come to terms with was that they had contracted HIV from their partners. Pain was expressed as participants had come to awareness that they were faithful partners to unfaithful men. Participants felt they had become HIV positive as a result of their partners' behaviour, not their own.

"It was so hard. I decided to call my family, all my family. And then I tell them that hey, I've got this HIV...now. And it's him." [6:54]

Except for one, every participant alluded to their partners as a feature of their lived experience of social support. Within this aspect of the lived experience of social support varying experiences from acceptance to rejection were described.

Upon receiving their HIV positive diagnosis, participants described feelings of loss of trust in their relationships with their partners.

"On that first day though I feel like I have trusted that guy , but in the end of that day, I didn't trust him because of what he looks on that day, like he knew and this is not the first time to know that he is positive. He didn't look shocked about HIV." [3:72]

Even participants who regarded their partners as a satisfactory aspect of their lived experience of social support had questioned them regarding where HIV had come from and then accepted what he had done.

"I asked him and he wouldn't give me any answer, because he was thinking inside the heart, not outside so no one answer those question." [3:68]

Varying levels of experience were articulated regarding the role of partners in the lived experience of social support. Experience was linked into whether participants had disclosed their status to their partners or concealed it. Those

who disclosed their status had experienced either acceptance or rejection from their partners. Those experiencing acceptance described their relationship with their partners as satisfactory. Table 6.2.1 describes aspects of satisfactory interpersonal relationships with partners.

Table 6.2.1 Characteristics of satisfactory interpersonal relationships with partners

Supportive partners	Quotes that describe the aspect of support	Reference
Accepting	<i>"He welcomed me still."</i> [2:29]	INT2-L
Available	<i>"If I have a problem he helps me, he is always there for us."</i>	F/UP-F
Giving	<i>"He knows that even the food he must buy something to give me to boost the immune system."</i> [5:71]	INT5-NU
Caring	<i>"Always asks, Are you ok today?"</i>	F/UP-F
Comforting	<i>"My boyfriend told me, don't cry, because it's not only you who've got HIV. There are a lot of the people they've got HIV."</i> [3:9]	INT3-NM
Encouraging	<i>"Don't think about death, just stay healthy."</i>	F/UP-NM
Financially supportive	<i>"He gives me money to buy medicine and food."</i>	F/UP-NU
Giving hope	<i>"He always gives me hope...all the time."</i> [5:72]	INT5-NU
Informative	<i>"There is a support group at Living Hope. You can... you can go and join there the support group."</i> [3:10]	INT3-NM
Loving	<i>"He still loves me more than anything."</i> [5:21]	INT5-NU
Still wanting to be sexually active	<i>"I am sexually active."</i> [6:141]	INT6-F
Understanding	<i>"He understands."</i> [5:67]	INT5-NU

Participants who were the recipients of rejection from their partners as a result of disclosing their status, described their partners as non-supportive. Interpersonal relationships with them were unsatisfactory and damaging:

“Because men, they have got a lot of problems. Maybe I’m going to love, love a man, you know, but is going to make me sick in the end because, sometimes I sit the whole night waiting, waiting and waiting you know?” [1:108]

These participants wanted nothing to do with men. They considered men to be troublesome. The support they had assumed would define their interpersonal relationships with their partners did not exist. Table 6.2.2 sums up characteristics of unsatisfactory interpersonal relationships.

Table 6.2.2 Characteristics of unsatisfactory interpersonal relationships with partners

Non-supportive partners	Quotes that described the aspect of non-support.	Reference
Denying	<i>“I know I don’t have a support at home because my husband always say that he’s not positive and also me I’m not positive, although that I know that I’m positive.” [7:33]</i>	INT7-NP
Marginalising	<i>“My husband...no one gives me support at home, because my husband’s saying that...if I want to go to Living Hope on the support group, I can go to meet the other people who are HIV positive. But never...I mustn’t go to the community to disclose; even at the clinic to saying that I am HIV positive because he has not accepted to be a-positive.” [7:51]</i>	INT7-NP
Non supportive financially	<i>“And he go...he go out up and down...with our money.” [9:87]</i>	INT9-DELI
Rejecting	<i>“I don’t want anything to do with you. After that, he sold everything And he came to tell me that look, here’s our thousand rand. I’ve sold everything. I said what? You are just one cruel bastard. I’m so sorry...I can’t take this anymore. Just go away to your girls.” [6:70]</i>	INT6-F
Unavailable	<i>“Ask where my husband is? No where to be found.” [6:20]</i>	INT6-F
Untrustworthy	<i>I don’t want any boyfriends because I don’t want him to hurt me, I don’t trust boyfriends or any men.”</i>	F/UP-DELI

A third level of reality existed for participants choosing to conceal their status from their partners. Concealment was a protective mechanism participants described using to prevent their partners from disengaging from them.

"I told myself, I'm going to play safe. I'm going to use condoms. That's the only thing that will help me. Keep me going. I told him 'no, we can use condom.' I haven't disclosed to him." [6:144-145]

6.3 "...And I was thinking of the family." - Family

"Now I feel better. But that's why I wanted to tell my family. I wanted to tell my family that I am positive, and that HIV positive is not curable. Because it is incurable, the end of HIV is to die. Before you die, you can get many sicknesses, I wanted to go to tell my family my real brother that ...I am positive; and therefore I can get sick anytime. And I can die anytime." [4:40-43]

Family emerged as a central theme in the lived experience of social support. Family included parents, siblings, grandparents, aunts and uncles. Many participants spoke of their dependence on their families for financial support and accommodation. Fear of their family's reaction to their HIV diagnosis was expressed. Participants experienced apprehension regarding discrimination and exclusion from family life. They anguished over the ramifications rejection would procure. Despite these fears, participants articulated a longing to disclose to their families.

"And then, I feel lonely, because I was thinking of the family. Maybe they won't support me about HIV. I want to...the family to know that I am positive, because I want the family to support me if I am sick. I want my family to know why I am sick" [3:36, 45].

Fear and longing were dealt with in two different ways. Participants gave account of either keeping their status a secret to avoid rejection or disclosing their status despite their fear of their family's reaction.

6.3.1 Keeping their status a secret to avoid rejection

Some participants withheld their status from their family, keeping it a secret to avoid rejection. Secrecy was chosen in an effort to protect themselves from the potential discrimination and stigma they may have to endure. These participants experienced no change in family relationships as their family did not know their secret.

"My family doesn't know about my status, but they don't treat me funny they support me like a child." [F/UP-NM]

Secrecy, however, was an emotional challenge. Participants related dissatisfaction with interpersonal relationships within the family. They felt unable to talk about HIV at home or outside of the home. They feared their family would find out from someone else if they disclosed their status to others.

"I am not ready to talk about my status outside, I want to start in my family, to my children and to my brother, so after that I can go and talk about my status outside. I didn't want to go outside first." [7:96-98]

Participants who identified this experience, perceived themselves to be unable to access deeper forms of support as they grappled with HIV. They also experienced fear as concern grew about who would care for them when they fell ill. One participant spoke of her longing to talk with her family about HIV and a desire to have her family accept her with HIV.

"And I want to be at home to feel free how to talk about HIV, even at home, to have the people to support me to talk about HIV. Because I don't feel free if I am...going to talk outside, because when I am at home, I can't talk about HIV because I think about the people inside my family, what are they going to say to me? I want them to support me even financially if I've got a problem, maybe when the time of sickness comes; I want the family to support me to take me to hospital and to look after my kids. I want that support." [3:48-53]

Participants withholding their status had a sense that, although interpersonal relationships within the family were to a degree satisfactory and supportive in nature, they were missing the richness of family support.

6.3.2 Disclosing despite the fear of the family's reaction

Participants who disclosed their status to their families experienced either, acceptance with HIV or deep rejection. Both reactions were described as components of the lived experience of social support. One participant described her sister's reaction to finding out that she was HIV positive: *"I stay with my...eh...with my sister, and my sister she didn't change anything"* [5:8].

Another described deep rejection:

"They were angry at me, made the funny things. Even when I'm cooking some food, they didn't eat it they just take the dishes and throw it away. They didn't want even to like to use the washing basin, they just said 'no, no can't use this basin because you are going to, you know, to make us very sick.' It was very, very hard for me and my children because they even chase my children away. They say 'no, no just stay there at your house with your mother don't come here to us because you are going to make us sick.' That, you know it was very hard for me. They didn't accept it yes; I was feeling very, very bad because I thought they are going to, to support me." [1:36-40]

Participants who indicated that their family accepted their HIV status defined their family as a supportive aspect of the lived experience of social support. Table 6.3.1 summarises the characteristics of satisfactory interpersonal relationships within the family.

Table 6.3.1 Characteristics of satisfactory interpersonal relationships within the family

Supportive family	Quotes that describe the aspect of support.	Reference
Accepting	<i>"No-one changed toward me."</i> [5:15]	INT5-NU
Advisory	<i>"If she saw that I have got another boyfriend, she came to talk to me, saying that is not good to have another boyfriend because you are HIV positive."</i> [5:78]	INT5-NU
Caring of the positive woman and her children	<i>"I don't have parents so my brother is like my parent, He didn't change to me, he always looks after my son."</i>	F/UP-C
Communicating	<i>"Then the family comes to support me about, talking."</i> [8:32]	INT8-OLIVIA
Concerned	<i>"My brother, sayings to me, must come to see doctors at Cape Town."</i> [8:42]	INT8-OLIVIA
Encouraging	<i>"They are always phoning everyday, asking me 'How are you?'"</i>	F/UP-C
Financially supportive	<i>"He is that one who always support my children, especially the twenty-one year old."</i> [4:56]	INT4-C
Friendly and loving	<i>"They are friendly and loving."</i>	F/UP-NU
Giving	<i>They bought me garlic, everything. If I need, vitamins, they will bring them. Pronutro everything."</i> [6:52]	INT6-F
Helpful	<i>"But the family helped me a lot...everything."</i> [8:8]	INT8-OLIVIA
Helping the positive woman to be able to live positively	<i>"I mustn't being worried about HIV positive."</i> [5:48]	INT5-NU
Non-discriminating	<i>"They are not funny on that day."</i> [8:9]	INT8-OLIVIA
Understanding	<i>"My granny is a understanding person."</i> [6:80]	INT6-F
Visiting me in the hospital	<i>"It was only my family that was coming in and out in the hospital."</i> [6:21]	INT6-F

Table 6.3.2 provides an understanding of the characteristics of families in which deep rejection and stigmatisation characterised this constituent aspect of their lived experience of social support.

Table 6.3.2 Characteristics of unsatisfactory interpersonal relationships within family

Non-Supportive family	Quotes that describe the aspect of non support	Reference
Antagonistic	<i>"So my...the sister of my brother is fighting...is fighting me and her brother is fighting me so I can't stay with the people, they are fighting me." [2:55]</i>	INT2-L
Discriminating	<i>"But when the times go, they are changed." [2:47]</i>	INT2-L
Isolating	<i>"...They make me feel lonely cause they told me you are AIDS we can't stay with you. Go away!" [2:56]</i>	INT2-L
Loss of family identity	<i>"...He put all my clothes on the fire...and my birth certificate and ID of my mother all my books from when I'm small...now if I am thinking I have a question, Why my father does this?" [2:103,105,106,114]</i>	INT2-L
Non-Supportive financially	<i>"...He didn't give me money to go to school. He didn't buy some food..." [2:102]</i>	INT2-L
Rejecting	<i>"So now the sister of my father told me you are not my child. You must going out cause I'm not staying with HIV positive and they called me HIV positive." [2:49]</i>	INT2-L
Rejecting	<i>"...they even chase my children away; they say 'no, no just stay there at your house with your mother don't come here to us because you are going to make us sick.' That you know it was very hard for me." [1:38]</i>	INT1-N

Table 6.3.2 continued

Non-Supportive family	Quotes that describe the aspect of non support	Reference
Silencing	<i>"And then my brother said, I mustn't tell anyone...in the Eastern Cape. He said that it is something for the inside house only. The only people that must know that...I am positive, eh, are the people who are the family, not all the other people. It was hurtful. Because I wanted to talk about my status, but now I find that it is difficult...to talk about HIV and my status."</i>	INT4-C
Uncaring	<i>"I was feeling so hurt by them because I thought they are my family I thought that they would always look after me when I've got a problem."</i> [1:123]	INT1-N
Withholding food	<i>"They treat me funny now...they didn't buy some grocery. So I can't stay out of food."</i> [2:50]	INT2-L
Without compassion	<i>"The way she takes me, she looks at me with no love; she's thrown me away from the home."</i> [1:73]	INT1-N

Family as a network of interpersonal relationships was unanimously cited as crucial in the lived experience of social support. Within family, however, the lived experience of social support was characterised by the potential for supportive interactions or a lack of support. If supportive relationships within the family did not exist and supportive interactions did not typify interpersonal relationships, emotional distress was great. This in turn led to a range of negative emotions being experienced.

Participants experiencing rejection were confronted with interpersonal relationships within the family that failed to provide care, love, valuing and esteeming. Deep loneliness and isolation resulted. Participants described being forced to turn elsewhere for care, love, valuing and esteeming (a space of

belonging). The alternative space of belonging differed from participant to participant. For one it was the extended family, for another it was organisations working with people who are HIV positive and for another it was the support group they attended. The alternative space of belonging was considered a place where interpersonal relationships were defined by supportive qualities. One participant described her alternative space of belonging as follows:

“But I’ve got another family in Khayelitsha it’s my, my father’s brother they come every time to support me, come to look after me and my children. I decided that I was going to go to Khayelitsha and talk to them about my virus. When I did, they accept it and say, ‘Don’t worry we are always looking for you, don’t worry if you’ve got the problem, you can call us any time to come.’ So the things are feeling better. Now I’m okay, I don’t worry about them you know, I don’t care about them, just say ‘Hello’ and go because I know I’ve got my real family. There’s a lot of family in Khayelitsha and they come to me even on this week-end I was there in Khayelitsha spending a nice week-end with them a sharing a lot of things and they have also gave me the support and encouragement. Uh, they, they you know when I am with them, they didn’t look like funny to me they always make me happy. And said, ‘no, don’t worry, everything is okay, we also love you, there’s nothing changed about you so we accept you, we know that you are living with this virus. But you are not sick and you are not going to die so you can make your dreams come true we are also watching at you’ and, they say to me every time, we love you.”
[1:41-47]

Within the theme of family, another dynamic emerged as a constituent aspect of the lived experience of social support, namely, being an extension of social support to family members. This aspect was manifest in the every day tasks of being women, and in some cases mothers in the home, as well as in caring for family members some of whom were HIV positive.

Participants’ spoke of their roles as primary care givers and the tasks those roles incurred. Tasks included household chores, caring for husbands, other family

members and children. On top of these normal duties participants described the responsibility they had in caring for other family members were HIV positive. NU explained how hard it was discovering her older sister was HIV positive. This meant the one she assumed would look after her, she would have to care for. The possibility that her sister would die before her, leaving her to bear the responsibility of looking after her sister's children was emotionally draining. NU explained,

"And also I was saying in my heart that I hope that I pass away before my sister because I can't cope to look after my sister's children. I want to pass before my sister because I want to be sick before my sister and then my sister must look after me, because I can't cope if my sister is going to be sick." [5:84]

6.4 "...I am the mother of the children." - Motherhood

"Oh, the first time, I was so sad and angry, because I thought I'm going to die on that day. You know I was so worried at that time because things were not going well because I was not working. I'm the mother of the children and the question I was asking is that who's going to look after my children?" [1:49]

The discussion of family, as an integral aspect of the lived experience of social support, constituted not only interpersonal relationships participants had with their parents, brothers, sisters and extended families. Family also included the interpersonal relationships participants indicated having with their children.

Motherhood emerged as a constituent aspect of the lived experience of social support and was described as a crucial role, which allowed room for interaction between mother and child. Participants expressed a range experiences regarding being mothers and coping with HIV. Experiences were strongly influenced by the age of participants' children.

Participants who considered their children too young to cope with the burden of HIV, expressed concern regarding continuing care for their children. They also

described sadness as they felt they would be unable to adequately perform the tasks of motherhood. For example, they felt they would be unable to nurture their children to independence and maturity.

“On that time I was crying, because I was thinking of my children because I have got two kids – seven years, and five years. I was crying on that time.” [3:8]

“I must be strong to see my two kids growing...up, to go to school, I must see my kids grow up and go to school.” [3:76]

“The second question, I am thinking of if...I can die...tomorrow, or any time, who going to look after my kids? And then there is no one to look after the kids. I am thinking of those questions.” [3:116,118]

Desire was expressed by these participants to stay alive until their children were older.

“So I’m praying that...I am praying that I can live for more than...five years, ten years then I can tell my children first.” [7:105]

Participants said that when their children were older they would tell them that they were HIV positive. Participants felt it important that they be the ones to tell their children, so that their children did not hear from someone else, *“Your mother died because of HIV” [7:103]*. Participants, whose children were older, spoke of the supportive role their children played. HIV had led to a different dynamic emerging in the mother-child relationship. Roles had reversed and participants recounted how their children cared for and nurtured them.

“My big boy, he’s 21 now, and he always comes to me every day come said hello Mum, how you, how do you feel, are you okay? I said no, it’s okay everything is good. They come with, they buy us some fruit, said here’s the fruit you can eat it you know so it makes me feel better and better and better and it makes me feel very strong and brave. When I see my children, they loves me and they also watching at me all the time. So I don’t care about anybody, now that my family know my problem I can see that they are

always looking at me. Sleeping besides me, and saying Mummy are you okay? I said no, I'm fine, you know, and she said, you know I think you are sick, and I said, no I'm okay my baby, she loves me, everything she just always watching out for me." [1:75-76]

Qualities of how children constituted a supportive aspect of the lived experience of social support are presented in Table 6.4.1.

Table 6.4.1 Qualities of children described as an important aspect of social support

Qualities of child	Quotes that describe the quality	Reference
Available	<i>"She is always sitting besides me, looking after me taking a lot of care of me."</i>	F/UP-N
Caring	<i>"He is always checking if I have taken my medication and asking me am I happy, am I well?"</i>	F/UP-F
Giving nutritional care	<i>"Even my daughter if she has a small break she comes to check me, make me porridge and give me treatment."</i>	F/UP-N
Loving	<i>"They are always saying we love you mummy, you must be well."</i>	F/UP-F
Non-discriminating	<i>"She is 16 and knows I am positive, the relationship is good, and she treats me normally."</i>	F/UP-C

Even participants, whose children were older, however, described feeling concern regarding their children's future. A longing still existed to be carers and nurturers who could provide for their children.

"The problem in my life is that I don't have any savings for my children, want them to go to school but I have not had enough jobs yet. Sometimes I just thinking: Oh God, my daughter is 19; she is doing Standard eight you know this year. So what can I do when she passed, matric? Maybe she wants to go to the university but I don't have any money to take her there. Then there is also my little one. Who is going also to help this little one also you know? That is my problem. I'm always thinking about that, because I didn't have enough, ah, jobs you know. Yes I like to see my children grow up and...and go to

school, finish their schools, you know? I would like to see them living with their houses, and having funds.” [1:143-144]

The role of family was central in view of the concern participants had for their children’s future. Family would seem the obvious network of interpersonal relationships to continue to care for their children. However, those who had experienced rejection from their family described feeling distress. They feared their children would be rejected because of their own HIV positive status. This was a burdensome but real aspect of the lived experience of social support.

“...the question I was asking is that who is going to look after my children. Especially because I was thinking, look at my family they are funny to me. So who’s going to grow these two little daughters, you know and I worried, because even me, I grew up without my mum around. So I know everything, you know to grow without your mother it was painful and I was thinking about that and so it was my pain in my life. I was so, so sad when I’m looking to my children like that, you know.”[1:49-50]

6.5 “...as from that day I know that I am not the only one person who is HIV positive.”- A community of individuals living with HIV

“And then I had hope that is all...is not only me who has got HIV. The most of the people...there’s a lot of people who’ve got HIV. When I was first diagnosed with HIV at first, in that first time, I know that I am positive. I stay alone in my house. And then I started to be better because I saw that I am not alone.” [4: 79-83, 90]

The pain of being diagnosed HIV positive exacted an agonising toll. An HIV positive diagnosis was described as an arduous thing to deal with. Participants spoke of their feelings of sadness, anger and loneliness, loss of hope and loss of future.

“When I diagnosed that I am positive, on that day I didn’t like it, outside it was dark and I was thinking about my children, I was thinking about my life and I was thinking about death. On that day it looked dark outside.” [4:4-9]

Participants expressed how upon receiving their HIV positive diagnosis their thoughts immediately turned to death. N described:

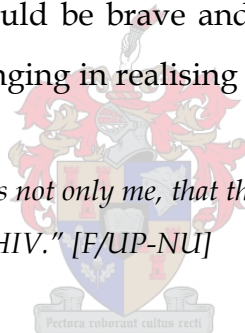
Because it makes you a lot of stress if you think, Ooh, I'm HIV ooh, God I'm going to die, maybe tomorrow, maybe tonight you know, its always ringing in your mind." [1:63]

Participants' discovery that they were not the only ones living with HIV enabled them to think about being HIV positive and life.

"When I saw them there, I see people who I know on the street and then I say that no it is not the end of my life, I am happy." [7:29-30]

Realising they were not alone was an important facet of the lived experience of social support. Interacting with others who were HIV positive gave participants hope, and a sense that they could be brave and strong with HIV. There was a sense of universalism and belonging in realising that they were not alone in their experience with HIV.

It gives me a hope because it is not only me, that there are others all who are HIV positive and it helps me to talk about HIV." [F/UP-NU]



"At the time I saw even the ladies came from Khayelitsha, they come and disclose here in Masiphumelele. And I look at them: hau, they are so beautiful and big like that I said hau, no and me also, I'm going to be like that if I can accept this virus you know. It was that time I said, 'Oh, its okay.' And since then I always keep my mind busy, not to stay and think I'm HIV or what I'm going to do?" [1:127]

6.6 "...come inside, sit and take your jacket off, because this is your home." – Support groups

"It was really the first day I was feeling very, much better than before because when I saw no, it's not me only living with this virus. There is a lot of others and they said, come inside, sit and take your jacket off, because this is your home." [1:55]

Participants spoke of seeing others who were HIV positive on the street and at meetings where individuals disclosed their status to the community. However the place participants most commonly recounted becoming aware that they were not alone, was in support groups. In support groups participants came into direct contact with others who were HIV positive. Support groups were collectively cited as an essential theme in the lived experience of social support. They were described as places where participants found a sense of belonging, mutual caring and sharing. See Table 6.6.1 for salient characteristics of support groups described by participants.

Table 6.6.1 Salient characteristics of support groups

Facilitative features of support groups.	Quotes that described the aspect of support	Reference
Activities were engaged	<i>"In the support group I really like to be doing these activities and things." [4:113]</i>	INT4-C
Ideas were shared	<i>For example, if I go to the support group, we are sharing ideas and I go at home feeling happy because we share-share ideas and help each other on that problem." [7:111]</i>	INT7-NP
Mobilisation took place	<i>"Now what are you going to do about that problem." [1:82]</i>	INT1-N
Openness was encouraged	<i>"If I have a problem I cry in front of them."</i>	F/UP-N
Personal skills were identified	<i>"And they said to me, do you know that you have counselling skills?" [6:113]</i>	INT6-F
Personal skills were developed	<i>"Why don't you try the counselling course?" [6:114]</i>	INT6-F
Strength and hope was imparted	<i>"They give me a lot of strength and hope, They pray for me."</i>	F/UP-N
Pro-active problem solving took place	<i>"So they are going to speak with the sister of my father." [1:39]</i>	INT2-L

Table 6.6.1 continued

Facilitative features of support groups.	Quotes that described the aspect of support	Reference
Problems were shared	<i>"I share my things if I have got a problem."</i> [7:31]	INT7-NP
Learning how to cope with HIV ensued	<i>"I could be able to cope with it."</i> [6:86]	INT6-F
Women didn't think about death but rather life	<i>"And I'm not thinking all the time about the death now."</i> [3:14]	INT3-NM
Women didn't think about death but rather life	<i>"I learn that just because I am positive. It is not the end of the life. I can stay normal for so many years."</i> [3:15]	INT3-NM
Sense of happiness was adopted	<i>"I was so happy to see the people who are HIV positive...I was so happy if I'm going at the support group."</i> [8:48-49]	INT8-OLIVIA
Women became comfortable to talk about the stigma of HIV	<i>"We are talking about the stigma of HIV there. So I like to be there."</i> [3:96]	INT3-NM
Women learned not to regret knowing her status	<i>"But for the first time I felt like it was a good decision to take the decision of going to the clinic to know that I am HIV positive."</i> [4:104]	INT4-C
Women realised they were not alone in their struggle to accept HIV	<i>"I realised that there are a lot of people who also struggle to accept that they are HIV positive."</i> [1:127]	INT1-N
Woman realised they were not alone in their struggle to accept HIV	<i>"And I started to be better because I saw that I am not alone."</i> [4:90]	INT4-C

Living with HIV was experienced as a heavy burden. Within support groups, members helped each other in carrying the burden of HIV. The support group was a place where participants could talk openly. It was described as a place where they knew others would understand as they shared similar experiences.

Interpersonal relationships between individuals in support groups were considered satisfactory. Support groups were demonstrated as one of the most critical features of the lived experience of social support (See Table 6.6.2).

“But the most important to my life is, eh my support group. I want to always stay in my support group.”[3:94]

Table 6.6.2 Characteristics of interpersonal relationships within support groups

Characteristics of interpersonal relationships within support groups	Quotes that described the aspect of support.	Reference
Advisory	<i>“Then the support group give you advice.” [1:82]</i>	INT1-N
Advisory	<i>“I learn that it is better to tell one person in the family at least for support.” [3:28]</i>	INT3-NM
Caring even outside the support group	<i>“...come to visit me at my home, if I don't go there then they say, are you ok?”</i>	F/UP-DELI
Comforting	<i>“Because we feel comfortable because I see that it is not only me who've got the problem.” [3:58]</i>	INT3-NM
Comforting	<i>“Because I feel better now, better than before.” [8:53]</i>	INT8-O
Communicating	<i>“On the support group is where I started to talk.” [4:77]</i>	INT4-C
Educating on healthy living with HIV	<i>“I must be health and look after myself, using a condom.” [3:16]</i>	INT3-NM
Educating	<i>“After I join the support group I know about HIV.” [8:55]</i>	INT8-OLIVIA
Encouraging	<i>“They support me and say I mustn't give up and I must have a hope that I am going to live for a long time.” [3:78-79]</i>	INT3-NM
Giving boldness to disclose	<i>“Then I am helping a lot to go to the community to disclose about being HIV positive.” [8:56]</i>	INT8-OLIVIA

Table 6.6.2 continued

Characteristics of interpersonal relationships within support groups	Quotes that described the aspect of support.	Reference
Helping to access financial support	<i>"If other people they need a grant they are told what they must do." [4:111]</i>	INT4-C
Helping	<i>"I feel supported when I can talk and have someone who is helping me a lot." [7:115]</i>	INT7-NP
Reaching out	<i>"The people from Eastern Cape they didn't know about support group, so we are going like a support group who are the first people going out so we are giving them a support group." [2:76]</i>	INT2-L
Referring to appropriate resources	<i>"Referred to the appropriate resources." [4:110]</i>	INT4-C
Respecting	<i>"We respect each other."</i>	F/UP-C
Stress relieving	<i>"And the stress goes away because I didn't think anything after that." [1:58]</i>	INT1-N
Atmosphere of trust.	<i>"People trust each other."</i>	F/UP-C
Place of belonging	<i>"They said, come inside, sit and take your jacket off, because this is your home." [1:55]</i>	INT1-N

6.7 "...It's very important to share, not to keep the things inside." - Sharing about HIV

"And the other thing, it's very important to tell one of your family, or your friend to talk to them, to tell them that you are HIV positive. If you just keep it as a secret you are going to be stressed a lot and sick, it's better to talk about this every time just talking, talking, talking don't be scared you know, it's very important." [1:34]

Being able to tell one's story emerged as a constituent aspect of the lived experience of social support. The emphasis was not to whom participants told

their story; but rather the necessity of telling it. There was unanimous feeling expressed that when a person doesn't share their story or talk about being HIV positive they will get very sick and die quickly.

"Oooh... I think it's, it's a big problem. Because if you won't share to anybody, you are going to be sick because you are always lonely, you know? Because you've got something inside, you know? Something that is bothering you. So I think it's not a good idea to keep it inside that's why it's important to share; to take one of your family or one of your friends, and share. Because if you can think you are going to...to...to keep it as a secret, it's going to...you are going to die! You are going to be sick, you know; always lonely, always angry with someone, you know? Because you've got something inside your heart." [1:90]

One way participants described being able to communicate their stories was by being involved in the Memory Box Project. Being involved in the Memory Box Project, story telling was facilitated. For various reasons the Memory Box Project was articulated as a vital aspect of the lived experience of social support.

"The Memory Box Project is the place where we share the stories of your life to write it down on the boxes. You make the boxes and you make the books also, and it helps us a lot who are HIV positive, because some people, they didn't have the people to share their problems. If you, have a memory box or memory book you can write all your stories or your problem down in your box or in your book. And you can share that with others. Then you can keep all your problems out of your mind." [1:67]

"I think its because you are taking out of your heart now, you know instead of keeping inside, you know its very important to take something, to talk about something instead of keeping the secret inside." [1:68]

One participant described: *"The Memory Box Project is helpful because I start writing down my history from start to the end and then I remember everything and it is helpful" [E/UP-OLIVIA]* .

Another one said *“It is so important to me...I share my stories with people, after that, when I am making that box, I take time and am thinking all my stories and the many problems I get in my life. So after I’m telling my story I can’t get any problems because I am just feeling well”* [2:143-145].

The Memory Box Project enabled an expression of stories promoting a sense of history and strength to face the future. Participants spoke of how it helped them to *“explore their feelings”* [6:166]. Sharing stories by means of the Memory Box Project was considered helpful in that, *“you are sharing your problems even if you don’t want to share with someone else you can share with your book or your box”* [F/UP-N]. To share one’s story emerged as crucial in the lived experience of social support because it *“makes the stress go away”* [F/UP-N].

Facilitators educating participants about the Memory Box Project were also described as a vital aspect of this constituent aspect of social support. Facilitators taught participants about the Memory Box Project and were available to assist participants with problems they may be experiencing.

“And, eh, the Memory Box Project also helps me a lot because they teach us a lot of things. And sometimes that there are ladies come from UCT for research. They come and teach us how to protect yourself when you are HIV positive. They teach us a lot of things so I’ve got a lot of experience to look after myself.” [1:130]

“If I have a problem I can talk with them, they are like a family to me.” [F/UP-OLIVIA]

The Memory Box Project allowed room for interpersonal relationships of a supportive nature to take place. These interpersonal relationships were between facilitators and participants, participants and others who were part of the project, and participants and their Memory Boxes. For the above reasons the Memory

Box Project emerged as a crucial and unique aspect of the lived experience of social support.

6.8 “...Education about HIV gives me hope in my heart that I can live.” – Gaining knowledge regarding HIV

“And then she started to talk about HIV education of HIV and then I started to listen and I get hope in my heart that I can live.” [7:21-22]

A key theme from participants’ stories about the lived experience of social support was the importance of gaining information about HIV. Participants demonstrated how upon receiving their HIV positive diagnosis they knew very little about HIV. As a result they believed that they would die any day.

“And, I didn’t have anything knowledge of HIV, so what I know, I know that I’m sick and I’m going to die any day.” [8:30]

Participants desired to know more about HIV, one participant explained:

“And I need to have more information, more knowledge about this HIV. Otherwise this is going to kill me.” [6:58]

The process of learning and receiving education about HIV involved other people. The people from whom participants learned about HIV, as well as the information they received, were considered vital in the lived experience of social support. Interpersonal relationships with individuals from whom participants received education regarding HIV are described in Table 6.8.1.

Table 6.8.1 Characteristics of interpersonal relationships with supportive educators

Supportive educators	Quotes that described the aspect of support	Reference
Helpful	<i>"I'm feeling okay because those people they are helping me" [F/UP-NM]</i>	F/UP-NM
Like a real family to me	<i>"...the way they treat me, because they care for me and are part of my family." [F/UP-NM]</i>	INT3-NM
Loving people who have sympathy towards me	<i>"The qualities of the people I have learned from about HIV are that they are loving people who have sympathy towards me." [F/UP-NM]</i>	F/UP-NM
Respecting	<i>"I can trust them and they respect who I am." [F/UP-NM]</i>	INT3-NM
Trustful	<i>"I can trust them and they respect who I am." [F/UP-NM]</i>	INT3-NM

Educational themes participants cited as crucial are summarised in Table 6.8.2.

Table 6.8.2 Educational themes

Educational themes	Quotes that describe the importance of the theme	Reference
Learning more about the illness of HIV	<i>"I didn't know about HIV, but now I learn more about HIV, then I am happy to be HIV positive." [F/UP-OLIVIA]</i>	F/UP-OLIVIA
Accepting the virus	<i>"the first thing they told me, they said that, if I don't accept this virus, this will be a big problem in my life. I must, I must accept this virus I must say, HIV you are my friend I just take you like that, you are my friend. Can't share anybody with you, it's just you and me. That is the first point that you must know, they said and it's very important to your life." [1:62]</i>	INT1-N

Table 6.8.2 continued

Educational themes	Quotes that describe the importance of the theme	Reference
Living with HIV	<i>"I'm learning about HIV and I feel happy and powerful because I know what HIV is and how to be strong and live for a long time."</i> [F/UP-NM]	F/UP-NM
Sexual health	<i>"I know now that I must be healthy. I must be healthy and look after myself, using a condom."</i> [3:16]	INT3-NM
Sexual health.	<i>"If you want to make a sex you must condomise."</i> [2:83]	INT2-L
The transmission of HIV	<i>"If we are staying with, HIV people, here they are saying you mustn't infect us with HIV. I said you don't get HIV by touching."</i> [2:44]	INT2-L
There are others who are HIV positive	<i>"And there are other young people they've got HIV. So learn that I am not alone to live positive."</i> [3:33]	INT3-NM
Financial Planning	<i>"People from other organisations, like the people from Standard Bank, come to talk about the policy, because we understand the people that are HIV positive they didn't talk to the Bank to open policies, but those things are not true. We know they are not true because of calling the people from Standard bank."</i> [7:81-83]	INT7-NP
Nutritional health - How to cook healthily and eat correctly	<i>"and the people who know how to cook, then those people come to teach us how to cook."</i> [7:84]	INT7-NP
Nutritional health - How to cook healthily and eat correctly	<i>"I am also try to get the food, the right food for my health you know? Always eating something like garlic, fruit, something like milk, juices everything to make me feel strong you know because this is very important to eat the right food, because it makes you very strong."</i> [1:110]	INT1-N

Participants spoke of receiving education about HIV from watching TV, listening to the radio and from the books they read. Media and books dealing with HIV/AIDS emerged as a constituent aspect of the lived experience of social support. Messages of hope were received from both books and the media. An indirect interaction between presenters talking on the TV, or radio, or the authors of books, dealing with HIV/AIDS, enabled participants to feel encouraged and satisfied on four levels:

1. Feelings of not being alone: *“On the TV people who are HIV positive talk and if I see those people I see that it is not only me it is other people”* [F/UP-DELI].
2. Feelings of positivism that one can live happily and healthily for a long time with HIV: *“It is helpful to read those books because I know that those people who write book, the stories I know that they are HIV positive and I get hope that I can still live for a long time, like those people who are writing the stories and maybe one day I think that I will write the story about myself”* [4:140-141].
3. Practically how to care for oneself with HIV: *“They say on the radio, if you are positive you are not going to die and they give healthy tips about HIV so that you know how to look after yourself”* [F/UP – F].
4. Others really care about individuals living with HIV: *“When I hear people talking on the radio about HIV I feel better because I see that people care about HIV because they talk about HIV it makes me powerful and gives me hope”* [F/UP-NM].

6.9 “...There is a lot of caring about HIV.” – Organisations within the community

“...So there is a lot of caring about HIV.”[3:87]

Many organisations work to help individuals living with HIV, these organisations emerged as a constituent aspect of the lived experience of social support. The following organisations were identified by participants as being

supportive for various reasons: Living Hope ministries, TAC, Vaccine project, Love life, and social services. Table 6.9.1 provides insight into the qualities participants highlighted that made the different organisations vital.

Table 6.9.1 Organisations as a constituent aspect of the lived experience of social support

Organisation	Qualities that made it supportive	Reference
Living Hope Ministries	Provide food	<i>"So we are dependent on living hope, they give us food." [7:37]</i>
Living Hope Ministries	Provide clothes	<i>"And then I told living hope, my child she is here. And then they tried to give me clothes for children." [7:41]</i>
Living Hope Ministries	Are supportive and helpful	<i>"I also know that I can go up to Living Hope and that they will help and support me." [4:103]</i>
Living Hope Ministries	Provide spiritual encouragement	<i>"If I have something stressful to me I can talk to Rev. N and then I feel better." [F/UP-C]</i>
Treatment Action Campaign	Provide food	<i>They are supportive of people living with HIV; they are giving the people who have HIV some food." [2:71]</i>
Treatment Action Campaign	Provide clothes	<i>"And if you don't have clothes, like a jacket they will give to you." [2:72]</i>
Treatment Action Campaign	Provide drugs	<i>"TAC its helping people get drugs." [2:139]</i>
Treatment Action Campaign	Try to reconcile you with your family	<i>"If I'm sick and I have a problem with my family, they try by all the ways for my family to come and see me." [2:98]</i>
Treatment Action Campaign	Deal with the fear of your family not burying you.	<i>"If your family, if you are died by HIV then maybe they'll say we don't take her to Orange Free State cause she died of HIV." [2:94]</i>

Table 6.9.1 continued

Organisation	Qualities that made it supportive	Reference
Treatment Action Campaign	Take you to your home when you die.	"...if you are very sick and you die, TAC keeps the money for you and then they are going to take you to where you are coming from."
Treatment Action Campaign	Facilitate the meeting of others who are HIV positive	TAC is helpful because I meet others who are HIV positive and we build a relationship and we visit each other" [F/UP-NM]
Treatment Action Campaign	Encourage people to disclose	"It helped me because now I am on my way to thinking about to go to the community to disclose my status." [3:126]
Vaccine project	Give drugs	"Vaccine project is giving out the drugs for the people who have HIV." [2:136]
Love Life	Give advice	"love life is giving the people advice." [2:137]
Social services	Give grants	"I must have that disability grant because of my CD 4. And that was a great help to me because I didn't have to worry so much about money." [1:96]

6.10 "...I saw that if I keep most of the time to be busy, I'm not thinking anything about HIV." - Activities: Keeping busy, thinking positively

"I don't want to think much about this virus because it is a funny thing. The time you give it a chance, it just comes, and attacks you. So you can't give it a chance to attack you, it has this chance when you just sit and you just say what I'm going to do? Oooh...I'm...oh, no man! I'm HIV! Oooh no! When you keep yourself busy though that thing's not coming in your mind, you know and then you don't give HIV a chance to attack. So that is why I say that it's very important; always keep busy. I've got a lot of things there at home. I've got mats, I've got bedspreads, I've got doily's, I've got frames, always do something. I'm always doing something; I can't just stay and sleep for the

whole day now. Don't like that, because I know I want to...always busy, you know? Don't want to just stay and think. It's very important. " [1:115]

Participants described the importance of keeping busy and thinking positively.

One participant explained:

"I know that I am positive but I must not only be thinking about HIV all the time. If I think about HIV all the time I get a lot of stress and become sick. If I always think about HIV you have a stress, if I'm always thinking all the time about all problems that I have no answers for. I have a lot of questions but no one who can answer, so if I think about this all the time I can not feel good all the time. That's why I don't want to think about, HIV all the time. I know that I am HIV positive, and I can't sit and think about I'm HIV positive, because then I am going to be sick with AIDS. But not always thinking something about AIDS and being busy keeps the thoughts out." [3:106-113]

Activities were an important feature of the lived experience of social support.

They were instrumental in helping participants keep busy and to think positively. One participant described:

"OK. I like to work; to do the things by hand. That's why I like the activities and I go there. When I first joined the support groups I know how to do sewing. But the beads, I learned there when I was at the support group. And then now I really like doing those things because if I am there I am always laughing for the whole day. Then I am not thinking that I am positive. Yes I feel so happy every Thursday if I go there. If I look at the machines on the table, and then I know that I'm going to do something and I feel happy because I like to do sewing. I go to the support group Tuesdays and Thursdays. So on those three days and the weekends what I am doing at home is that I have got a machine at home. Then I look, for material and do something at home. Those activities they make me happy." [4:113-120]

Another described her focus:

"I'm working hard, always keeping busy, because I don't want to think about HIV, I don't want to think that I am dying." [F/UP-C]

Participants articulated how activities provided a way of managing continuous rumination regarding self and HIV. Activities also provided space for satisfactory interpersonal relationships between participants and others involved in various activities. Involvement in activities enabled participants to feel normal. Individuals with whom they related whilst busy with activities treated them in a non-discriminatory fashion. Being involved in activities that HIV negative people were partaking in served as a reminder to participants that they were living with HIV rather than dying. Activities were an important feature in the lived experience of social support because of their power to normalise participants' lives and enable them to live in the present:

"It is good to be a part of the activities, because just because someone is positive, it doesn't mean that that person can't do anything. And doesn't mean that person she is going to get sick. I can do everything that even someone who is negative can do. That is why I want to do activities to join the activities knitting and sewing. The people who I do activities with they give me support, they treat me like they treat other people." [FUP-DELI]

"The relationship with the people in the groups I am in are important because they help me not to lose hope they make me powerful and make me feel like I am still a human being." [F/UP-NM]

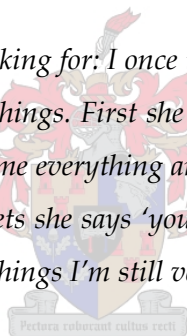
Participants identified involvement in several activities. These included: doing bead work, sewing, working in the garden growing spinach and onions, knitting, crocheting, reading literature, singing in the choir and playing netball.

Participants who were unemployed placed significant emphasis on being involved in activities. Being unemployed, long days of being unable to escape continuous thinking were described. Activities provided feelings of happiness and solace from rumination.

"I also am happy, because I know that I am busy during the day because I am not working. Because I am only alone in the house. So I want to always to be busy, because I didn't want to stay in the house all the time and then thinking about lots of things. Because if I am going to stay in the house, and thinking, I will think about HIV although I have already accept about to be positive. So I feel happy if I can be busy all the time."
[8:80-86]

Participants, who were employed, explained how employment was a form of activity in which they were involved. They described employment as a component of the lived experience of social support fulfilling the same role as the activities described by unemployed participants. Employed participants expressed the role their employers and colleagues played in their lived experience of social support.

"The lady in Fish Hoek I'm working for: I once told her I'm HIVsShe always gives me lot of support. She gives me some things. First she buy me some veggies; tins, everything to make me feel strong. She's told me everything and sometimes she buys me some tablets at the chemist, and I use that tablets she says 'you can use this can make you very strong', so it's OK. Because of all these things I'm still very strong and brave." [1:78-79]



Another participant described the importance of her colleagues:

"They listen to me. I can be honest with them, ask them to give me advice. They are helpful to me and give me something. At work sometimes if I talk about the disease I know that they can help me with my problems because I know they love me and I know they won't tell anyone." [F/UP-F]

6.11 "...My community, it is very important to me." – The community

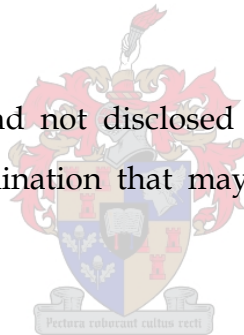
"And the community neighbours also coming maybe sometimes I'm just not feeling okay. But my neighbours always come into my house and I say 'No we didn't see you this morning outside, what is wrong with you?' I said 'oh no I'm, I'm not feeling well.' Then they say, 'okay we are going to make some tea;' that makes me feel...I feel very, very, you know, stress free about that. Because I know even my family are not here – they are in

Khayelitsha...but I've good family here in Masiphumelele, like my neighbours and the community. If I am walking around they said 'Hello!' I said 'Hi!' you know its ok. I like it that I am always friendly with everyone and they are friendly with me. There are a lot of people in Masiphumelele that knows I'm HIV they all say "Hello!" and I say 'Hi...hi girls...hi!' so I like that." [1:77]

Shack to shack living, with friends and community neighbours in and out of their homes was the way participants depicted the close living setup of their communities. Within this context, the practical care community neighbours provided was a constituent aspect of the lived experience of social support.

"The neighbours are kind, they don't talk about me. If I don't have anything in my house I can go to their houses and they can make me rooibos." [F/UP-NU]

Participants, however, who had not disclosed to their community, expressed anguish regarding the discrimination that may result from their status being discovered.



6.12 "...It's God who knows and I'm thankful for that." - Spirituality

"The other thing that made my stress go away is that I started going to church again, at church I share things to God. Talk of your problem, you can tell the problem to God, you can open your heart to God and God can help you, I believe in God." [1:64]

Believing in God, going to church, and praying were all manifestations of this critical facet of social support. Both prayer and having a relationship with God were described as forms of interpersonal relationship that were supportive in nature. Furthermore, participants described their relationship with God as something that broke into the lived experience of being HIV positive in a relational way that was satisfying.

"If you pray and you tell God your problem, God is there for you." [7:85-86]

Several participants identified satisfaction resulting from being in relationship with God. In relationship with God, they felt unconditional acceptance, a sense of belonging and protection.

"Because I know, he loves me and he is always watching me you know, He can't leave me alone all the time, even now He's beside me and He's always watching me, I know that and I believe in Him. If I got any problem, I'm just talking to me Lord and said 'Please God, I've got this problem and I know you're going to help me and he helps.'" [1:65]

Having this very real form of spirituality, participants were able to think more positively about life and not lose hope:

"I am feeling strong because I believe that God is here for me and I know that if I hope and believe in God everything is going to be going well to me." [9:22-23]

Within the theme of spirituality, church was expressed as a significant. Church allowed space for satisfying interpersonal relationships. One participant verbalised *"The most important for me is to go to church"* [2:84]. Table 6.12.1 sums up qualities that defined relationships within the church as satisfactory.

Table 6.12.1 Qualities of interpersonal relationships within the church

Interpersonal relationships within the church	Quotes that describe the quality	Reference
Accepting	<i>"It is nice for me to go to the church group because one day I told one of the men who attended the church, 'I am HIV positive' and he didn't change to me."</i>	F/UP-NM
Trustworthy	<i>"They give hope and can be trusted and love me like any other person."</i>	F/UP-DELI
Loving and Friendly	<i>"Loving and friendly people."</i>	F/UP-C
Good listeners	<i>"If I tell them things they always listen and are friendly."</i>	F/UP-C
Helpful	<i>"If I talk to the priest he helps me because he has trained about HIV."</i>	F/UP-F

Table 6.12.1 continued

Interpersonal relationships within the church	Quotes that describe the quality	Reference
Spiritually encouraging	<i>"They said to us every week, come and we will pray for you."</i>	F/UP-F
Gentle	<i>"They treat me like an egg."</i>	F/UP-N
Caring	<i>"Every week they come in my house and come to visit me."</i>	F/UP-DELI

Once again those who had not disclosed their status to the members of the church felt that they had not been able to fully access this facet of social support. In their interaction with other church members they felt they were missing out on the richness of support but considered disclosure as too risky.

6.13 "...because of this interview, I feel happy." - Being involved in research

"I learned a lot because of these questions. Being a part of this research has helped me to understand more about my social support." [F/UP-DELI]

Pectora robustant cultus recti

Another theme emerging from the data as a constituent aspect of the lived experience of social support resulted from being involved in this study. Participants felt they had been given opportunity have a renewed look at their lives. As a result they felt they understood more about their own lived experiences of social support. Participants described surprise at the realisation of how much support they had available to them. They discovered their experience of social support was much broader than just the "support group" or "that one who is helping me" [F/UP-DELI].

Various participants spoke with the researcher concerning issues they had felt unable to express to anyone. As a result they considered being part of the

research an aspect of their lived experience of social support: *“I haven’t ever told anyone those questions; this is my first time to talk about them”* [3:119].

Participants requested a copy of the research because they felt it had been helpful.

“Can you write down the things we were talking about because it was so helpful. I can see that my experience of social support is much bigger than I originally imagined.”
[F/UP-C]

In response to the question, *“What would you say is most important in your experience of social support?”* one participant said:

“Your interview because now I feel happy because you talk about everything. Things I haven’t wanted to explain to anyone I have explained to you and it helps me to feel better.” [F/UP-DELI]

6.14. “...I learn a lot when I am helping others.” – Meeting the needs of others

“It has been helpful to help others, I like that.” [1:132]

Finally, the lived experience of social support emerged as including an extension of social support to others. This bi-directional manifestation of the lived experience of social support was demonstrated as being made up of, caring for family members and caring for others living with HIV. Participants felt since they had become HIV positive they had acquired much knowledge and life experience surrounding issues of HIV/AIDS and as a result found it beneficial to be involved in giving advice to others.

“I’ll give others advice.” [2:12]

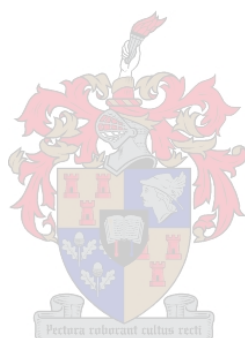
“I learn a lot when I am helping other it is part of my experience of social support because I share and help others.” [F/UP-N]

The fourteen themes discussed (summarised in Table 6.1) emerged from the data as constituent aspects of the lived experience of social support. Themes were described as interactions impacting on participants' lives both in satisfactory and non-satisfactory ways. These interactions served to propel participants forward in their journey of being HIV positive. One participant articulated:

"Mm I think that social support is all the things that have helped me to today be the hero of my life. Cause even though difficult times come to my life I have reached a stage to accept my life and now I look forward to me life and my children's future. Ja it is all the things that have helped me to be strong and brave. I am always praying and trusting, and now I can think that the best is on my life. So it is all the things that have helped me to be the hero today. I'm the hero of my life." [1:133]

In summary, the analysis of the nine interviews and follow-up sessions for each participant provided in-depth descriptions of the lived experience of social support for the sample. Descriptions of the fourteen themes (Health care professionals, partners, family/children, support groups, meeting the needs of needs, story telling, Memory Box Project, media and books, organisations within the community, activities, community neighbours, being involved in research and spirituality) have provided valuable understandings of the world of interpersonal relationships constituting the lived experience of social support for the sample. Each theme, illustrated by direct quotes from interviews, explored constituent aspects of the sample's lived experience of social support. A polarity was identified in the lived experience of social support. Although the concept of social support refers to interactions of a supportive nature as discussed in sections 3.3 – 3.6, the lived experience of social support emerged as constituting interactions that had the potential to be satisfactory and supportive as well as non supportive. A diagrammatical representation of the world of interpersonal relationships constituting the lived experience of social support for the sample of Black South African women living with HIV follows in Figure 1. The diagram is

a summary of the findings and provides a context of understanding for the ensuing discussion. Findings will be discussed further in the following chapter.



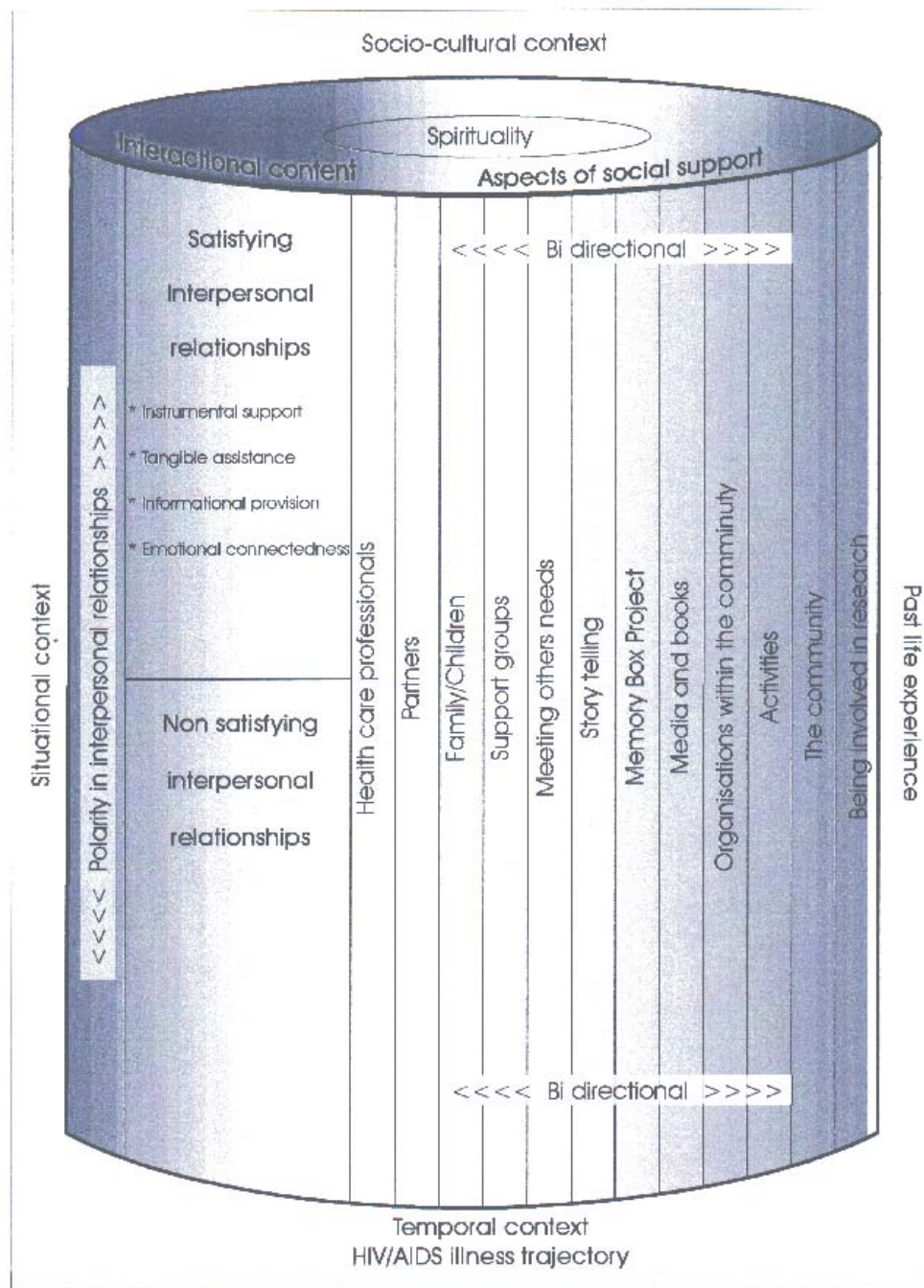


Figure 1: The world of interpersonal relationships constituting the lived experience of social support
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CHAPTER 7: DISCUSSION

The findings of this study have provided expansive descriptions of the lived experience of social support for the sample of Black South African women living with HIV. The lived experience of social support emerged as a multifaceted, bi-directional concept made up of a network of relationships considered constituent aspects of social support.

This network of relationships includes interactions with health care professionals, partners, family, children, support groups, organisations within the community, community neighbours, God, and members of churches. Interpersonal relationships within this network either satisfy or do not satisfy specific needs.

Within this network, analysis of the interactional content of various interpersonal relationships provides evidence that a polarity exists within the lived experience of social support. For example, family emerged as a constituent aspect of the lived experience of social support; however, within the notion of family, an experience defined by either acceptance or rejection, could result from HIV disclosure. Explained further, in the lived experience of social support a tension exists between two poles, each with contrary qualities. On the one side interpersonal relationships are experienced as satisfactory and defined by instrumental support, tangible assistance, informational provision and emotional connectedness. On the other hand, interpersonal relationships are experienced as unsatisfactory. Certain activities comprise further constituent aspects of the lived experience of social support. For example, hobbies, employment, story telling, Memory Box Project, prayer, engaging with media and books and being a part of research.

While the lived experience of social support emerged as including engaging in interpersonal relationships and activities leading to specific needs being met or not, the lived experience of social support is also identified to comprise a bi-directional component. This bi-directional component displays the reality that relating to others in ways that meet the needs of others whether within families, support groups or the broader community is also an aspect of the lived experience of social support.

Once research findings have emerged, phenomenology emphasises the importance of engaging with theory and other literature (Burch, 1989). Research findings must be situated within a greater theoretical world of knowledge (Burch, 1989). In this chapter each constituent aspect of the lived experience of social support, emerging from the data as summarised in Table 6.1 will be presented and discussed.

Where possible, analysis of the interactional content of interpersonal relationships will take place. This will display how the lived experience of social support is defined by various interpersonal relationships which function on an instrumental, tangible, informational and emotional level (House & Kahn, 1985).

Findings will be situated within a greater theoretical world of knowledge. Consideration will be given to three contexts assumed to shape the experiences of individuals living with HIV (Greene, Frey, & Derlega, 2002). These three contexts include:

- Socio-Cultural contexts - Participants were assumed to come from a similar socio-cultural context. Experiences emerge from socio-cultural contexts. These contexts are influential in shaping meaning about the world. Aspects of the socio-cultural context will be highlighted where necessary.

- Temporal context - The illness trajectory of HIV to AIDS takes its course within the bodies of individuals living with HIV determining that the needs of individuals living with HIV are in a state of constant change. The temporal context determines that individuals living with HIV are faced with the reality that ultimately HIV will progress to AIDS and death. Even with the knowledge that this may take many years the finite nature of life is brought to the forefront of the persons mind; this knowledge impacts the life world of individuals who are HIV positive. Features of the temporal context impacting the lived experience of social support will be considered.
- Situational context - Situational factors are factors specific to one individual making their experience variant from the general experience. The overlap in description given by the sample regarding the lived experience of social support means that much of the lived experience of social support can be spoken about in general terms. However, where important, situational factors determining one participant's experience variant from the sample, will be mentioned.



7.1 Health care professionals

Living with HIV is a complex medical and psychological challenge. Results of this study revealed the critical role of health care professionals in the lived experience of social support.

Most primary health care needs for Black South African women are dealt with in clinics and hospitals. As a result the discovery of an HIV diagnosis generally takes place within health care structures such as clinics or hospitals. Health care promotion in South Africa presently aims to care for illness in a holistic manner including medical care and psychological wellbeing (Peterson & Swartz, 2002). Especially with regards to HIV/AIDS, this approach has been adopted ensuring

individuals having HIV tests receive both pre- and post-test counselling. This has been identified as important because of the “evidence that psychological well being increases resistance to full blown AIDS” (Peterson & Swartz, 2002, p.1007).

Although health care professionals emerged as playing a critical role in the lived experience of social support, two differing experiences, representing a polarity in this constituent aspect of social support, were described. On the one hand efficient health care defined by positive interactions with doctors, nurses and lay counsellors who met physical, informational and emotional needs was highlighted. On the other hand unsatisfactory health care, where particularly informational and emotional provision was lacking was described. This polarity will be demonstrated by examining the interactional content in both satisfactory and unsatisfactory interpersonal relationships with health care professionals.

7.1.1 Examining interactional content

7.1.1.1 Satisfactory interpersonal relationships with health care professionals

An examination of the interactional content of interpersonal relationships between participants, and health care professionals (Table 6.1.1 and 6.1.2) reveals that satisfactory interaction provides instrumental support, tangible assistance, informational provision and emotional connectedness. A few examples follow:

- a. Instrumental support: Doctors were instrumental in listening to physical problems and diagnosing illness. Doctors, nurses and counsellors had an important role in encouraging participants to disclose to at least one person. Counsellors had an ongoing supportive role in the lives of the participants. Participants described how they returned to talk to their counsellor when they encountered problems.
- b. Tangible assistance: Doctors and nurses were looked to for the treatment of the symptoms of the many illnesses the HIV/AIDS trajectory created.

- Doctors and nurses prescribed appropriate medication. Where illness was severe, participants spoke of being admitted to hospital. Doctors also aided participants in accessing disability grants. Counsellors were described as caring beyond the boundaries of the hospital. One participant expressed how when she missed her appointment with the doctor the counsellor came to her house. The counsellor asked if everything was ok and if there were specific needs with which she could assist.
- c. Informational provision: Doctors, nurses and lay counsellors had an important role to play in providing information regarding HIV/AIDS. HIV has been associated with extensive physical, mental and emotional damage. This coupled with general low educational levels, and minimal prior understandings of HIV/AIDS contribute to uncertainty regarding the effect HIV will have in one's body. Health care professionals have an important role to play in imparting information and education concerning HIV/AIDS. Informational provision was essential as being generally uninformed about HIV, made coping difficult. NM explained *"The information they gave me there was important because I didn't know anything about HIV. And now I know about HIV, and I know that I must use a condom, and I know that I can live more years because of the CD4 counts I got"* [3:24-25]. Informational provision involved imparting new information as well as correcting misinformation.
- d. Emotional connectedness: Health care professionals provided reassurance that living with HIV was possible. *"At the clinic they took a...a CD4 count. And there they said that my CD4 count is still high. And then they give that hope...that I can live more than...ten or five years"* [3:23]. Counsellors performing pre- and post-test counselling explained that HIV was not the end of life. Those words brought comfort and encouragement, impressing that living with HIV was

possible. This in turn alleviated the heavy emotional toll of HIV. Health care professionals were instrumental in referring participants to appropriate resources and support groups.

7.1.1.2 Unsatisfactory interpersonal relationships with health care professionals

Despite satisfying interpersonal relationships with health care professionals, results revealed that unsatisfying aspects may present themselves:

- Confusion as to what an HIV diagnosis really meant was a problem, even after lay counsellors had provided sufficient explanation about HIV/AIDS.
- Anger was displaced towards doctors when doctors verbalised that they suspected an HIV positive result and then test results confirmed the suspicion.

Unsatisfactory relationships with doctors can be damaging. The dominant influence of doctors in the lives of those diagnosed as HIV positive has been confirmed by past research. Taylor (2001) argues that doctors have both the power to define individuals as sick and, in the case of HIV potentially expose them to stigma. Olivia's experience of receiving an HIV diagnosis illustrates this. The doctor disclosed her status in front of her family, exposing her to potential rejection and stigmatisation.

Brashers et al. (1999) describe the importance of demystifying HIV/AIDS and the negative impact of HIV/AIDS uncertainty. Once again Olivia's case illustrates this. Upon being diagnosed HIV positive, information regarding HIV was withheld from her. This left both her and her family with only one reality; Olivia was sick and would die any day. Counsellors were not made available to help her to work through the emotional trauma of being given a HIV diagnosis. On top of that doctors in the particular hospital she attended were alleged to say

“You have HIV, you are going to die, we don’t care about you” [F/UP-OLIVIA]. The pain of this treatment was immense. The false deterministic association between HIV and immediate death that remains uncorrected by those in a position to educate the newly diagnosed individual and their family regarding living positively with HIV was described as leading to loneliness and depression.

Particularly in light of the socio-cultural context of participants, the critical role of health care professionals can be more clearly understood. Low economic status, dependence on families and partners to meet practical and basic needs, as well as low educational levels, are all influential in determining the crucial role of health care professionals in the lived experience of social support. As a result of these factors, health care professionals are needed to provide instrumental support, tangible assistance, informational provision and emotional connectedness. Where these needs are not met by health care professionals, this constituent aspect of the lived experience of social support is unsatisfactory and negatively impacts on the individual living with HIV. The implications of the role of health care professionals in the lives of those living with HIV need careful consideration.

7.2 Partners

Transmission of HIV primarily takes place through sexual intercourse. To this end participants articulated the central role their partners (husbands and boyfriends) played in their HIV diagnosis. Participants’ partners emerged as a constituent aspect of the lived experience of social support.

An HIV diagnosis may expose relational unfaithfulness. Participants indicated that knowing that they had become HIV positive as a result of sexual intercourse with their partners, had led to a loss of trust in relationship. Results displayed that the reality that HIV has been contracted from one’s partner was dealt with in

different ways. Participants chose either to disclose their status to their partners or to conceal it. Varying levels of experience within relationships with partners were uncovered. Those disclosing their status experienced a range of reactions from acceptance and support to denial, rejection and non-support. The polarity in the lived experience of social support, was therefore again displayed.

On examining the interactional content of relationships between participants and their partners it becomes evident that supportive partners are active in providing instrumental support, tangible assistance, informational provision and emotional connectedness.

7.2.1 Examining interactional content

7.2.1.1 Satisfactory interpersonal relationships with partners

The interactional content of satisfactory interpersonal relationships with partners, described in Table 6.2.1 can be analysed. Partners who were experienced as supportive provided:

- a. Instrumental support: F explained how when she had a problem her boyfriend would always help her [F/UP-F]. Others experienced their partners helping them with the problems HIV created in their lives.
- b. Tangible assistance: NU's boyfriend was supportive, buying food he knew would boost her immune system.
- c. Informational provision: Participants described how their partners provided them with information regarding HIV. Partners also provided encouragement and helped participants to access support groups where they could meet others who were HIV positive.

- d. Emotional connectedness: Participants expressed how when their partners showed a desire to continue to engage in protective sexual activity, emotional connectedness was felt.

7.2.1.2 Unsatisfactory interpersonal relationships with partners

Participants defined unsatisfactory interpersonal relationships with partners as failing to provide instrumental, tangible, informational or emotional support (Table 6.2.2). Participants whose partners denied their HIV status described the pain of this. They felt that they were blamed for giving their partners HIV. Participants described how this created deep tension in their relationships and led to unsatisfactory interpersonal relationships.

As a result of being diagnosed HIV positive, some participants left their partners. If they were to carry on seeing them they would have to continue to engage in sexual activity. They felt this would negatively impact their health. Participants who chose to leave their partners opened themselves up to vulnerability, because of the low economic status of Black women in a South Africa. Many perceive the worth of Black South African women to be proven through their ability to have and keep a male partner. Single women become relatively isolated (Mager, 1999). Participants described how bold a step it was for them to leave their partners.

Deli and N both left their partners and had no desire to be involved with men again. In the face of betrayal and hurt they experienced hatred towards men and feelings of inability to ever trust again. This reality comprised a painful component of the lived experience of social support.

At this point the socio-cultural context within South Africa needs consideration. Within South Africa a gender imbalance exists making women particularly at risk of becoming HIV positive (MacPhail & Campbell, 2001). For example in

South Africa “Sexual cultural norms allowing men to have many sexual partners leave women particularly vulnerable to HIV, usually as the monogamous partners of non-monogamous men” (Haour-Knipe & Aggleton, 1998, p.264). There are widespread beliefs that males are biologically programmed to need sexual relations regularly with more than one woman. Such beliefs are consistent with traditionally polygamous societies. Research has found these beliefs to be held as strongly by Black South African women as by Black South African men” (Leclerc-Madlala, 2000). Participants spoke of their partner’s infidelity providing evidence that within the sample the widespread beliefs just highlighted did exist.

Haour-Knipe and Aggleton (1998) indicate that women may be unaware of their partner’s sexual behaviour, past or present. They (Haour-Knipe & Aggleton 1998) argue that women may deny the possibility that their partners are not faithful for romantic reasons or because they have limited personal resources making them economically vulnerable and highly dependent on their partners. Participants spoke of being confused about where HIV came from confirming the findings of Haour-Knipe and Aggleton’s work (1998).

An HIV diagnosis exposes relational unfaithfulness and results of this study have revealed its critical influence on interpersonal relationships between participants and their partners. The emergence of the role of partners in the lived experience of social support determines that culture specific gender issues can not be ignored. The issue of nondisclosure to partners also needs addressing as nondisclosure to sexual partner raises multiple ethical issues (Herek, 1996). When exploring the implications of the results of this study on effective intervention strategies HIV gender issues should be addressed.

7.3 Family

Results revealed the theme of family (referring to grandparents, parents, siblings, aunts, uncles and children) to be a constituent aspect of the lived experience of social support. Integration into family was described as being important. Upon receiving an HIV diagnosis, a longing was expressed to disclose to one's family. However, there was concern regarding the effect their HIV positive status would have on interpersonal relationships within the family.

Family is a social structure in which children spend most of their time. Even in to adulthood, the nuclear and extended family is a crucial aspect of an individual's life. Family is a structure in which interpersonal relationships defined by care, love, valuing and esteeming of its members take place. A place where a sense of identity and belonging is developed (Louw, Van Ede, & Louw, 1998).

Participants indicated that disclosure to family, as well as the community was a considerable psychological stressor. Gielen et al. (2000) suggest that fear of abandonment, rejection, public stigma, loss of financial support and housing are all barriers to disclosing. Results of this study verify this. Results of the present study revealed how a longing existed to disclose to family. However, for the above mentioned reasons a choice was made to manage an HIV positive diagnosis in an attempt to reduce stigma and avoid rejection.

Results of this present study emerged in line with research conducted by Lee and Craft (2002). Lee and Craft (2002) address the ways individuals choose to manage information in an attempt to reduce stigma and avoid rejection. Results of the present study along with the Lee and Craft study (2002) demonstrate that individuals living with HIV, either, choose to keep their illness a secret, concealing information about their status, or alternatively they choose to disclose before their secret is exposed.

- **Keeping one's illness a secret**

Results of this study displayed that choosing not to disclose to family was a means of protecting oneself. Adjusting to the knowledge of a newly emerging status and fear of the consequences of disclosure can lead to a decision to keep one's status a secret.

Lee and Craft (2002, p. 282) found that individuals chose not to disclose their status in an attempt to maintain relationships and their "pre-disease identity." This choice has consequences. Results of the present study show that sharing one's status can negatively impact on relationships. However "keeping the secret jeopardises the opportunity to reflect on reality accurately and potentially receive the support needed" (Lee & Craft, 2002, p. 278). Secrecy elicits a great emotional toll.

Participants described how choosing not to disclose to their family prevented them from experiencing the fullness of family support. The kinds of support needed from family to cope with the illness stressors of HIV were not received. NM's family didn't treat her differently because of HIV as they didn't know her status; however she felt lonely and isolated as a result.

NM chose not to disclose her status to her family. Her situational context informed this decision. She had been divorced and had another partner. Only after she was divorced and started seeing her other partner had she become HIV positive. Her fear of potential stigmatisation leading to disgrace from within the family, influenced her choice not to disclose her status.

- **Disclosing status before one's secret is exposed**

Results revealed how disclosing one's HIV status meant opening one's self up to a range of possible reactions from acceptance to rejection. The interactional

content of families in which acceptance was experienced will be examined as well as interactional content of families in which rejection was experienced.

7.3.1 Examining interactional content

7.3.1.1 Acceptance: Satisfactory interpersonal relationships within family

For some, upon disclosing to their family they experienced no change in family relationships. This was described as enabling effective coping. When interpersonal relationships within the family were satisfactory (Table 6.3.1) results demonstrated how the need for instrumental support, tangible assistance, informational provision and emotional connectedness were met.

- a. Instrumental support: Participants spoke of receiving family support with problems. Deli described how she felt everyone in her family was on her side and would help her with problems.
- b. Tangible assistance: F spoke of how her family bought her food, *“They bought me garlic, everything. If I need, vitamins, they will bring them Pro Nutro everything [6:61].* Not only providing food but also housing, money and clothes were other ways participants described the family providing tangible assistance.
- c. Informational provision: Informational provision was felt when families concerned themselves with finding out as much as possible about HIV. Families did this in order to impart information enabling positive living with HIV. Gaining knowledge from the family about HIV was one of the most crucial aspects of social support. It allowed participants to feel they were surrounded by a people who cared for them. This provided them with a sense that they were not alone.

- d. Emotional connectedness: The life changing nature of HIV determined that participants questioned their future. This led to a deep sense of aloneness and sadness. Emotional connectedness to family at this time was indicated as crucial.

7.3.1.2 Rejection: Unsatisfactory interpersonal relationships within family

Once an HIV diagnosis is disclosed, interpersonal relationships within family may be strained. Compared to other chronic illnesses, Taylor (2001) argues that HIV provides great opportunity for negative aspects of social relationships to come into play. Results of this present study illustrate how disclosure can lead to rejection and stigmatisation within the family.

“Stigma is an exercise of power over people. It acts to reinforce social norms thereby defining deviance” (Taylor, 2001, p.794). The stigma attached to HIV because of the association of HIV with immorality, dirtiness, sin and evil (Sontag, 1991) was experienced by some participants. The stigma attached to HIV led to participants being rejected from family life. Unsatisfactory interpersonal relationships within the family were then experienced. Stigma, defined as “a distinguishing mark of social disgrace” (Collins, 1993, p.1132) results in being driven from the family home, with no means of instrumental, tangible, informational or emotional support from family. Table 6.3.2 describes some of the characteristics of these unsatisfactory relationships. L described how painful this was *“Like it makes me feel...It makes me feel lonely cause they told me you are AIDS. We can't stay with you, go away” [2:56]*.

The importance of instrumental support, tangible assistance, informational provision and emotional connectedness is critical because of the socio-cultural context in which participants were situated. The realities leading to inequality and vulnerability discussed earlier, along with the general low economic status

of participants, manifest in low levels of education, employment, and therefore low levels of income. These social determinants influence health resulting in sometimes the most basic needs being unmet (Walker & Gilbert, 2002b). Malnutrition, stress and susceptibility to illness make living with HIV a difficult task (Streubel, 1995). In light of these realities, family emerged as a constituent aspect of social support. Family was described as aiding participants in living with HIV, acting as a buffer against negative social determinants exacerbating the illness stressors of HIV. Family, therefore, positively influences health. Implications of this study must address how family can more effectively be challenged about their potential to positively impact the health of Black South African women living with HIV.

The lived experience of social support, however, revealed that family held within it the potential for both satisfactory and unsatisfactory interpersonal relationships. Unsatisfactory interpersonal relationships resulting from disclosure, stigma, rejection and discrimination negatively impacted on participants. Once again a polarity in the lived experience of social support is demonstrated. Implications of the emergence of this polarity in the notion of family as a constituent aspect of the lived experience of social support must tackle the reality that many do not have available to themselves the support necessary to cope with HIV. Disclosure, rejection, discrimination and societal stigma need to be addressed, in developing strategies impacting on the health of Black South African women living with HIV.

Shefer (2004) suggests that the search of individuals diagnosed with HIV for accepting and affirming responses particularly from within the family implies self stigmatisation. Subtly individuals living with HIV may feel to blame for their illness as having “transgressed moral codes” so that they should be “so happy when people are actually nice to them” (Personal communication, T Shefer,

November, 2004). This is evident in the present research. Participants expressed sadness when their family responded negatively and happiness when responded to positively. Although this may be natural human reaction “to want to be liked and have people be nice to you” implications of the present study must address this problematic discourse and provide strategies that aid in the deconstruction of self stigmatisation.

7.4 Caring for family members and children

Within the theme of family, the lived experience of social support emerged as having a bi-directional concept. Social support was not simply a process whereby personal needs were met. The lived experience of social support also reflected involvement in interpersonal relationships which led to others’ needs being satisfied. Results provided evidence for an understanding of the constituent aspect of the lived experience of social support involving caring for family members, children and others (addressed later).

7.4.1 Caring for family members

Results demonstrated a component of social support whereby participants related in ways that led to others needs being satisfied. This was particularly evident within the family, where sometimes personal needs took a secondary place to meeting the needs of family members. Participants described their responsibility for household tasks, cooking, cleaning and nurturing the family. Participants, who still lived with their mother or older sister, described how when the primary care giver could no longer perform her household tasks they as younger women in the family would be expected to assume these roles. These tasks were described as creating space for interpersonal relationships in which the needs of others were met. These kinds of interpersonal relationship were often experienced as difficult but nonetheless emerged as an aspect of the lived experience of social support.

Being a woman, the bi-directional component of the lived experience of social support emerged as a reality. Especially within the socio-cultural context of South Africa, women are generally entrusted with the care of family members. They face a double burden of being sick and being primary care givers to family members and their children (Walker & Gilbert, 2002b).

In addition, in light of the pandemic of HIV in South Africa, women, younger and older, who themselves are HIV positive may have family members or children living with HIV who need to be cared for (Taylor, 2001). The results of the present study exemplify this reality. Finding out that a family member is HIV positive was described as shocking and emotionally taxing. NU explained how difficult it was that she knew her older sister was HIV positive. The reality that her older sister may die before her, leaving her to assume the household tasks and responsibilities including caring for her sister's children made coping difficult, and care-giving an inevitable duty.

Caught within the temporal context of the illness trajectory of HIV/AIDS, caring for ones' family and for members of the family who may be HIV positive is often difficult to manage but a duty that must be performed (Taylor, 2001).

7.4.2 Caring for children

Primary care giving for members of the family extended to caring for children. The maternal relationship made up a crucial aspect of the lived experience of social support. Mothers living with HIV continued caring and nurturing their children. However, as HIV compromised some of the tasks of motherhood, participants described how when they disclosed their status to their children, their children began to care for and nurture them.

Disclosure to children was cited as a particularly difficult issue to grapple with. Participants disclosed to their children if they perceived their children to be old enough to cope with the burden of HIV. Researchers in South Africa have discovered many mothers indefinitely delay disclosing to their children because they believe their children are too young to understand HIV (Stein, 2004). Further studies suggest that disclosure to children is dependent on the illness stage of the mother (Greene, Frey, & Derlega, 2002). Results of the present study provide evidence for both of the above statements.

Participants disclosed to their children if their children were older or if they became extremely ill. One participant in the study whose children were older (teenagers) described disclosure: "...One day I came from the church and I said to them I want to share something with you so can we talk and they said okay Mum just sit in my room. I told them I am HIV positive" [1:74]. Results indicated that disclosing to older children may result in a degree of reversal in the mother-child role; children became the carers and supported their mothers.

7.4.2.1 Examining interactional content

The interactional content of the mother-child relationship was described as being beneficial to the mother. Table 6.4.1 describes the interactional content which provided support. An analysis of the interactional content of the interpersonal relationship between mothers and children provides evidence that children afford:

- a. Instrumental support: *"My big boy he's 21 now, and he always comes to me every day come says hello Mum how you? How do you feel? Are you ok? I said no, its okay everything is good" [1:75].*

- b. Tangible assistance: *“They come everyday and buy us some fruit, and said here is the fruit you can eat it you know so it makes me feel better and better and better and it makes me feel very strong and brave” [1:76].*
- c. Emotional connectedness: *“They are always saying “ I love you mummy, you must be well, I know that they are always concerned about me” [E/UP-F].*

Results revealed that when children were too young to understand about HIV, mothers expressed desire to stay alive long enough to tell children about their HIV status. They did not want their children to find out from someone else about their HIV status. The temporal context of the progression of HIV to AIDS, however, constantly challenges this desire.

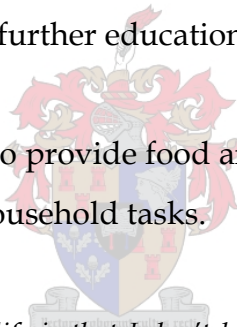
In light of the temporal context of HIV, caring for children, young or old, is a considerable challenge. In being a nurturer and carer of children as well as being HIV positive, not only the usual stress of caring for children is faced but also the stress of becoming more ill and death. With an awareness of the finite nature of life as a result of an HIV positive diagnosis, participants' who were mothers described worrying about who would continue to care for their children when they were unable to. Especially where interpersonal relationships within family were unsatisfactory, this concern became a major psychological stressor. N described how, because of her family's reaction to her HIV status, she was wondering who would look after her children. Rumination over children's futures took place.

The responsibility of parenthood assumes mothers will nurture their children to independence and adulthood, and then continue to care for their children's children. Caught in the temporal context of the trajectory of HIV/AIDS tasks of motherhood are at risk of being unfulfilled. When thinking of children,

participants described how the question resounded “*what if I should die tomorrow?*” [3:76]

Whether children were older or younger, results uncovered that the stressors of motherhood were wrapped up in:

- a. Concern regarding stigmatisation of children because of the mother’s HIV status. Stein’s study (2004) supports this suggesting that the impact of parental stigma on children is feared. Goffman refers to this as courtesy stigma where children face “ostracism and discrimination because of their association with a person living with HIV” (in Herek, 1996, p.1111).
- b. Concern regarding lack of financial provision and savings for children who need schooling and further education.
- c. An inability to continue to provide food and nutrition as one becomes sick and unable to perform household tasks.



N explained” *The problem in my life is that I don’t have any savings for my children want them to go to school but I have not had enough jobs yet, Sometimes I just thinking Oh God My daughter she is 19 she is doing grade 10 you know this year, so what can I do when she passed matric? Maybe she wants to go to university but I don’t have any money to take her there”* [1:143]

Emerging from the lived experience of social support, a reality existed for mothers living with HIV that the support they longed to give their children they would to some extent, be unable to give. Stein (2004) suggests that it is important that children are part of the parent’s journey with HIV/ AIDS. Parental disclosure to children is essential for both the child and the parent (Stein, 2004). Implications of this study must address strategies to assist mothers to recognise

the importance of disclosure to children and strategies to enable mothers living with HIV to break from continuous rumination over children's future.

7.5 Support groups

Results of the present study displayed the crucial role of support groups in the lived experience of social support. The benefits of belonging to support groups were unanimously cited by participants. Within support groups participants became aware that they were not alone in their experience of being HIV positive. That knowledge alone relieved the heavy burden of HIV. Within support groups a sense of belonging, mutual caring and sharing is experienced. Blom (2003) suggests that this shared experience offers built-in support.

Table 6.6.1 summarises qualities of support groups. Interpersonal relationships within support groups were described as being supportive. An analysis of interpersonal relationships within the support group provides insight into the nature of support provided by interpersonal relationships within support groups. Insight into why support groups are an indispensable aspect of the lived experience of social support is also developed.

7.5.1 Examining interactional content

7.5.1.1 Satisfactory interpersonal relationships within support groups

Table 6.6.2 addresses interpersonal relationships within support groups defined as satisfactory. Results reveal that interpersonal relationships within support groups provide instrumental support, tangible assistance, informational provision and emotional connectedness. In addition participants described how they experienced hope that living with HIV was possible because they had assistance in carrying the burden of HIV.

- a. Instrumental support: In support groups participants described being able to share their problems. The group advised and encouraged proactive

thinking about problems. Problem solving took place. Participants felt able to live with HIV and share their story during the support group. Van Dyk (2001) describes support groups as safe places where in confidentiality members can talk about difficulties or simply relax and enjoy the company of others with whom they share HIV. Participants described their support groups in a similar manner.

L's situational context practically reveals the instrumental support of the support group. L's father, mother and aunty rejected her completely, burning her clothes, identity document and birth certificate. L's experience of isolation, discrimination and stigmatisation was great. The members of the support group along with L responded pro-actively to this problem by going and talking with the family about the way L had been treated. They endeavoured to reconcile L to her family.

- b. Tangible assistance: Support groups were places where participants were free to openly talk about their practical and basic needs. Participants received tangible assistance in the form of food parcels and clothes.
- c. Informational provision: This was a very strong focus of support groups. Participants explained how upon joining support groups they knew very little about HIV but after a while they learned a lot about HIV. Having developed knowledge about HIV, participants felt a sense of hope that living with HIV for a long time was possible. One participant said "*We do there education, education, education and education*" [3:89]. Education is crucial. Upon being diagnosed HIV positive information sharing is particularly important. Although information giving does not necessarily solve problems, it brings to mind new perspectives on problems as well as correcting misinformation (Van Dyk, 2001). Information helps in

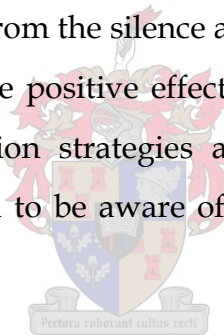
understanding stigma. This allows for individuals living with HIV to realise that it is due to a lack of education communities hold to certain misconceptions about HIV (Van Dyk, 2001). In support groups, participants described how they could openly discuss their fears, problems and receive information that alleviated their fears.

- d. Emotional connectedness: Hope, happiness, encouragement and empowerment resulted from attending support groups. Participants articulated how in their support groups they learned to feel glad that they knew their HIV status. They also described how they were able to think positively about the future. *"The support group has helped me a lot because I know that I can live for a long time and I'm feeling strong"* [9:56]. Participants recounted how in their support groups they could openly express their emotions. Without judgement, group members just listened. The support group was likened to home. Van Manen (1984, p.15) defines home by saying "(i)n the concept of home or dwelling, there is a strong sense of watching over something, preserving a space where the human can feel sheltered and protected." Support groups were a home to participants. They were described as safe places where sharing with others who share and embrace similar life experiences could take place.

The interactional content within support groups demonstrates how support groups emerged as a constituent aspect in the lived experience of social support. Interpersonal relationships within support groups enabled participants to see that there were others living with HIV and they were therefore not alone. One participant described: *"When I started going to Living Hope, to the support group, I met other people there, who are positive. And I saw that I am not the only who is HIV positive"* [3:11-12]. Participants explained that upon being given their HIV diagnosis they were informed that there were others who were HIV positive. They wondered,

however, if others really did exist. Support groups provided space where, through interpersonal relationships, participants realised the truth that they were not alone. This enabled them to envisage life with HIV: *“So it was that time I felt very much stronger than before because when I was first told I have HIV I thought this is the end of my life I can’t do anything now because I’m HIV, but then I joined the support group”* [1:128].

Results revealed that in support groups the burden of HIV was shared with others who understand the experience of being HIV positive. Blom (2003) suggests that support groups provide regular opportunity for the sharing of one’s own experiences and the witnessing of others experiences without being judged, blamed or isolated. Particularly within a South African context, support groups are crucial because of the stigma attached to HIV. Within support groups an opportunity exists to break from the silence and isolation caused by the fear of stigmatisation (Blom, 2003). The positive effect of belonging to support groups has implications for intervention strategies aiming to care more effectively. Support group facilitators need to be aware of the crucial role they play in the lives those living with HIV.



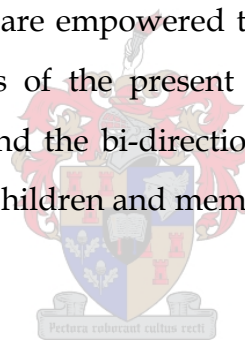
Other elements of support groups, cited as constituent aspects of the lived experience of social support, are meeting the needs of others, story telling, education, and recreational activity. These manifestations of social support within the support group are explored under their own sections which begin with a discussion on how they are facets constituting the supportive nature of the support group. Following from there, each will be considered as constituent aspects of the lived experience of social support.

7.6 Meeting the needs of others

7.6.1 Caring for members of support groups

The bi-directionality of the lived experience of social support has already been discussed in reference to family and children. Results displayed that support groups also encompassed a bi-directional facet. Being able to help and advise members of the support group, therefore, meeting the needs of others within the support group, emerged as a fundamental characteristic of support groups: *“I am always talking in the support group. I’ve had this virus for a long time so I’m always saying, don’t give up, you will be ok. I feel happy because I see that those people they come to me for advice” [F/UP-DELI].*

Van Dyk (2001) proposes that in support groups members of the group become experts of their own lives and are empowered to help care and satisfy needs of other group members. Results of the present study verify Van Dyk’s (2001) assertion. Caring for others and the bi-directionality of social support extends further than caring for family, children and members within the support group.



7.6.2 Caring for others

Results show that caring for others extends beyond the boundaries of family, and support groups. Active involvement in enabling others to live with HIV emerged as a facet of the lived experience of social support. Interacting in relationships in which the needs of others were satisfied highlighted once again the bi-directionality of the lived experience of social support. F assists others to live positively with HIV through work in a counselling capacity. F has trained as a lay counsellor and works in a government hospital. She explained *“I told myself that I needed to do something because I have a lot of information and I wanted to help others” [F/UP-F].* L does voluntary work at Love Life where she says many people come with problems. She feels able to give them advice and support because she said she knows what it feels like to be HIV positive. N and DELI explained that due to

their vast amount of experience in dealing with HIV they feel able to advise and help other people.

Assisting others has therapeutic value for oneself, especially living with HIV. Taking the focus off the self, personal problems and being involved in interpersonal relationships where caring for and helping others is at the core, emerged as an important facet of social support. Implications of the knowledge that the lived experience of social support constitutes a bi-directional facet must be considered.

7.7 Story telling

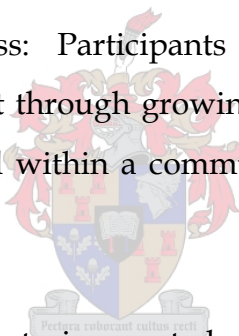
Results indicated the importance of sharing one's story. Strong feeling was expressed that when an individual living with HIV does not share their stories the emotional toll on the person will be high. Unanimous feeling was articulated that when individuals living with HIV do not tell their stories, the progression from HIV to AIDS is hastened. *"The time you're thinking. That things that's bothering you inside and it makes something in you blood you know, even in your...your body feels very weak. You don't have any power; not even any appetite...doesn't ever eat something when you've got something inside. Just always sleepy on the bed...lying on the bed...nothing to do you know? It's very important to share, not to keep the things inside" [1:91-92].*

Support groups emerged as facilitating members in appreciating the importance of sharing their stories. Broadly speaking, interpersonal relationships providing opportunity for the sharing of one's story surfaced as an essential aspect of the lived experience of social support.

7.7.1 Examining interactional content

Interactional content of story telling can be evaluated, displaying its supportive components:

- a. Instrumental support: Story telling enables the sharing of problems and concerns, allowing space for advice giving and discussion round pro active problem solving.
- b. Tangible assistance: Story telling allows for openness leading to the expression of various forms of need, including food, clothing, money etc.
- c. Informational provision: Hearing the experiences of others promotes learning as individuals relate to experiences more easily than trying to relate to and understand facts that seem to have little or no relevance to their situations (Van Dyk, 2001).
- d. Emotional connectedness: Participants described how story telling provided encouragement through growing awareness that they were not alone but rather situated within a community of individuals living with HIV (Weingarten, 2000).



Results displayed how sharing stories created emotional closeness. Weingarten (in Blom, 2003) suggests that story telling allows individuals living with HIV to expand their boundaries of support beyond their family and partners to a community of caring friends. Individuals no longer have to bear the pain of HIV alone once their story is told. N described the therapeutic value of story telling, *“I think its because you are taking out of your heart now, you know instead of keeping inside, you know its very important to take something, to talk about something instead of keeping the secret inside” [1:68].*

7.8 Memory Box Project

The Memory Box Project emerged as a constituent aspect of the lived experience of social support. It was started in South Africa by Jonothan Morgan to aid

individuals living with HIV to express their stories in creative ways (Morgan, 2001). The Memory Box Project focuses on facilitating individuals in telling their stories; whether it is to another person or whether they just write it in their book or box. The role of the Memory Box facilitators in the lives of the participants and the supportive nature of interpersonal relationships within the Memory Box Project made up some of the factors that determined it a crucial aspect of social support.

7.8.1 Examining interactional content

Analysis of the interactional content of interpersonal relationships within the Memory Box Project illuminates its supportive qualities:

- a. Instrumental support: The Memory Box Project assists expression of areas of the self that may be difficult to verbalise and helps focus on pro active problem solving.
- b. Tangible assistance: Working for the Memory Box Project is a form of employment. Participants valued receiving a small payment. This tangible assistance is an invaluable source of financial income. *“The memory box, it helps me a lot because then I starting to write my story from the day I was diagnosed to now. There is education in that, if someone is positive I can share about HIV and my story also. So the memory box helped me a lot of writing stories and sharing ideas with other people. I also am happy because I know that I am busy during the day because I am not working. I am working there at memory project. I know that if you stay in Friday, I going to be there on the memory project and I know that in the end of the month they are going to give something” [8:76-81].*
- c. Informational support: Memory Box Project has an informational component. Learning about HIV occurs, from hearing others stories and receiving education from Memory Box facilitators.

- d. Emotional connectedness: Making the box, telling one's story and writing down problems one is unable to share with others is comforting. Participants described its positive impact on their lives.

Involvement in the Memory Box Project emerged as an element of the lived experience of social support. Participants demonstrated how the Memory Box Project taught them to record their life stories, their identity, family history, life style, culture, beliefs and experiences of HIV in boxes or books, containing photos, stories, poems and other mementos of family and friends (Van Dyk, 2001). The Memory Box Project facilitates the creation of a "treasure trove of memories" (Van Dyk, 2001, p.337). This treasure trove holds personal meaning and significance. Blom (2003) suggests that sharing boxes or books with others or telling one's story creates a context for understanding and support

Various structures and interpersonal relationships from which participants learn about HIV have been discussed. Results indicated the acquisition of education and informational provision to be a strong theme in the lived experience of social support. The significance of receiving information regarding HIV/AIDS in coping with illness was expressed. Participants articulated that at the commencement of receiving education about HIV they listened and then began to attain hope that living with HIV was possible.

7.9 The role of the media and books in providing education

The importance of messages of hope and educational themes from radio, television and books were acknowledged. Popular press in South Africa provides opportunity for the experiences of women living with HIV to be shared. In 'Isidingo', a television programme participants spoke of watching, there is a young woman living with HIV called Nandipha. Nandipha provides a mechanism to deal with day to day issues for women living with HIV (Allen,

2003). Messages from media and books, for example, *“Living openly: Stories and Images of HIV positive South Africans”* (South African Department of Health, 2000) reiterate that there is a community of HIV sufferers. Participants described how these educational efforts gave them hope that they had a future, because they can learn how to live for a long time with HIV. They also indicated that educational efforts provided a sense that others really do care.

In light of the socio-cultural context already examined, the importance of education has been highlighted. Research on uncertainty in illness demonstrates the important role information plays in the illness experience (Brashers et al., 1999). The present research too demonstrates this importance. Participants described how lack of information about HIV and a lack of an ability to predict illness related symptoms and treatments were contributing factors to stress and depression. In order to live with HIV, participants suggested that they wanted to gain as much information as they could about the illness. Information was gained from satisfactory interactions with health care professionals, family members, partners, support group, Memory Box Project, media, and books on HIV/AIDS. Results of the present study displayed that acquisition of knowledge fuelled empowerment. Strategies of health care and management, therefore, need to address the issue of education seriously, seeking to provide messages of hope.

7.10 Organisations within the community

Organisations working to help individuals living with HIV were named as being effective in giving hope to participants. Their valuable intervention into the lives of individuals living with HIV was considered critical. Living Hope Ministries, Treatment Action Campaign, Vaccine Project, Love Life and Social Services emerged as organisations considered by participants to be facets of the lived experience of social support. Analysis of the interactional content within these

organisations brings to light some of the reasons these organisations were considered supportive (See Table 6.9.1).

7.10.1 Examining interactional content

Living Hope Ministries: Living Hope was described as a safe place for individuals living with HIV. It was expressed as being a place where needs for informational provision and instrumental support were met. The provision of tangible assistance (food parcels and clothes) was essential for participants, many of whom were destitute. Participants also valued the emotional connectedness they had with individuals at Living Hope. Support groups were run from Living Hope.

Treatment Action Campaign: The TAC is an activist movement whose goal is to make ARV's available for all living with HIV. Participants indicated TAC in the provision of tangible support (food and clothing). TAC also provided participants with instrumental support and emotional connectedness. Where family dissention exists, the TAC works to reconcile individuals living with HIV to their families. TAC undertakes to fulfil their members' wishes with regards to where they will be buried. TAC encourages disclosure and provides opportunity for individuals living with HIV to meet together and share experiences.

Vaccine Project: The Vaccine Project works to make drugs available to individuals living with HIV.

Love Life: This organisation provides informational assistance to those living with HIV/AIDS.

Social Services: The government provides services aiding individuals living with HIV. Participants described how individuals meeting specific prerequisites are

able to access both disability grants and child grants from social services providing tremendous tangible assistance.

In light of participants' socio-cultural context, the need for instrumental support, tangible assistance and informational provision become critical. Living with HIV and its illness trajectory as well as loss of relationships, and many other personal losses, determine that HIV affects every area of life. Belonging to organisations particularly, Living Hope Ministries, TAC and Love Life, emerged as facets of the lived experience of social support. Sikkema et al. (2000) found that organisations provide greater social network integration, instrumental support, tangible assistance and a broader knowledge of how to live positively with HIV. Furthermore, belonging to organisations provides emotional connectedness; results of the present study verify these findings.

Taking a look at macro level perspective of individuals living with HIV, research conducted by Greene et al. (2002) found that individuals affiliated to organisations working to positively impact the lives of individuals living with HIV use more problem focused coping and less emotion focused coping. Greene et al. (2002) also found individuals belonging to organisations had greater knowledge about HIV, treatment, and greater social network integration. Participants of this present study described how being a part of organisations enabled them to have a greater knowledge of HIV and greater social network, and therefore confirm results of the Greene et al. (2002) study.

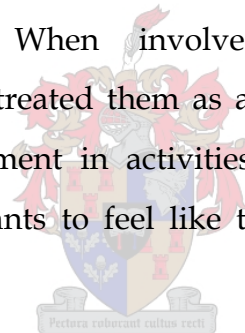
7.11 Activities: Keeping busy, thinking positively

The results of the present study shed light on the importance of being involved in activities. Recreational activities enabled participants to keep their minds busy. The nature of HIV brings with it continuous thinking and worrying. Activities and keeping busy emerged as providing escape from continuous

rumination. In support groups, participants highlighted activities they were involved in such as bead work, sewing, crocheting, and gardening. Involvement in other activities within the community emerged as facets of social support. These included the community choir, netball team, and household chores.

Activities give each day meaning allowing individuals living with HIV to see themselves living with HIV and not dying. Davies (1997) describes the importance of finding a way to live in the present, suggesting that activities are an important way of learning to cope with HIV. Activities enabled participants to live in the present and to cope with HIV.

Participants indicated that activities created opportunity for satisfying interpersonal relationships. When involved in activities participants demonstrated that colleagues treated them as a *“normal person, not someone living with HIV”* [F/UP-NM]. Involvement in activities was crucial in inciting hope, power, and allowing participants to feel like they were worthy and valuable human beings.



Participants involved in making badges and other activities where the end product was sold, received small profits. This tangible assistance was helpful. Participants whose activity was employment described their jobs as an aspect of their lived experience of social support having the same effect as the activities described above.

Activities also serve to keep one's mind busy, preventing HIV from consuming the mind. Fleishman et al. (2000) found being HIV positive to be strongly associated with elevated levels of anxiety and depression. Participants highlighted that when one ruminates continuously about HIV, stress and

sickness resulted. An effort was made to disengage from rumination about HIV/AIDS; activities provided solace from continuous rumination.

Within the South African context, low formal educational levels among Black South African women have led to high rates of unemployment (Stats SA, 2004; Walker & Gilbert, 2002b). The sample reflects this reality. Ruminating about HIV is exacerbated by unemployment. In Black townships any time of the day one passes through large numbers of women sitting outside of their homes, seemingly unoccupied, are observed. Being unemployed brings with it hours of unstructured time to ruminate on various aspects of HIV/AIDS (Personal communication, Skolweni, June, 2003). Continuous ruminating about chronic illness has to be managed. Participants indicated how thoughts and, therefore, HIV could be managed by keeping busy.

7.12 The community

Practical care from community neighbours surfaced as a constituent aspect of social support for participants. Neighbours, with whom participants described having satisfactory interpersonal relationships, provided instrumental support, tangible assistance, informational provision and emotional connectedness.

7.12.1 Examining interactional content

- a. Instrumental support: N described how when she does not go outside in the morning her neighbours come to her and ask if she is ok. She described how her neighbours would help her should she be experiencing problems.
- b. Tangible support: Neighbours were cited as important as they bought vegetables and medicine for participants.

- c. Informational support: Individuals within the community to whom participants disclosed often came and shared information regarding HIV.
- d. Emotional connectedness: NUs neighbours were kind to her she felt that they accepted her and would come into her house, without concern and make themselves tea. These neighbours did not change the way they treated her after she disclosed to them.

Results of the present study confirm Leenerts and Magilvy's (2000) findings that, when diagnosed with HIV, individuals protect themselves through a process involving one of two strategies: Hiding their status or selectively disclosing their status. Results of the present study displayed that selective disclosure was chosen.

Participants chose only to make known their status to those whom they felt they could trust and they perceived would care. As a result of HIV stigma within the community, anguish was expressed at the thought of having ones status revealed to the entire community. Participants described isolation and loneliness when community neighbours remained unaware of their status. Concealment, however, was chosen over disclosure in an attempt to protect oneself. Results suggested that participants remained concerned about being discriminated against should their HIV status be revealed.

Nondisclosure is a concerning issue for people living with HIV, not only because it creates a barrier preventing individuals living with HIV from accessing necessary support, but nondisclosure also reflects "an internalising of societal stigma by people living with HIV/AIDS" (Herek, 1996, p.111). This internalising of societal stigma can lead to self-loathing, self blame and self destructive behaviours as individuals living with HIV subtly feel as if they are to blame for

their illness (Personal communication, T. Shefer, November, 2004). Implications of this study need to address self stigmatisation as well as societal stigmatisation of people living with HIV. The community also needs to be made aware of their role in the lives of Black South African women living with HIV.

7.13 Spirituality

Spirituality emerged as a facet of the lived experience of social support. Spirituality included prayer, reading the bible, a relationship with God and attending church meetings. All of these offered participants a way to allay their fears, doubts and uncertainties, instilling a sense of hope and meaning. N stated, *"I'm strong because I believe that God is here for me" [9:23].*

Within the temporal context of HIV results demonstrated that belief in a God who was seen to be in control and who knows what is going to happen in the future was a critical aspect of the lived experience of social support. NP expressed *"What is important to me is that I know that with God I can live more than ...years. I can say that it is God only who knows what is going to happen in my future because it is only God who knows that, this disease is not curable even. So it's only God who knows and I am thankful for that" [7:100, 117-117].*

Fryback and Reninert (1999, p.13) postulate that:

When individuals must deal with potentially fatal diseases their lives change in many ways. Medical treatments often can provide the necessary respite from physical pain and discomfort but can do little to ease the mental anguish related to the knowledge that death may be imminent. Spirituality is viewed often as a bridge between hopelessness and a sense of meaning. Spirituality can provide individuals with a basis for coping by giving them a sense of purpose and meaning.

Results of the present study indicate similar experiences regarding the impact of spirituality on the lives of participants. Participants described the essential role spirituality played in their lived experience of social support. Kahn and Steeves (1993) report a decrease in suffering when individuals with terminal illness connect with a force that is bigger than they are. The present study confirms this. Spirituality is an aspect of social support enabling a refocusing of one's life, discovery of hope, acceptance, strength and comfort.

N highlights how spirituality provided a refocus to life. Aware of her mortality, N realised she needed to create a sense of meaning for herself. Before her diagnosis, she was alcohol dependent and sexually promiscuous. Diagnosed HIV positive, she felt the need to refocus her life. She expressed how she made a decision to change her life. She decided not to waste time on boyfriends and drinking, she wanted to be a better mother and go to church; she prayed "*God, I am here for you.*" [1:126].

7.13.1 Examining interactional content

Within the notion of spirituality, church was described as a significant aspect of social support. Interpersonal relationships within the church were crucial to participants, providing a social network that was indispensable in participants' lives. Table 6.12.1 describes qualities of interpersonal relationships with members of the church which can be understood as providing various forms of support.

- a. Instrumental support: Church members talked about problems with participants and joined participants in praying for answers to problems.
- b. Tangible assistance: Visitations from the priest and church members who assisted with basic food and clothes were described as crucial to participants.

- c. Informational provision: Deli explained how the members of her church talked with her about HIV and reminded her that just because she was HIV positive it was not the end of the world. She felt that they were supportive of her.
- d. Emotional connectedness: C articulated how upon disclosing her status to members of the church, she felt they still treated her in the same way as before. Deli explained that people from the church continually reminded her that she was accepted and loved.

7.14 Being involved in research

Finally, results demonstrated an unexpected theme that emerged primarily during follow-up interviews. During follow-up interviews participants expressed their gratitude to the researcher for the opportunity to be a part of the study. The interview positively affected participants who described feeling happy, knowing that they had made a contribution to research on HIV/AIDS.

7.14.1 Examining interactional content

The study was understood as being a source of social support that provided opportunity for interpersonal relationships of a satisfactory nature. The following was provided:

- a. Instrumental support: During follow-up interviews participants described how aspects of the first interview had allowed them to understand a certain problem they were grappling with. Deli expressed how she felt more confident about how to deal with the problems she had with her husband after the interview.
- b. Tangible assistance: Each participant was presented with a food parcel at the conclusion of the first interview.

- c. Informational provision: Participants articulated how the study had afforded them the opportunity to learn a lot about their own experiences of social support. Results were presented to participants as themes during follow-up interviews. The researcher, with the participant, then assessed whether accurate understandings of their lived experience of social support had ensued. Participants spoke of having looked at their lives afresh. Engaging with their lives in this way, participants described gaining a renewed and deepened experience of social support.
- d. Emotional connectedness: The interviews were conducted in such a way that participants felt empathised with. They highlighted that they felt understood, and like they had something valuable to share. This created an atmosphere of emotional closeness. *“This interview is so important to me because now I feel happy because you talked about everything, things I haven’t wanted to explain to anyone I have explained to you and it helps me to feel better” [F/UP-DELI].*

In summary, health care professionals, partners, family, children, support groups, organisations within the community, as well as the community itself, are all constituent aspects of the lived experience of social support comprising the social network of interpersonal interactions. Analysis of interactional content in terms of instrumental support, tangible assistance, provision of information and emotional connectedness enables an establishment of the nature of interpersonal interactions considered satisfactory or unsatisfactory. Story telling, Memory Box Project, being a part of research, engaging with media, books and in activities, are part of the multifaceted experience of social support. The bi-directional component of social support is expressed in primary care giving and engaging in interpersonal relationships that serve to meet other’s need. Finally, spirituality as a source of social support is highlighted.

Phenomenological inquiry has, therefore, led to an unfolding of the nature of social support for the sample revealing the constituent aspects of the lived experience of social support. Discussion of the constituent aspects of the lived experience of social support in light of three relevant contexts, keeping in mind a greater theoretical world of knowledge has led to deepened understandings of the lived experience of social support.

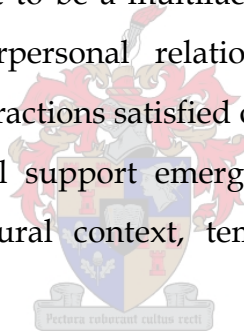
In the concluding chapter, the implications of these deepened understandings of social support on effective intervention will be considered. Implications and recommendations for future research will also be addressed.



CHAPTER EIGHT: IMPLICATIONS, RECOMMENDATIONS AND CONCLUSIONS

The study's purpose was to develop deepened understandings of the lived experience of social support for the sample of Black South African women living with HIV. The focus was on the perspectives of the women in the sample, their worlds, and their lived experience of social support within those worlds. The powerful concept of social support was explored in order that a definition of the lived experience of social support for the sample could be constructed. The definition was then represented diagrammatically.

Results revealed social support to be a multifaceted, bi-directional concept that constituted a world of interpersonal relationships. Within the world of interpersonal relationships interactions satisfied or did not satisfy specific needs. The lived experience of social support emerged as being held within three contexts, namely a socio-cultural context, temporal context and situational contexts.



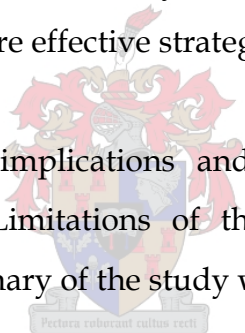
The study therefore has assisted in laying foundations for a culturally contextualised understanding of the lived experience of social support. Phenomenological research opens up the potential for a rich source of learning and practical application (Robertson-Malt, 1999). By reflecting on participants' descriptions of the lived experience of social support, valuable insights can be identified that have implications for effective intervention strategies seeking to purposefully care for those living with HIV in South Africa.

Despite the focus of this study on Black South African women living with HIV, implications will be discussed in terms of intervention strategies that could generally impact women living with HIV in South Africa found within similar

contexts to the sample. To attach the implications of the present study only to Black South African women, may be misconstrued as an essentialising and racialising process and may give the impression that the sample accurately represented all Black South African women or that Black South African women are a unitary homogenous group of people that share the same experiences (Personal communication, T. Shefer, November, 2004).

Due to the emergence of a polarity in various constituent aspects of the lived experience of social support, awareness has been developed that many social support needs of women living with HIV in South Africa may remain unmet. Implications, therefore, are addressed to health care professionals, educators and support group facilitators. This community of carers are in a position to learn from the study and develop more effective strategies of care.

Furthermore in this chapter implications and recommendations for future research will be addressed. Limitations of the present study will also be indicated. In conclusion a summary of the study will be provided.



8.1 Health Care professionals

8.1.1 Doctors and Nurses

Results of the present study revealed the critical role of doctors and nurses in the lived experience of social support. With doctors and nurses being amongst the first people that individuals newly diagnosed with HIV encounter, their role is crucial. Their role, therefore, needs careful consideration in the development of effective care strategies.

In South Africa health care aims to care for illness in a holistic manner including medical care and psychological wellbeing (Peterson & Swartz, 2002). Due to decrease, however, in hospital staff and an increase in the need for medical care

resulting from the AIDS pandemic, doctors and nurses often have neither the time nor the motivation to holistically care for those living with HIV. Tending to focus on physical symptoms, doctors and nurses have been criticised for the abrupt and impersonal manner patients are at times dealt with (Personal communication, R. Badenhaurst, June, 2004).

Doctors and nurses need to be reminded of their influence on the lives individuals living with HIV. Deepened understandings of the socio-cultural context in which many South African women live, may increase sensitivity and empathy as well as providing an understanding of the need for:

- Instrumental support: For example, playing an advisory role regarding medical and emotional problems.
- Tangible assistance: For example, aiding in the filling out of grant forms providing individuals diagnosed with HIV with the tools to access financial grants or other appropriate resources in the community.
- Informational provision: This is particularly important with regard to reducing uncertainty surrounding the illness of HIV and AIDS. As well as informing individuals newly diagnosed with HIV about support groups and the importance of talking to a counsellor.
- Emotional connectedness: Time must be taken to deal sensitively and empathetically with individuals living with HIV. This is essential as doctors and nurses are typically among the first people with whom individuals newly diagnosed with HIV interact.

The positive impact of interpersonal interactions of a satisfactory nature with doctors and nurses needs re-emphasis. A programme within hospitals and clinics consisting four sessions is recommended. The emphasis of the training programme would be on contributing to health care professionals' awareness of

their role in the lives of those living with HIV. A broad outline of the programme is provided in Table 8.1.

Table 8.1 Developing an awareness of the important role of health care professionals in the lives of South African women living with HIV.

Session	Issues to be addressed
One	<ul style="list-style-type: none"> * Health care professionals should be thanked for their tremendous work, in positively impacting the health of women living with HIV. * Reminder of the sensitivity and care needed to continue to effectively deal with women living with HIV should ensue.
Two	<ul style="list-style-type: none"> * The context of women living with HIV in South Africa should be presented. This would serve to reiterate the need for the provision of various forms of support not simply, a focus on physical symptoms. * This context could be illustrated through the medium of multi-media.
Three	<ul style="list-style-type: none"> * A South African woman living with HIV should be invited to tell her story of being HIV positive to health care professionals. * What was helpful and hurtful should be addressed.
Four	<p>In this final session, small groups should be formed. Within these small groups difficulties health care professionals experience in dealing with South African women living with HIV could be discussed. Time should be given for feed back and response to concerns.</p>

8.1.2 Lay Counsellors

Results of the study indicated the critical role of lay counsellors. Lay counsellors working in hospitals have an immense responsibility to be aware of the impact of health care professionals on individuals living with HIV. Often lay counsellors can act as buffers between nurses, doctors and patients. They give time to patients where doctors and nurses are unable to. The role of the lay counsellor is essential as they are the first person with whom individuals diagnosed with HIV will interact. The skill needed in imparting information in a sensitive, empathic and empowering manner should not be undermined.

In light of the pivotal role of lay counsellors in the lived experience of social support, refresher courses for counsellors are recommended. These refresher courses should emphasise the importance of efficient pre- and post-test counselling.

During pre-test counselling time should be taken to ensure deep understandings of HIV are grasped. This determines that before an individual receives an HIV positive diagnosis much of the uncertainty surrounding HIV and AIDS has already been demystified, providing an understanding that living with HIV is possible. Pre-test counselling is often rushed because of the vast number of individuals needing counselling especially in government hospitals (Personal communication, R. Badenhurst, June, 2004). In response, however, to the results of the study, the importance of lay counsellors in providing adequate pre-test counselling needs re-emphasis.

Results revealed the positive impact of an awareness of the varying forms of social support available to individuals living with HIV. During post-test counselling along with eliciting emotional responses, dealing with fears and positive living, potential sources of support should be highlighted. To this end the diagrammatical representation of the world of interpersonal relationships

constituting the lived experience of social support for Black South African women living with HIV should be presented to lay counsellors (Figure 1). Lay counsellors can then assist individuals living with HIV to envisage an entire network of relationships available to them facilitating positive living with HIV.

Results displayed the important ongoing role lay counsellors' play in supporting individuals newly diagnosed with HIV. During post-test counselling, therefore, as well as discussing potential struggles, follow-up counselling sessions should be set up. During these follow-up counselling sessions specific needs including various instrumental and informational needs, tangible and emotional needs should be addressed. The importance of being able to meet various kinds of needs determines that lay counsellors require access to diverse resources. Having access to many resources, lay counsellors would be able to refer individuals newly diagnosed with HIV to these resources. A twenty four hour telephonic service (HIV 911), providing a range of information regarding support services available to individuals living with and affected by HIV/AIDS could aid this cause. Church partnerships and partnerships with organisations working to positively impact the lives of individuals living with HIV and could further aid this cause (Personal communication, A. A. Smyth, June, 2004). Although ongoing counselling and support may be time consuming, the long term effects of this kind of quality counselling can not be undermined.

Presentation of the diagrammatical representation of the world of interpersonal relationships constituting the lived experience of social support (Figure 1), to lay counsellors, as already mentioned should occur. This will enable lay counsellors to procure deepened understandings of social support and its capacity to positively impact health. Lay counsellors, then, armed with a clearer understanding of the concept can impart information regarding social support, empowering those living with HIV and impacting health.

Finally, disclosure, societal and self stigma, discrimination and rejection should be a focus in counselling. These are barriers preventing individuals living with HIV from accessing much needed social support and these issues need to be dealt with.

8.2 Educators

Educators need no longer talk in vague terms about social support and its definitions; they need no longer rely on westernised conceptual models for understanding social support. Educators having access to the diagrammatical representation (Figure 1) can educate in a contextually relevant way concerning social support. Almost every educational programme dealing with HIV/AIDS gives time to social support and its importance for positive living. Social support can now be understood to be located within socio-cultural, temporal and situational contexts. Within these contexts there exists a multifaceted, bi-directional network of relationships whose interpersonal interactions satisfy or do not satisfy specific needs. Certain activities comprise important sources of social support (story telling, Memory Box Project, being a part of research, organisations, engaging with media and books) because of their interactional content and ability to provide solace from the continuous rumination caused by HIV. It is recommended that the diagrammatical representation of social support (Figure 1) be incorporated into training packages and educational programmes.

Educators should also begin to focus on targeting various sources of support highlighted as constituent aspects of the lived experience of social support. For example, target training advances could include imparting knowledge to families of those living with HIV, older children, partners, support groups, community neighbours and churches, all of whom emerged as crucial aspects of the lived experience of social support. These target training advances need to focus on

educating constituent aspects of social support concerning their potential positive impact on those living with HIV. These target educational advances should incorporate a strong counselling component and could be advertised from hospitals, clinics, support groups, churches and community centres.

Results revealed the powerful impact of education and informational provision in the lived experience of social support. This theme emerging from the study should not be ignored. Educators, having received training themselves regarding the world of interpersonal relationships constituting the lived experience of social support, should become increasingly aware of the importance of education. Particularly in light of the socio-cultural context within South Africa, education regarding issues around HIV/AIDS for individuals living with HIV should be dealt with in a comprehensive manner. Concerns should be addressed, as well as societal stigma and self stigma, disclosure, discrimination, rejection and uncertainties surrounding living with HIV. In order to live with HIV, accessing information about the illness and acquisition of knowledge was indicated as fuelling empowerment. Educators should be aware that other constituent aspects of social support such as family, the community etc. may fail to provide adequate education for individuals living with HIV. Educators, therefore, play a crucial role in demystifying HIV/AIDS, relieving the emotional toll of HIV and encouraging individuals living with HIV to voice concerns and questions freely. In this way educators aid positive living with HIV, impacting health.

8.3 Support group facilitators

Support groups were unanimously cited as one of the most powerful aspects of the lived experience of social support positively impacting the health of the sample. The power of the support group lies in its ability to enable comprehension that living positively with HIV is possible. The influential role of

support groups indicates the deep need for individuals living with HIV to be linked into support groups. However, a lack of support groups has been made evident. For example, in the Southern Peninsula at the time of the study, just two support groups were being run (Aids Resource Centre, 2003).

In order to increase the amount of support groups being run, it is recommended that lay counsellors in hospitals and clinics receive training in becoming support group facilitators. This will enable support groups to be run at hospitals and clinics servicing those who have been diagnosed within the particular hospital or clinic. For this to take place, however, funding is needed as many lay counsellors are working in a voluntary capacity or for very little remuneration (Personal communication, F. Okufufu, April, 2004). Adding the task of support group facilitation to the overly consuming job description of a lay counsellor, would be unrealistic without considerable financial incentive.

Mentoring of support group facilitators also becomes necessary in light of their tremendous responsibility in caring for people living with HIV. Caring for individuals living with HIV can become overwhelming; especially where understandings of the concept of social support have been narrowed down to mean the support group. Once broadened understandings of social support have been grasped support group facilitators can invest time into educating support group members around the various forms of support available to them. Educating support group facilitators using the diagrammatical representation of social support (Figure 1) is recommended. Education of support group facilitators would provide deepened understandings of social support. This would alleviate overwhelming feelings that they are the sole "life-line" for support group members (Personal communication, Skolweni, January, 2004). Educating support group facilitators would also provide opportunity for them to receive encouragement regarding their invaluable impact on the lives of their

support group members as well as describe concerns, express difficulties and receive feedback regarding how to deal with particularly problematic issues.

Results of the study provided insight into the positive effects participants attributed to being a part of the present study. Participants attributed these effects to the fresh look the study gave them into their own lives. Participants also spoke of the insight it provided into their own experience of social support, and opportunity it afforded them to discuss issues they had not spoken about before. In response to the positive impact of being involved in the present study, for the above mentioned reasons, a ten week programme is presented in Table 8.3. The programme is proposed for existing support groups whose members are from similar contexts as the sample.

The fourteen themes emerging from the study as constituent aspects of the lived experience of social support are used to guide topical discussions. These topical discussions will result in group members developing deepened understandings of the world of interpersonal relationships constituting the lived experience of social support. A broad outline is proposed:

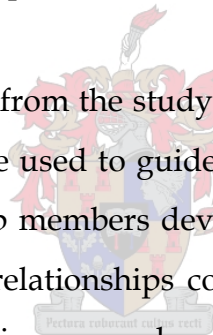


Table 8.3 Ten week programme educating support groups about the world of interpersonal relationships constituting the lived experience of social support.


Wk.	Aspect of social support.	Procedure	Purpose
One	Health care professionals	<p>*Allow time for group members to think back to when they were diagnosed HIV positive.</p> <p>* How where they treated? What was helpful, what was harmful?</p> <p>* How did they feel having someone who didn't know them giving them their HIV positive diagnosis?</p> <p>* What was going through their minds?</p> <p>* Allow for discussion time centring on group members differing experiences in health care facilities.</p> 	<p>* Health care is essential to women living with HIV. Many may have had negative experiences with health care professionals, creating a barrier preventing them from accessing essential health care.</p> <p>* Telling stories of experiences has therapeutic value.</p> <p>* Hearing the stories of others who may have had beneficial interaction with health care professionals, may encourage those who feel negatively toward health care professionals to once more access health care, with their negative experiences no longer at the fore front of their minds.</p> <p>* This will have positive impact on health.</p>

Table 8.3 continued

Wk.	Aspect of social support.	Procedure	Purpose
Two	Family and close friends	<p>* Allow time for group members to discuss their experiences of family as an aspect of social support. A range of differing responses should be expected. Issues of stigma and disclosure should be grappled with.</p> <p>* The role of children in the lives of mothers who are HIV positive should be discussed, the necessity of allowing children to be a part of their mothers HIV journey should be highlighted</p> <p>* Concern regarding children's future should be brought to light.</p> <p>* Household tasks and responsibilities women still have to bear despite their HIV status that causes difficulty or stress should be discussed.</p>	<p>* Issues group members are struggling with, within the family can be brought into the open and proactively approached.</p> <p>* Where disclosure to family members has not yet taken place, individuals could be assisted in preparing to disclose to family members or close friends.</p> <p>* Self and societal stigma can be dealt with</p> <p>* Needs can be freely brought into the open.</p> <p>* Group members will be provided with an opportunity to be referred appropriate resources.</p>

Table 8.3 continued

Wk.	Aspect of social support.	Procedure	Purpose
Three	Partners	<ul style="list-style-type: none"> * Issues around disclosing to partners and various reactions can be discussed. * Ethical concerns of nondisclosure can be addressed. * Gender issues and HIV focused on. * For women who do not have partners their experiences of being single women living with HIV can be discussed. * Allow time for group members to draw up a benefits chart in which they verbalise the: benefits of being in relationship with partners? As well as the draw backs? Or the benefits and draw backs of being single? * Allow time for discussion in small groups centring on benefits chart. 	<ul style="list-style-type: none"> * Women struggling with various aspects of intimate relationships can be given room to voice their experiences. * Learning from group members can take place. * Dependence on partners, causing the women to remain with partners even if they are abusive or non-supportive can be discussed. * Benefits and drawbacks of being in intimate relationships or being single can be reflected on.
Four/ Five	Story telling	<ul style="list-style-type: none"> * Time should be given to allow each group member to tell their story. Where groups are too big, divide off into smaller groups. Within these groups members can listen to each other's stories, without judgement or discrimination. * Guest speaker from the Memory Box Project introduces the Memory Box Project and the benefits of keeping a Memory Box. * Making of a Memory Box is practically displayed. 	<ul style="list-style-type: none"> * There is deep therapeutic value in sharing one's story. * Group members will be set within a context of a supportive community. * Expanding of the boundaries of support to a group of caring persons. * Introduction of Memory Box Project will practically aid group members in creatively coming to terms with their story.

Table 8.3 continued

Wk.	Aspect of social support.	Procedure	Purpose
Six	Organisations	<p>* Organisations working to positively impact the lives of women living with HIV are introduced. Group members are encouraged to become involved in organisations.</p> <p>* Guest speakers present various organisations and the benefits of belonging to the organisations.</p>	<p>* Information is imparted about organisations.</p> <p>* This will enable group members to identify personal areas of need. As well as how those areas can be met by different organisations.</p>
Seven	Issues in the community	<p>* Group members discuss different reactions they have experienced from the community.</p> <p>* Discussion regarding stigma and disclosure can take place.</p> <p>* Not all of the members will have disclosed their status in the community, however, all of them will have experience regarding life in their community since their HIV positive diagnosis.</p>	<p>* To allow group members to see that the experiences of those who have disclosed are not only negative</p> <p>* This may aid group members in considering the benefits of disclosure.</p> <p>* The practical outworking of stigma in communities can be elicited</p> <p>* Benefits and drawbacks of disclosure can be learned through the medium of stories.</p>

Table 8.3 continued

Wk.	Aspect of social support.	Procedure	Purpose
Eight/ Nine	Spirituality	<p>* The supportive role of spirituality should be highlighted. Religious leaders, church pastors or priests invited to talk to group members.</p> <p>* Counselling for group members should be offered. This may be especially supportive where reactions of family and friends have resulted in rejection and discrimination from home. Or where individuals feel a sense of aloneness and an inability to cope because of a lack of instrumental, tangible, informational and emotional support.</p>	<p>* The benefits of faith in a higher power will be presented.</p> <p>* The supportive nature of prayer will be highlighted.</p> <p>* As well the supportive nature of interpersonal relationships within the church or other religious organisations.</p> <p>* The potential of the various aspects of spirituality to assist in meeting needs will be demonstrated.</p>
Ten	Exploration of hobbies	<p>* The positive effects of keeping busy and thinking correctly should be highlighted.</p> <p>* This will take the form of an arts and crafts evening.</p> <p>During the evening group members are introduced to various activities enabling them to identify a hobby that could occupy their minds, providing solace from continuous rumination about HIV.</p>	<p>* The importance of keeping busy and thinking correctly is highlighted.</p> <p>* Exploration of various hobbies that could assist group members in developing productive ways of occupying their minds enabling them to think correctly.</p>

8.4 Implications for future research

The present study has provided an informed understanding of the lived experience of social support for the sample of Black South African women living with HIV. Quantitative and qualitative studies could further examine the results

of the current study. These studies could explore the practical impact of social support (as defined by the study) on different aspects of the health of women living with HIV. The proposed programme for existing support groups could be used as a pilot study investigating the effects of various aspects of social support on health.

The positive impact of social support on the health of South African women living with HIV needs examination. For example, the impact of social support defined by interpersonal relationships fulfilling needs for instrumental support, tangible assistance, informational provision and emotional connectedness, on the illness trajectory for HIV/ AIDS could be investigated.

Utilising the world of interpersonal relationships constituting social support for Black South African women, further studies could elicit aspects of social support that have the greatest impact on health.

The emergence of the polarity of the concept of social support needs further exploration, assessing the impact of both satisfactory and unsatisfactory aspects of social support on health.

The emergence of the bi-directional nature of social support needs further examination eliciting the impact of caring for others on the health of women living with HIV within a South African context.

The concept of social support as it emerged from this present study provides raw data from which a scale of measurement could be derived and used in clinical settings. The scale of measurement could provide identification of areas of social support that are strong and those lacking by filling in a five or ten minute questionnaire. This would enable those caring for individuals living with HIV to

elicit areas where intervention is most needed, most urgently, positively impacting health.

8.5 Limitations of the present study

The present study attempted to understand, explore and deepen awareness of the lived experience of social support for nine Black South African women living with HIV. Results emerged as rich descriptions of constituent aspects of the lived experience of social support and provide deepened understandings of the concept of social support for the sample.

The study, however, is limited by the small, sample group, all of whom were Black South African women living in the South Peninsula. The results of the study are, therefore, bound within a specific context and to a specific group of people. Future research could be extended to other groups of women within a South African context. This would allow for a broader understanding of social support from within different contexts in South Africa.

A second limitation is that the sample was chosen by identifying valuable participants who would be able to generate rich descriptions of the phenomenon of social support. The sample may, therefore, be criticised for being unrepresentative, limiting the value of the findings even to other South African women found in similar contexts living with HIV.

Phenomenological research relies to some degree on the ability of the researcher to adequately describe results in a language that takes the reader to the essence of the phenomenon. The study, therefore, is limited by the researcher, whose ability to describe emerging results may have filtered some of the richness of the phenomenon. The study may have also been limited by the researcher as a result

of multiple differences between herself and the participants in terms of race, language, class, sero- status etc.

The phenomenon may also have been represented differently had the researcher been from a similar socio-cultural context as the participants and had the study been conducted and written up in one language. That the researcher was not able to understand Xhosa, limited a richer interpretation that could have ensued had the researcher been from a similar cultural context.

8.6 Recommendations for future research

Re-examination of the lived experience of social support for Black South African women, in their first language is needed to distil further themes of importance.

The power of social support to impact on the health of men living with HIV has been identified and researched. However, most research surrounding men and HIV has focused on homosexual, white males (Allen, 2003). In order for effective intervention into the lives of heterosexual South African men, a study of a similar nature would be beneficial. The voices of Black South African men are probably even less heard than Black South African women in academic literature. Their lived experiences of social support from a South African context remain unrecorded. A study of this nature would also identify the differences in the lived experience of social support for women in comparison to men. This would enable those caring for individuals living with HIV to identify differences in care needs of men and women.

Large-scale, longitudinal research into social support South African women and men would provide understandings of the dynamic nature of social support that this research has not. The research described the lived experience of social support which was caught up in participant's past and present experiences of

social support. The continual and changing experience of social support over the course of the HIV/AIDS trajectory was, therefore, not captured. Research on social support over longer time periods should be pursued. For example, the lived experience of social support during stage one, stage two, stage three, stage four and full blow AIDS stage for women and men would highlight the dynamic nature of the concept of social support. Each stage may require differing needs and therefore differing experience of social support.

8.7 Conclusion

Through phenomenological inquiry the present study aimed to describe the lived experience of social support for the sample of Black South African women living with HIV. Firstly the study highlighted, wider understandings of the gravity of the HIV/AIDS situation within a South African context. The vulnerabilities of particularly Black South African women to HIV were indicated. This was done by exploring various realities contributing to the spread of HIV in the Black African sector of the South African population.

The link between social support and health was considered. Consideration of this link took place by highlighting key findings of the field of psychoneuroimmunology, as well as exploring a model of stress and coping that provided understandings of the buffering role of social support against the negative effects of stress.

Past social support research was presented providing a broad understanding of the concept of social support. Limitations of social support research and the impact of social support on the health of individuals living with HIV were delineated. Rationale was, therefore, provided for the necessity of the present study's inquiry into the lived experience of social support for Black South African women living with HIV.

It was identified that particularly from within a South African context a study of this nature would assist in defining a culturally contextual way of conceptualising social support, laying groundwork for future social support research as well as implicating care strategies aiming to positively impact the health of women living with HIV.

Space was created for nine Black South African women living with HIV to describe their lived experiences of social support through in-depth interviewing. Results provided rich descriptions of the lived experience of social support, which emerged as a multifaceted, bi directional concept located within three contexts:

- A socio-cultural context: This context provides an understanding of the needs of many Black South African women living with HIV. The general low status of Black South African women as a result of a lack of education, low levels of employment, social inequalities, for example their subordinate role in the family, dictates them most vulnerable to infection (due to cultural norms in Black South African society). It also determines them least able to access efficient access to treatment (because of limited personal resources), most responsible for caring for the sick and dying and least able to sustain life with HIV for long periods (Walker & Gilbert, 2002).
- A temporal context: This context incorporates factors such as epidemiological stage, disease stage and life stage.
- Situational contexts: The situational context allows for a consideration of each participant's unique situational factors. These factors were considered to influence individuals' lived experience of social support.

Social support emerged as constituting a network of interpersonal relationships in which interaction satisfied or did not satisfy specific needs. A polarity, therefore, became evident in the lived experience of social support. At the one pole, needs for instrumental support, tangible assistance, informational provision and emotional connectedness were met. At the other pole they were not. The following themes emerged as constituent aspects of the lived experience of social support:

- Health care professionals
- Partners
- Family
- Children
- Support groups
- Story telling
- Memory Box Project
- Education, from media and books
- Organisations within the community
- Activities
- The community
- Being involved in research



Social support also emerged as encompassing a bi-directional component in which caring for others took place. For example, caring for particularly family members, children, support group members and others living with HIV were all interactions containing a bi-directional component.

Finally, social support had a spiritual aspect. Spirituality included prayer, reading the bible, a relationship with God and attending church. Spirituality had a supportive and empowering role.

This present study, therefore, provided deepened understandings of the lived experience of social support. A definition of the lived experience of social support emerged and was represented diagrammatically.

The research findings had implications that were addressed to specifically health care professionals, educators and support group facilitators. Implications were considered critical in impacting strategic intervention aiming to truly care for and impact the health those living with HIV. In seeking health within illness or illness management (Moch, in Jones & Meleis, 1993) strategies, were focused on that would positively impact health and facilitate an experience of adequate social support, aiding acceptance of HIV and assisting a proclamation that: *"I am the hero of my life, because even though difficult times come to my life I have reached a stage to accept my life and I now look forward to my life, I am the hero of my life"* [1:133]

In light of the devastation of the HIV/AIDS pandemic on South Africa, the challenge of providing effective care strategies enhancing quality of life, wellbeing and improving the health of many living with HIV may seem an overwhelming task. With the world of interpersonal relationships constituting the lived experience of social support clearly illuminated, however, the task may be more manageable. The caring community can begin to envisage themselves as simply aspects of an entire network of interpersonal relationships. If each constituency was to become more aware of its potential to positively impact the health of women living with HIV, and to commit to work more effectively together, intervention strategies aiming to purposefully care for those living with HIV, could begin to radically impact health.

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APPENDIX A: STANDARD LETTER

Dear Research Participant

My name is Laura Smyth; I am a master's psychology student at the University of Stellenbosch. I am presently conducting a study, which aims to develop a clear and deep understanding of the experience of social support in the lives of women living with HIV. Your participation in this study will provide valuable information about the kinds of social support you have experienced in your situation.

Your information will be very helpful and will aid in understanding social support, as well as how women living with HIV have to cope and deal with the reality of their situation. Your information will also help to better target the social support needs of women living with HIV, as well as being helpful in the future to plan programmes and groups to provide more effective support for women living with HIV and assist in helping with the resources they lack.

If you are willing to participate in this study, you will be required to take part in one interview. The interview will be conducted at your convenience at Fish Hoek Full Gospel Church office (transport will be arranged) with one follow-up session to take place in January. You will also be required to fill in a general information sheet. The interview will take approximately 45-90 minutes and will be tape-recorded then transcribed for analysis. In the follow-up session you will be shown the analysis and results and asked to comment on them.

Please be informed that your name is not required, will not be written down, or used in any way in the general information sheet or during the interview. You can therefore be assured of your privacy. It is however necessary that you sign the informed consent form if you choose to be part of the study. A code name will be assigned to organise the information and protect your privacy. Only the research team consisting of: Laura

Smyth - Researcher, Tony Naidoo - Supervisor, Skolweni - Translator and a transcriber will have direct access to the interview material as well as the general information sheet. Only the researcher and translator will be able to connect the interview material back to you. The interview material will be kept in a safe place to further ensure confidentiality.

Because of the sensitive nature of this topic you can arrange with the researcher for one-on-one counselling sessions to talk about issues that may have arisen during the interview once your interview is completed. These will be held at False Bay Hospital where the researcher is currently working on Thursday mornings. After the interview you will be presented with a food parcel to thank you for participating in the interview. The follow-up session will then be scheduled.

At the end of this study if you would so wish, you will be given verbal feedback of the study. A completed and bound copy of the research can be made available to you for your comment. You will also be the first to be informed about any groups that may be started as a result of this research.

Please indicate your willingness to be a participant in this study by signing the informed consent form attached. You retain the right to withdraw from the study at any stage. If you should choose to withdraw, you may request that all the general information, your informed consent form, interview tapes, transcriptions and any analysis be returned to you.

Please feel free to ask me any questions about this study or the general information sheet and please feel free to contact me at any time on 0829341824 or my supervisor Tony Naidoo on 021- 808 3466.

Thank you for your willingness to participate in this important study.

Yours sincerely

The Researcher: Laura Smyth

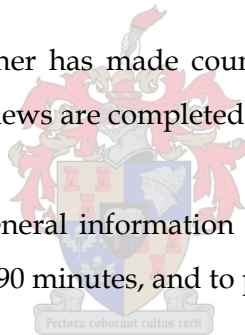
APPENDIX B: INFORMED CONSENT FORM

I _____ have read through the letter informing me about the study presently being conducted and the purpose for which my information will be used.

I hereby agree to participate in the study as I realise that the information I share will inform the research question and may be beneficial to other women who are HIV positive and to myself. I have been informed that my information will be handled with strict confidentiality, that my name will not be associated with the information provided, and that I retain the right to withdraw from the study at any time.

I am also aware that the researcher has made counselling support available through False Bay Hospital once the interviews are completed.

I give my consent to fill out a general information sheet, participate in one interview which will take approximately 45-90 minutes, and to participate in a follow up session.



Date: _____

Name: _____

Signature: _____

Yes I would like to receive verbal feed back at the end of the study _____

Yes I would like to receive a bound copy of the research at the end of the study _____

Address:

APPENDIX C: GENERAL INFORMATION SHEET

General information sheet

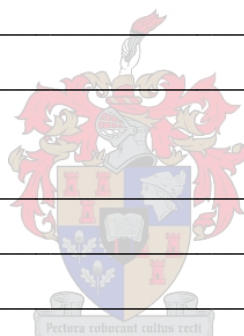
Personal details:

1. How old are you?

Less than 25?	25-29	30-34	35-39	40-44	45-49
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2. Where do you live?

2.1. With whom do you live?



2.2 What is your present living arrangement?

Long-term	Temporary
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3. What is your religion?

3.1 How important is your religion to you?

4. Where do you consider home?

4.1 What is your home language?

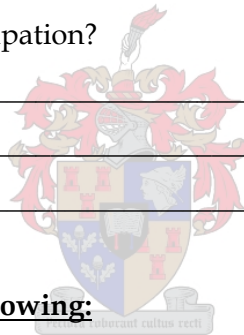
5. Where did you attend school?

5.1. What are your highest school qualifications?

6. Have you had any other form of training?

7. What is your present job or occupation?

8. If relevant please fill in the following:



Where does your family stay?

8.1 Number of brothers: _____ Ages:

8.2 Number of sisters: _____ Ages:

8.3 What is your position in the family?

8.4 Is your mother: Living?

Deceased?

What is her occupation?

8.5 Is your father: Living?

Deceased?

What is his occupation?

9. What is your relationship status?

Single	Engaged	Married	Separated	Divorced
Widowed	Remarried	Living with someone	Involved with someone	Other - please specify

10. If relevant please fill in the following:

10.1 How long have you been involved with your partner/husband?

10.2 Where does your partner/husband currently live?

10.3 Would you consider yourself to have a good relationship with him?

10.4 Are the two of you sexually involved?

10.5 How many sexual partners have you had in the last five years?

11. If relevant please fill in the following:

11.1 How long have you been married for?

Less than 1 year?	1-5 years	5-10 years	10-15 years	15 +
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11.2 How good do you consider your relationship with your partner/husband to be?

11.3 Where is your partner/husband currently living?

11.4 What is his occupation?

11.5 Are the two of you still involved in sexual intercourse?

11.6 Do you practice safer sex?

11.7 How many children do you have?

11.8 How many boys? Please also give their ages:

11.9 How many girls? Please also give their ages:

11.10 Where are your children currently living?

12. How many income earners are in your home?

13. What is your monthly family income?

R 1 - R 500	
R 500 - R 1000	
R 1100 - R 1500	
R 1600 - R 2000	
R 2100 - R 2500	
R 2600 - R3000	
R 3100 - R 4000	
R 4100 - R 5000	
R 5100 +	
Don't know	

14. Information about being HIV positive:

14.1 How long have you known that you are HIV positive?

14.2 What made you originally go for a HIV test?

14.3 How did you feel initially about being diagnosed HIV positive?

14.4 Who was the first person you told about being HIV positive?

14.5 How did they respond to you?

14.6 Would you consider yourself to be fairly open about your status?

14.7 How do you feel generally people respond to you?

14.8 How do you feel generally people feel about HIV/ AIDS, especially in your community?

14.9 Were you employed at the time of finding out that you where HIV positive?

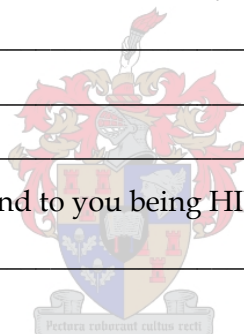
14.10 Did you tell people at your work about your status?

If you answered yes to the above question, what were their responses?

14.11 Who or what would you consider to give the most support since you have been diagnosed as being HIV positive?

14.12 How does your partner/husband respond to you being HIV positive?

14.13 How does your family respond to you being HIV positive?



15. Please fill in specifically how each member of your family has responded to you:

15.1 Your mother?

15.2 Your Father?

15.3 Your brothers?

15.4 Your sisters?

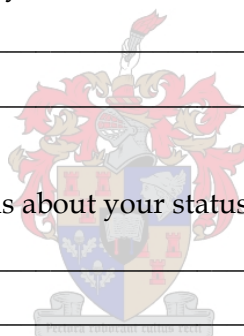
15.5 Your partner/husband?

15.6 Your Sons?

15.7 Your daughters?

15.8 Your partner/husband's family?

16. Did you tell a lot of your friends about your status? What were their reactions?



17. How physically sick has being HIV positive made you so far, please name your symptoms?

17.1. At what stage of the HIV illness are you?

18. Who has cared for you most whilst you have been sick?

19. Are you presently on any medication?

20. Do you attend any sort of support group?

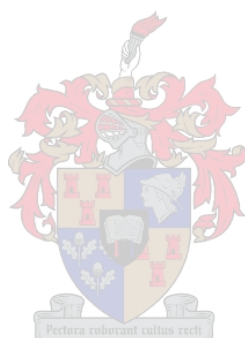
20.1 If you answered yes to the above question please explain the nature of the group and why you attend?

21. How do you feel today about being HIV positive?



THANK YOU SO MUCH FOR TAKING TIME TO FILL THIS INFORMATION SHEET IN!

APPENDIX D:
APPROVAL FROM THE UNIVERSITY OF STELLENBOSCH





UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvennoot • your knowledge partner

23rd January 2003

To whom it may concern

This is to confirm that Laura Smyth is a masters student in the Department of Psychology at Stellenbosch University.

Her masters research study titled **A phenomenological inquiry into the lived experience of social support for women living with HIV** has been approved by the department. In conducting the study, Ms Smyth is required to adhere to stringent ethical principles and practices to ensure that the rights, privacy and confidentiality of the participants are maintained at all times. Participants have the right to volunteer for the study, to withdraw at any stage, and to have their personal information handled confidentially for the purpose of the current study only. Information given by participants will be coded to protect the anonymity of the participants. Participants will also be offered counselling and supportive services when warranted. In appreciation of their participation, the researcher will be providing food parcels to the participants.

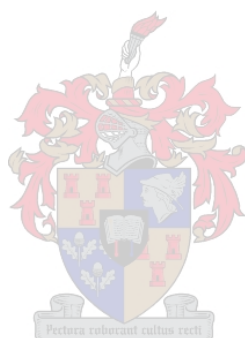
Please feel free to contact me should you have any questions regarding the study.

Sincerely,

Prof AV Naidoo
Supervisor



APPENDIX E:
PERMISSION FROM FISH HOEK FULL GOSPEL CHURCH





Kevin & Linda O' Donoghue
(Pastoral Couple)

To: Laura Smyth

It is with pleasure that I respond to your request to utilise the church office to conduct your interviews, for your study on the lived experience of social support, and inform you of the permission I am willing to give you to use the office during the months of October and November 2003 and then at a later stage for follow-up interviews, as well as permission to use the sound equipment to record the interviews, as requested. Please get into touch with the church secretary as and when you need the keys for the room and the sound box.

All the best

God Bless

Kevin O' Donoghue

APPENDIX F:
REFLECTION ON A FEW ESSENCES EMERGING FROM
INTERVIEW ONE WITH N.

Essence 5:

Continuing care for children	Because of Ns family's reaction to her HIV status she became very worried about her children's future.	14, 38, 49, 50, 143, 144
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"So it was so bad to me, because I was thinking about my children's future." [1:14]

"It was very, very hard for me and my children because they even chase my children away, they say no, no just stay there at your house with your mother don't come here to us because you are going to make us sick, that you know it was very hard for me." [1:38]

"Oh, the first time, I was so sad and angry, because I thought I'm going to die on that day you know I was so worried at that time because things were not going well because I was not working, I'm the mother of the children and the question I was asking is that who's going to look after my children?" [1:49]

"Especially because I was thinking, look at my family they are funny to me, so who's going to grow these two little daughters, you know and I worried, because even me, I grew up without my Mum around, so I know everything, you know to grow without your mother it was painful and I was thinking about that and so it was my pain in my life, I was so, so sad when I'm looking to my children like that." [1:50]

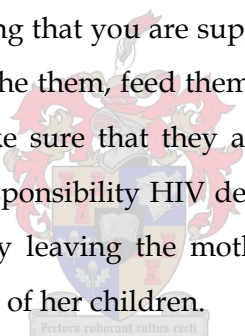
"The problem in my life is that I don't have any savings for my children, want them to go to school but I have not had enough jobs yet. Sometimes I just thinking: "Oh God. My daughter is 19; she is doing Standard VIII you know this year, so what can I do when she passed, er, matric? Maybe she wants to go to the university but I don't have any money to take her there. Then there

is also my little one who is going also to help this little one also you know? That is my problem. I'm always thinking about that, because I didn't have enough, ah, jobs you know." [1:143]

"I- like to see my children grow up and...and go, go to school, finish their schools, you know? (Ja) I would like to see them living with their houses, and having funds." [1:144]

Memo

HIV has robbed her of the certainty that for the rest of her life she will be a mother and a carer of her children. Instead of knowing that she will love and nurture her children to maturity she is now uncertain of her own future. How long will she be alive? Resulting is an uncertain of her ability to be able to care for her children. *"I am the mother of my children but who is going to look after those little ones?"* For any mother terminal illness would have this same effect. Mothering is a sense of responsibility, its knowing that you are there for your children, knowing that you are support for your children. She worries about their futures – who will clothe them, feed them, school them and then when they are finished school who will make sure that they are living with houses and having funds? Mothering is a life long responsibility HIV determines that you are not going to be able to fulfil this responsibility leaving the mother with legitimate and very real concerns about the continuing care of her children.



Essence 7:

Financial constraint and assistance	Before she was diagnosed N did not have enough work, she has her children's school fees to worry about, rent to pay, food to buy. This was all emphasised because of her assumption that she was to die soon. But because N had become so sick she was helped by her doctor to access a disability grant and as well as a disability grant she also accessed further financial assistance as a HIV positive mother. All of this financial assistance meant that she felt better because she now has money to share with her children	15, 16, 17, 18, 19, 20, 96, 143, 144,
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"Because I was not working on that time that things are just um not working alright, so I was living with my friend on the other place, and I rent of a I rent a house, a small house a rent of R200 a month." [1:15]

"The problem in my life is that I don't have any savings for my children, want them to go to school but I have not had enough jobs yet. Sometimes I just thinking: "Oh God. My daughter is 19; she is doing Standard VIII you know this year, so what can I do when she passed, er, matric? Maybe she wants to go to the university but I don't have any money to take her there. Then there is also my little one who is going also to help this little one also you know? That is my problem. I'm always thinking about that, because I didn't have enough, ah, jobs you know." [1:143]

"I- like to see my children grow up and...and go, go to school, finish their schools, you know? I would like to see them living with their houses, and having funds." [1:144]

"After I was diagnosed with HIV though, last year I was suffering of T.B. So I was at the False Bay Hospital, sleeping there and the Doctor S make me the disability grant." [1:16]

"Ja, yes...the...the...the time that I had TB...TB, they gave me the application form to get a disability grant. This has helped me, because I was not working and no body was supporting me. Also I was quite sick because when they did a CD four count; my CD four was oh very low. I was

in stage...my CD 4 was...ah... it was 147 I...and I was feeling very, very weak, even I...my weight it was, 62 so that's why ...my doctor decided to...to give me this disability grant....because they told me I must have that disability grant because of my CD 4. And that was a great help to me because I didn't have to worry so much about money." [1:96]

"Yes, so it was there at that time that things were going better for the first time since I was diagnosed with HIV, because every month now I know that I have got the disability grant to share with my children." [1:17]

"There's also a um a group there at the pink house for the HIV people so I was joining that group also and that group are helping us to pay the fees for my children at school, buying the uniforms and everything." [1:18]

"So that things are going better now than when I first found out that I am HIV." [1:19]

"The Memory Box also paid us every month and S.F.C.M. programme is also paid us because we are working around the community, looking after the children's and the parents." [1:20]

Memo:

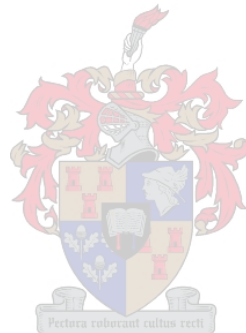
In the face of poverty the realities of HIV hit hardest. Ns reality when she was diagnosed with HIV was that she had no real income. Immediately some of her major concerns were wrapped up what am I going to do because I have no money? Being a mother she feels the many financial responsibilities that she has that she is not going to be able to meet. She also thinks of their future and knows that she doesn't have enough jobs to set aside some savings for her children when she is going to die, and an even closer reality is "how am I going to afford my own health care that I know that I a going to need as a HIV positive women in light of the fact that I have no money?"

Poverty becomes more devastating when it disempowers you to such an extent that you cant imagine what you are going to do in the situation that you are in because you have no money to do anything. "How am I going to be able to afford rent, taxi fare, food, clothes, medicines, children's school fees, and a number of other things if I have no

savings and now I'm going to be too sick to work?" For N being able to access financial assistance has been a great support and help to her, she goes as far as saying *"When I got the disability grant (which means she must have been very sick CD4 lower than 200) things were better for the first time."*

Since N was diagnosed with HIV and has come to accept her HIV status she has also become involved in other income generating groups. For N accessing this financial support with the help of her doctor and others has brought some sense of relief into her life.

This is an essential aspect of social support – social because the places where she is getting her income from are places where there are other people and other people have been an integral part of her being able to access financial assistance.



Essence 9

Not talking is killing people with HIV	N places a strong emphasis on how talking has helped her to accept HIV, and that those who are not talking, who are just keeping HIV to themselves as a secret because they are scared of the reactions of others, are getting sick very quickly and then dying.	23, 24 30, 31, 34, 90, 91, 92
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"Because a lot of people there in Masiphumelele have a problem, they don't want to talk about this virus." [1:23]

"They are so scared of the people because the other, the others are laughing at us you know saying just look at this little girl this HIV she's going to die any time." [1:24]

"I really did want all the youngsters to know that they've got a problem, they don't want even to tell their families about this virus." [1:30]

"Because of this they just stay with the virus for some months and then they just get sick and die." [1:31]

"And the other thing, it's very important to tell one of your family or your friend to talk to them to tell them, that you are HIV positive, because if you just keep it as a secret you are going to be stressed a lot and sick, it's better to talk about this every time just talking, talking, talking don't be scared you know, it's very important." [1:34]

"If you won't share to anybody, you are going to be sick because you are always lonely, you know? Because you've got something inside, you know? Something that is bothering you. So I think it's not a good idea to keep it inside that's why it's important to share; to take one of your family or one of your friends, and share. Because if you can think you are going to...to...to keep it as a secret, it's going to...you are going to die! You are going to be sick, you know; always lonely, always angry with someone, you know? Because you've got something inside your heart." [1:90]

"Yes; because...ah...the time you're always thinking about that thing that's bothering you inside, and it makes something, in your blood, you know, even in your...your body feels very weak."
[1:91]

"You don't have any power not even any appetite...doesn't even eat something when you've got something inside. Just always sleepy on the bed...lying on the bed...nothing to do, you know? It's very, very important to share, not to keep the things inside." [1:92]

Memo:

Ns experience of HIV is that when you talk you feel better; she says over and over again that it is important to share and not keep things inside. She has found within herself that she has become brave and strong because of talking. She says you must just take someone a friend or family member and just tell them even if it is one person. The support of knowing that you are not the only person who knows this secret is tremendous. She has noticed that a lot of young people don't want to talk to anyone, they just keep this thing inside of themselves and then they are alone (there is no one there for them, there is no one who can support them) when you are alone she says, you are just lying on your bed, sleeping and thinking the whole time and then you get sick and you die. Interesting to note that Ns first experience of disclosing was not a positive one in fact her family rejected her and yet she still places such an emphasis on finding one person that you can tell. Its almost like she is saying, people are so essential for living with HIV that you must go about somehow just finding someone. Because other people's words and actions are so powerful in our lives, the fear of people's reactions towards HIV must be a truly scary thing. N experience was not a good one when she first told her family about HIV status their reactions, actions and words were very harmful and yet she still says you must speak, you need to speak, if you don't you will die quickly.

Essence 14:

Seeing others who are HIV positive	Realising that there are others living with HIV was a great source of comfort to N. She recalls seeing the ladies from Khayelitsha when they came to disclose this HIV status and she said, "They were so big and so beautiful and me, I am also going to be like that"	55, 127, 129
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"It was really the first day I was feeling very, much better than before (Really) because when I saw no, it's not me only living with this virus, there is a lot of others and they said, come inside, sit and take your jacket off, because this is your home." [1:55]

"At the time I saw even the ladies came from Khayelitsha, they come and disclose here in Masiphumelele and I look at them: hau, they are so beautiful and big like that I said hau, no (Laughter). And me also, I'm going to be like that if I can accept this virus you know. It was that time I said, 'Oh, its okay.' And since then I always keep my mind busy, not to stay and think I'm HIV or what I'm going to do." [1:127]

"Even to advise anyone who is HIV positive, and I like to do this, I like to talk with the others in my community and they also comes to my house and say, 'How are you? How did you feel the day you were standing in front of us telling us that you are HIV?' I said...and they said 'Look at you, you are so beautiful and fat, you know? So that's why I need to talk to you, and then they will say "I am also HIV, but you are the first person I told you I am HIV" If I ask them why you come to tell me about you are HIV positive they say, "because I know you are HIV positive, and you are so brave because you stood in front of the community so I think I can talk to you", and then I tell them they must come to the support group." [1:129]

Memo

Often when we see others who are in a similar situation to ourselves we are encouraged so much, we realise that others have done what we are doing and others have successfully managed to make something of their life despite their ailment. I guess this is something of what N felt when she saw other women who were also disclosing

Essence 16:

Information and Education reduces stress	N explains that the ladies from Khayelitsha came and taught her about HIV, being taught about HIV she says makes the stress less.	59, 62, 63, 110,
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"Some time after I joined the support group then that time there were ladies from eh Khayelitsha, they come teach us." [1:59]

"The first thing they told me, they said that, if you don't accept this virus, this will be a big problem in your life, you must, you must accept this virus you must say, HIV you are my friend you just take it like that you are my friend, I can't just share anybody with you, it's you and me. That is the first point you must know, they said and it's very important to your life." [1:62]

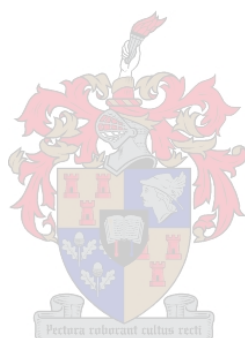
"Because it makes you a lot of stress if you think, ooh, I'm H.IV, ooh God, I'm going to die, maybe tomorrow maybe tonight you know, it's always ringing in your mind, but the you must reach the time when you can accept it "you HIV and me, we are friends." [1:63]

"I, ah, I'm also try to get the food the right food for my health you know? Always eating something like garlic, fruit, eh, something's like milk, juices...everything to make me feel strong, you know, because this is very important to eat the...the right food, because it makes me very strong." [1:110]

Memo

At first when she found out that she had HIV she thought she was going to die, the role of education about HIV and positive living is a critical aspect of the HIV positive women's process of personal acceptance, the more you know about something the less fear you experience about that thing because you are less in the dark about it. N expresses how being taught things about HIV and being educated about positive living was critical for her as it gave her practical ways to better her life. Once again this informational support is a form of social support because everything that she speaks about learning she speaks about learning for other people who shared with her. She was

told that if she didn't accept HIV me and you are friends then she would just die.



Essence 19:

Practical care of her employer	N works as a char for a lady in Fish Hoek, who she disclosed her status to, she buys her tablets, vegetables and fruit and says “you can use this... its make you very strong.”	78, 79
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“So, and my...the lady in Fish Hoek I’m working for: I once told her I’m HIV. Hauw. She always gives me lot of support.” [1:78]

“She gives me some things. First she buy me some veggies; tins, everything to make me feel strong. She’s told me everything and sometimes she buys me some tablets at the chemist, and I use that tablets...she says “you can use this...make you very strong” so it’s OK. Because of all these things I’m still very strong and brave.” [1:79]

Memo:

N says that the lady she works for gives her a lot of support – straight away she moves into explaining that she buys things for her, tablets, vegetables and fruit which says to me that a big part of her support that she receives from this women is that she buys her things that maybe she would not be able to buy herself. It is these things specifically that aid N to be able to say “I am still very strong and brave, because of these things” This tangible support is obviously essential for N and it is channelled through a person once again showing that it is a very strong aspect of social support for N.

I hate the men	N seems to harbour a real fear and hatred for men, she explains that she feels no pleasure with them anymore, she gets a bad feeling around them – she suggests that it could be because of the virus and she acknowledges that it is a problem. But she has decided that it is not good for her to have a boyfriend because she feels that men have a lot of problems, and she is the basin into which a man will pour his problems both physical (because he could be HIV positive) and emotional	102, 103, 104, 105, 108
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Essence 22:

“But when he comes, I say to him ‘you can go, because you...you...I’m taking you like a friend to me, you know? But he knows me, I’m HIV I told him now I’m HIV positive so I don’t want anything now, you know? So he just said no, it’s OK...but I still love you, you know? But I don’t want to...to sleep with him.” [1:102]

“I’m so scared, I’m so scared, even of any man in the world, you know? I don’t want any man, I don’t know why but since I was HIV positive, I’m so scared about men, I don’t know why. It is a real problem for me. I’ve got a bad feeling when I’m thinking about my boyfriend, and about any man; I don’t know why, you know?” [1:103]

“I don’t know, ‘cause sometimes I said: ‘Why?’ I don’t know what is wrong with me, but even when was staying with my boyfriend, and sleeping with him, I’ve got...I didn’t have any feeling, you know? I don’t know, why but I’m so scared of men. When I’m looking at him, I said Oh...no I don’t know why.” [1:104]

“They...they are laughing at me one day when I...I...I’m talking about this at the...at the living hope. I said to them, ‘Hey girls, I’ve got a problem. I HATE the men!’ They were laughing and said, ‘No...maybe it’s still early because...eh...because of the virus. Maybe that when the times goes, you are going to be OK. I said, ‘I don’t think so.’ They’re laughing at me.” [1:105]

"Because men, they have got a lot of problems. Maybe I'm going to love, love a man, you know, but is going to make me sick in the end because, sometimes I sit the whole night waiting, waiting and waiting you know?" [1:108]

Memo

If I put myself in Ns shoes, I think I would also hate men, I would know that a man was responsible for infecting me with HIV, for putting this finiteness on my life, I would fear him because maybe she was responsible in asking the men that she slept with if they where or where not HIV positive and they lied, and if they lied about that kind of thing they can lie about much more. In my experience of dealing with black women, they seem to accept that their husbands sleep around "it's a mans things" I hear over and over again its like men can't control their sexual impulses and a women is vulnerable because of that. If she sleeps with a man who is HIV positive she can get his HIV making her viral load and HIV worse and more serious maybe being responsible for her going to stage four and then death. I would also be scared and fearful of the one who did this thing to me or men who represent the one who probably knowingly slept with me even though he was HIV positive. The fact that even when she was with her boyfriend she would experience no pleasure when they slept together suggests to me that she has been unhappy in her relationship for quite some time and maybe HIV gave her a way out. Her friends seem to understand what she is saying and speak from experience "*maybe its just because its early in the virus*" suggesting that many other HIV positive women initially feel the same way that N feels abut men but then get over it.

Essence 23:

Busying yourself and thinking right	N explains how she always tries to keep herself happy, this happiness mostly includes avoiding not being busy, so that she doesn't just sit and think and sleep. She says that HIV is a funny virus and the time you give it a chance to attack it will. When you keep yourself busy, she explains then the thought of "ooh man, I am HIV oo no" is not coming into your mind and then you don't give HIV a chance to attack.	111, 112, 113, 114, 115
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"I always try to keep myself happy always happy; not thinking about bad stuff, for me this is the best thing." [1:111]

"Just...like me, I'm always, ah, staying with my children; watching TV. Sometimes I've got a radio for the...I like the Gospel music played for the whole day...watching TV movies during the night it makes me very happy," [1:112]

"And I'm always busy of our crocheting...I know, I'm always crocheting something mats, like scarves and things; mats and doyleys...everything. I'm always keeping myself busy. I don't want just to stay...and think, I'm always doing something, you know? To keep you busy, not always thinking, thinking and thinking." [1:113]

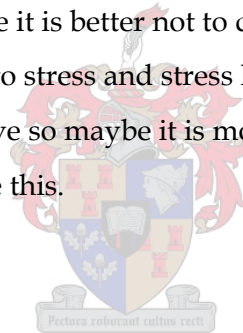
"Yes, it is very important to keep yourself busy! Not just sleeping on the bed all the time because if you are always sleeping...is the time you are also thinking a lot of things in your mind. All the things are coming back to your mind and start stressing you. You must always keep yourself busy doing something. Maybe crocheting, ah, maybe, ah, um, reading the books, you know? Its, um, very important not to just sit doing nothing." [1:114]

"I don't want to think much about this virus because it is a funny thing. The time you give it a chance, it just comes, and attacks you. So you can't give it a chance to attack you, it has this chance when you just sit and you just say what I'm going to do? Oooh...I'm...oh, no man! I'm HIV! Oooh no. When you keep yourself busy though that thing's not coming...coming in your

mind, you know and then you don't give HIV a chance to attack. So that is why I say that it's very important; keep always keep you busy. I've got a lot of things there at home. I've got mats, I've got bedspreads, I've got (cough) doyleys, I've got frames, always do something. I'm always doing something; I can't just stay and sleep for the whole day now. Don't like that, because I know I want to...always busy, you know? Don't want to just stay and think, it's very important." [1:115]

Memo:

N says she constantly tries to keep happy and then seems to almost define happiness as not thinking. For me, I wonder if this constant effort to keep busy is denial, or just that she has reached a stage of true acceptance and now wants to just move on with life. To constantly keep yourself busy, so that you don't think for myself is not necessarily the most healthy way of dealing with a problem but on the other hand, HIV is so strongly influenced by the mind that maybe it is better not to dwell on your sickness too much because as N says that then leads to stress and stress lowers your immune system anyway without being HIV positive so maybe it is more of a positive thing than I initially thought when she told me this.



Being a support to others	Because N has realised that she is the fighter of her life and she is the hero of her life, she is strong and brave and likes to help others who are HIV positive to get to that same place - in fact helping others to deal with their own HIV status is something she likes doing she said. N explains how she likes to advise anyone who is HIV positive and she likes to talk to others in her community about their HIV status.	131, 132
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Essence 25:

"So I've got a lot of experience (cough) about, ah, my...to look after myself even to advise anyone who is HIV positive, and I like to do this, I like to...to talk with the others in my community and they also comes to my house and say, 'How are you? How did you feel the day you were standing in front of us telling us that you are HIV?' I said...and they said 'Look at you, you are so beautiful and fat, you know? So that's why I need to talk to you, and then they will say "I am also HIV, but you are the first person I told you I am HIV" If I ask them why you come to tell me about you are HIV positive they say, "because I know you are HIV positive, and you are so brave because you stood in front of the community so I think I can talk to you", and then I tell them they must come to the support group." [1:131]

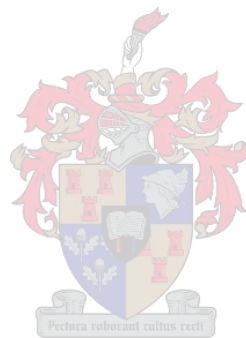
So it's been helpful to you to help other people as well?

"As well. Yes I like that. Yes" [1:132]

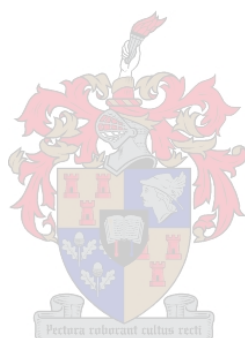
Memo:

N realises that life process that she has been through in her walk with HIV and the context in which it took place, has afforded her much experience in the whole area of HIV. She enjoys passing on the experience that she has had with others who are HIV positive. People come to her to disclose this status for the very first time and they trust her because they perceive her to be so brave and strong, it's almost like because she shared her status in front of the whole community she is a bit of a role model in the HIV arena. She tells them what she has learnt and that they must come to the support group -

why does she choose to mention this? Maybe because the support group has been one of her biggest forms of help in her personal process of acceptance.



APPENDIX G:
MAIN ESSENCES TABLE FROM INTERVIEW ONE WITH N.



	Essence	Definition	NMU
1.	Acknowledging HIV status	N is HIV positive she openly speaks about her status and seems to define herself to some extent by the fact that she is HIV positive.	6, 26
2.	Motherhood	Ns desire to be a good mother to her children is very linked into her own experience of being mothered- HIV has just robbed her of her ability to be the kind of mother she wished to be for her children.	8, 49, 50
3.	Desire to tell her family and be supported by them	When the doctor told her she was HIV positive she decided to tell her family.	9
4.	Rejection because of HIV status	When she told her family that she was HIV positive "things were changed" They chased her and her children away.	10, 11, 12, 13, 36, 37, 38, 39, 40, 44, 72, 73, 122, 123
5.	Continuing care for children	Because of Ns family's reaction to her HIV status she became very worried about her children's future.	14, 38, 49, 50, 143, 144
6.	Being cared for by children	HIV causes to some extent a role reversal in the mother/child relationship. N is now cared for by her children they are the nurturers and supporters of her rather than visa versa. N has learnt to be joyful in this care that her children give her rather than perceiving herself to be neglecting her mothering responsibilities.	74, 75, 76
7.	Financial constraint and assistance	Before she was diagnosed N did not have enough work, she had her children's school fees to worry about, rent to pay and food to buy. This was all emphasised because of her assumption that she was to die soon. But because N had become so sick she was helped by her doctor to access a disability grant and as well as a disability grant she also accessed further financial assistance as a HIV positive mother. All of this financial assistance meant that she felt better because she now has money to share with her children	15, 16, 17, 18, 19, 20, 96, 143, 144,
8.	Disclosing to the community	On the first of December 2002 N disclosed her status to the whole community; with Bishop Tutu there she became the "hero of the community" because she was so brave and strong.	22, 25, 29

	Essence	Definition	NMU
9.	Not talking is killing people with HIV	N places a strong emphasis on how talking has helped her to accept HIV, and that those who are not talking, who are just keeping HIV to themselves as a secret because they are scared of the reactions of others, are just getting sick very quickly and then dying.	23, 24 30, 31, 34, 90, 91, 92
10.	Living with HIV not dying - a future hope	At first N explains how she thought it was the end of her life and that she was going to die but slowly with time she accepts that she can live with HIV N knows that she is living with HIV she is not dying of HIV. She has realised (aided by support) that she is going to live for a long time and she has a future, and she can have a future hope and therefore be brave and strong.	51, 63, 128, 24, 27, 28, 52, 61, 86, 109, 121, 133
11.	A process of personal acceptance	N acknowledges that it is not easy to accept you have HIV, it takes a long time. She says that you are just thinking " <i>Lord you know everything</i> " but you still take long to accept the virus. Once you accept the virus, you have power.	32, 33, 62, 63, 85, 87, 89, 124, 133
12.	Accessing real family - the place of belonging and acceptance	Because of the reaction of Ns family to her, she was forced to find another family who would care for her and love her, who she could depend on to continue caring for her children, this family was her uncles family who throughout the rest of the interview she referred to as her "real family."	41, 42, 45, 46, 47, 80, 138
13.	A place to belong, share feelings with others who understand what it is to be HIV positive and learn to deal with HIV	The first day when N went to the support group, the ladies said " <i>come inside and sit down, take your jacket of because this is your home.</i> " Realising that there are others living with HIV was a great source of comfort to N. Learning how to take things out of her heart instead of keeping them inside her heart has been important to her.	54, 55, 56, 58, 81, 82, 83, 127, 128, 141, 68, 69
14.	Seeing others who are HIV positive	Realising that there are others living with HIV was a great source of comfort to N. She recalls seeing the ladies from Khayelitsha when they came to disclose this HIV status and she said, "They were so big and so beautiful and me, I am also going to be like that"	55, 127, 129
15.	Memory Box Project(M.B.P)	The ability to creatively express ones story is facilitated through the M.B.P	60, 66, 67, 130
16.	Information and Education reduces stress	N explains that the ladies from Khayelitsha came and taught her about HIV; being taught about HIV makes the stress less.	59, 62, 63, 110,

	Essence	Definition	NMU
17.	God, Prayer and the church	Ns life is centred around God it is very obvious that everything she has been through and her personal process of acceptance has been linked up into God, she explains that knowing God makes the stress become less <i>"to God you can talk your problems, you can open your heart and believe in Him then you can share things with Him"</i> she says. God has been a source of strength and hope and made her strong and brave.	64, 65, 120, 142, 134, 136, 137
18.	Practical care of community neighbours	Sometimes N explained, she does not feel well and then her neighbours always come into her house and say <i>"No we didn't see you this morning outside, what is wrong with you?"</i> They make tea and care for her. This aids her and makes her feel stress free because it makes her realise that even though her family rejects her she has a good family in her community.	77, 80, 139
19.	Practical care of her employer	N works as a char for a lady in Fish Hoek, who she disclosed her status to, she buys her tablets, vegetables and fruit and says <i>"you can use this... its make you very strong."</i>	78, 79
20.	Access to efficient health care facilities	N explains how when she was very sick she went to the clinic; she knew that she would be cared for by the sisters there. The sisters at the clinic sent her to the hospital for an X-ray to see if she had TB, there she got TB medication. She knows that there is always a doctor at the hospital who will see her even if it is every Wednesday and every Friday - If she does not feel well they will treat her and give her medication.	93, 94, 95
21.	Acceptance of HIV and accessing care and support has led to positive future orientated life decisions.	At the time that N accepted her HIV status, she says how she felt like she had power to make positive life decisions these included: <ul style="list-style-type: none"> • Caring for herself and her children. • Just saying with her children, with no boyfriend. • Living a new life. • Make her dreams come true. • Go to church. • Not sleeping with men because of the vulnerability of being female. • Not getting drunk anymore. 	99, 100, 102, 109, 126

	Essence	Definition	NMU
22.	I hate the men	N seems to harbour a real fear and hatred for men, she explains that she feels no pleasure with them anymore; she gets a bad feeling around them. She suggests that it could be because of the virus and she acknowledges that it is a problem. She has decided that it is not good for her to have a boyfriend because she feels that men have a lot of problems, and she is the basin into which a man will pour his problems of both a physical (because he could be HIV positive) and emotional nature.	102, 103, 104, 105, 108
23.	Busying yourself and thinking right	N explains how she always tries to keep herself happy, this happiness mostly includes being busy, so that she doesn't just sit and think and sleep. She says that HIV is a funny virus and the time you give it a chance to attack it will. When you keep yourself busy, she explains then the thought of "ooh man, I am HIV oo no" does not dominate your thoughts and then HIV is not given a chance to attack.	111, 112, 113, 114, 115
24.	The fighter of my life	Even when things are difficult, N says that she has become the fighter of her life, she doesn't lose hope, and she is strong and brave. This ability to be the fighter of her life or the hero of her life, she attributes to prayer, a future hope and the care she has received from many. She says that social support to her is all the things that have helped her to be the "hero of her life" and all the things that have helped her to be brave and strong.	116, 117, 118, 119, 120, 121, 121.5, 133, 134, 136
25.	Being a support to others	Because N has realised that she is the fighter of her life and she is the hero of her life, she is strong and brave and likes to help others who are HIV positive to get to that same place. Helping others to deal with their own HIV status is something she likes doing. N explains how she likes to advise anyone who is HIV positive and she likes to talk to others in her community about their HIV status.	131, 132

APPENDIX H:
FULL SUMMARY OF SOCIAL SUPPORT FOR INTERVIEW ONE
WITH N.

N is HIV positive. She is also a mother; the role that she has as a mother is part of the context in which her experience of social support takes place. Motherhood is a role that exists that allows room for interaction between mother and child and is therefore an essential aspect of Ns experience of social support. Motherhood is a role that demands of a woman that she be a carer and a nurturer. HIV now enters the lived experience of the HIV positive mother causing concern “ *I am the mother of children, and now I have the question who is going to look after my children*” [1:49] This was an especially painful question for N to think about because she herself lost her mother when she was five and so she knows the pain of growing up without a mother around, [1:8, 50] The realisation that she can not be the kind of support that she longed to be to her children is painful and worrying.

“*My big boy, he is 21 now, and he always comes to me everyday come said hello Mum, how you, how do you feel are you okay? I said no, its okay everything is good.*” [1:75] The lived experience of being supported, nurtured and cared for by your own children causes almost a switch in the dynamic of the mother child relationship and her children now become an vital aspect of Ns experience of social support. (*Qualities of the child-mother relationship that makes it so supportive*)

When N was diagnosed as being HIV positive she immediately decided to disclose to her family, she explains “*The day the doctor told me I’m HIV positive I decided to tell my family, so I go back to my home to my step mother and my sister and brothers*” [1:9] “*And I sit down and told them, but the things were changed*” [1:10] She explains how her family “*made the funny things even when I’m cooking some food, they didn’t eat it they just take the dishes and throw it away, they didn’t want even to like to use the washing basin, they just said no, no can’t use this basin because you are going to, you know, to make us very sick,*” [1:37] She refers to the rejection that she experienced from her family many times. This rejection was a painful facet of her experience of social support. She says they “*Looked at her with no love*”

[1:73] and the “made funny things to her” [1:37] For N her HIV diagnosis removed a family support structure that she assumed would be in place and she says that she “was feeling so hurt by them, because I thought they are my family I thought that they would always look after me when I’ve got a problem. At the time I told them they are just, didn’t accept me because now I have this thing. I – I was so angry about them.” [1:123] (Qualities that made it so non supportive)

Because of the reaction of Ns family to her, she was forced to find another family who would care for her a love her, who she could depend on to continue caring for her children she says “I’ve got another family in Khayelitsha it’s my, my fathers brother they come every time to support me,” [1:41]_“Uh, they, they you know when I am with them, they didn’t look like funny to me they always make me happy and said, no, don’t worry, everything is okay, we also love you, there’s nothing changed about you so we accept you, we know that you are living with this virus, but you are not sick and you are not going to die so you can make your dreams come true we are also watching at you and we love you they say to me every time.” [1:47] (Qualities that make it supportive)

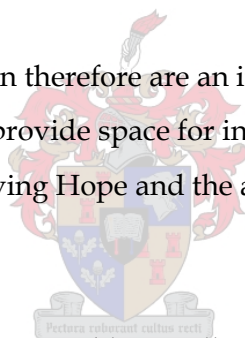
Another feature of Ns experience of social support is her support group. N was introduced to the support group by her cousin and she says that she was welcomed into this group and told “this is your home.” “It was really the first day I was feeling very, much better than before because when I saw no, it’s not me only living with this virus, there is a lot of others and they said, come inside, sit and take your jacket off, because this is your home,” [1:55] Ns support group has become a place of shelter, protection and a place where she belongs. (Qualities that make it supportive)

At her support group N describes how she felt really very much better because she saw that it is not only her living with this virus, there is a lot of others. This realisation that there are others living with HIV is very important in Ns experience of social support. She describes the importance of this by recalling when she saw ladies come from Khayelitsha she says “At the time I saw even the ladies came from Khayelitsha, they come and disclose here in Masiphumelele and I look at them: hau, they are so beautiful and big like that I said hau, no. And me also, I’m going to be like that if I can accept this virus you know. It was

that time I said, 'Oh, its okay.' And since then I always keep my mind busy, not to stay and think I'm HIV or what I'm going to do." [1:127]

N places a lot of emphasis on keeping her mind busy, and *"not just thinking about bad stuff" [1:111]* She explains *"I don't want to think much about this virus because it is a funny thing. The time you give it a chance, it just comes, and attacks you. So you can't give it a chance to attack you, it has this chance when you just sit and you just say what I'm going to do? Oooh...I'm...oh, no man! I'm HIV! Oooh no. When you keep yourself busy though that thing's not coming...coming in your mind, you know and then you don't give HIV a chance to attack. So that is why I say that it's very important; keep always keep you busy. I've got a lot of things there at home. I've got mats, I've got bedspreads, I've got doilies, I've got frames, always do something. I'm always doing something; I can't just stay and sleep for the whole day now. Don't like that, because I know I want to...always busy, you know? Don't want to just stay and think it's very important." [1:115]*

The activities that she is involved in therefore are an important feature of her experience of social support. These activities provide space for interaction between the people with whom she does the activities at Living Hope and the activities are instrumental in helping N to think positively.



N emphasises the importance of being able to talk about HIV. Sharing the secret with others has been significant in her experience of social support. She says *"and the other thing, it's very important to tell one of your family or your friend to talk to them to tell them, that you are HIV positive, because if you just keep it as a secret you are going to be stressed a lot and sick, it's better to talk about this every time just talking, talking, talking don't be scared you know, it's very important" [1:34]* She says that if you don't speak *"You don't have any power; not even any appetite...doesn't even eat something when you've got something inside. Just always sleepy on the bed...lying on the bed...nothing to do, you know? It's very, very important to share, not to keep the things inside." [1:92]*

Because of the meaning that N has placed on talking about HIV she decided to stand in front of her community and talk about her HIV. *"That day I told them many people are coming to me and they are saying you are the hero of the community because you are the first*

time to just stand in front of the community.” [1:29] N has felt it so important to share HIV with others that as part of her own experience of social support she describes helping others and encouraging others. She articulates that being a support to others has been helpful to her. Sharing and encouraging others creates an interaction that breaks into Ns lived experience of being HIV positive and is therefore an aspect of her own experience of social support.

A social support structure that is in place which encourages HIV positive individuals to tell their story is the Memory box project she explicates *“It helps us a lot who are H.I.V. positive, because the other people, they didn’t have the people to share their problems and if you, you, you have a memory box or memory book you can write all your stories or your um your problem down in your box or in your book and you can share that with others And then you can keep all your problems out of your mind.” [1:67]*

N has received a lot of practical care from community neighbours. She describe how *“The community neighbours also coming. Sometimes I’m just not feeling okay, but my neighbours always come into my house and I say “No we didn’t see you this morning outside, what is wrong with you?” I said “oh no I’m, I’m not feeling well” Then they say, okay we are going to make some tea; that makes me feel...I feel very, very, you know, stress free about that, because I know even my family are not here – they are in Khayelitsha...but I’ve good family here in Masiphumelele, like my neighbours and the community...if I am walking around they said ‘Hello!’ I said ‘Hi! ‘You know it’s OK; I like it that I am always friendly with everyone and they are friendly with me. There are a lot of people in Masiphumelele that knows I’m HIV they all say “Hello!’ and I say ‘Hi...hi girls...hi!’ y’know, so I like that.” [1:77]*

Not only has she received practical care from her neighbours, but she has also been cared for and supported by the lady in Fishoek that she is working for. She highlights this interaction as important in her experience of social support. *“So, and my...the lady in Fish Hoek I’m working for: I once told her I’m HIV. Hau. She always gives me lot of support.” [1:78] “She gives me some things. First she buy me some veggies; tins, everything to make me feel strong. She’s told me everything and sometimes she buys me some tablets at the chemist, and I*

use that tablets...she says "you can use this...make you very strong", so it's OK. Because of all these things I'm still very strong and brave." [1:79]

N has received information and education from various groups and people that has helped to reduce her stress. *"Some time after I joined the support group then that time there were ladies from eh Khayelitsha, they come teach us" [1:59] "Mm, the first thing they told me, they said that, if you don't accept this virus, this will be a big problem in your life, you must, you must accept this virus you must say, HIV you are my friend you just take it like that you are my friend, I can't just share anybody with you, it's you and me that is the first point you must know, they said and it's very important to your life" [1:62] "because it, it, it makes you a lot of stress if you think, ooh, I'm HIV, ooh God, I'm going to die, maybe tomorrow maybe tonight you know, it's always ringing in your mind, but the you must reach the time when you can accept it "you HIV and me, we are friends." [1:63]* Receiving this kind of education and information from others has been a critical aspect of Ns experience of social support.

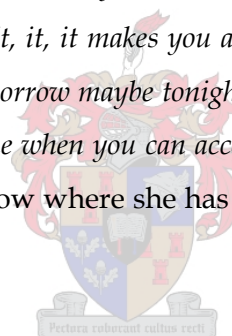
N highlights to me the importance of being able to access efficient health care facilities which are therefore a component of Ns experience of social support. *"I just go straight to my doctor. I've got my doctor there. Every, Wednesdays and Fridays Doctor S, she always looking at me; if I've got a problem I just go straight to her and told her I'm not feeling all right, and they give me something to help me." [1:95]*

Health care facilities are a structure that exists that creates room for interaction of a supportive nature. N highlights that the health care facilities she goes to are supportive. *(Qualities that make up efficient supportive health care)*

N explains that another thing that has been of great help to her is going to church, believing in God and praying very hard for her life. *"The other thing that made my stress go away is that I started going to church again, at church I share things to God. Talk of your problem, you can tell the problem to God, you can open your heart to God and God can help you, I believe in God." [1:64]* This faith aspect of support is something that she highlights in her experience of social support.

In the face of poverty HIV hits hardest. N's reality when she was diagnosed with HIV was that she had no real income. Immediately some of her major concerns were wrapped up in what am I going to do because I have no money? Since N was diagnosed with HIV she has become involved in income generating groups and she has been able to access a disability grant. This is an essential aspect of social support because interactions that she has had with others has led to her being able to access financial assistance.

Because of all of these interactions and forms of social support N is able to say "I am HIV positive" she is unashamed of her status because she has learnt with the help and care of others, to accept the fact that she is HIV positive. She says that it was not easy to accept the virus *"For a long time you are just thinking Lord you know everything but you still take long to accept you have to try when you are HIV to accept this virus this is a very important."* [1:33] She continues *"It, it, it makes you a lot of stress if you think, ooh, I'm HIV ooh God, I'm going to die, maybe tomorrow maybe tonight you know, it's always ringing in your mind, but the you must reach the time when you can accept it you HIV and me, we are friends."* [1:63] She has reached the point now where she has a future hope and she is *"living with HIV not dying."* [1:28]



Because she has learned not to lose hope and she is strong and she considers herself *"the fighter of her life"* [1:116] now she can look forward to her future. Because she has been able to accept her HIV due to the care and support she has received she has been able to make positive future orientated life decisions. She says that *"An important decision that I made after I accept that I am HIV positive is that I first thing I was decided to do when I know I am HIV positive, it was the time I decided to stay with my children without anybody in my life. I've got no boyfriend; just staying with my children because...when I was thinking about my life, I just said, ah, I'm living a new life now, so I must look after myself you know. So it was the time I decided to make my dreams comes true and to care about myself and my children's future and not to waste time looking after anything like boyfriends; nothing. I want to just stay at home with my children. Go to the church, and doing my things, you know. Because I realised its very, very important for me to look after myself and my children, not boyfriends or anything."* [1:99]

Many Black women are disempowered; they don't have enough work to generate an income for themselves and are therefore dependent on a boyfriend or a husband who can provide for them. Just a short while after N was diagnosed as being HIV positive, she accessed a few income generating things which led to her ability to start making decisions about her own life. HIV brings to reality the finiteness of life and has made N realise life is short so you might as well make the most of it. N starts to make decisions when she is diagnosed with HIV that are positive life decisions, they are decisions that are now important for her because they are what have been some of the most helpful things to her in the past two years.

Finally the role of men in N's experience of social support is important to note. She says that *"They...they are laughing at me one day when I...I...I'm talking about this at the...at the Living Hope. I said to them, 'Hey girls, I've got a problem. I HATE the men!' They were laughing and said, 'No...maybe it's still early because...eh...because of the virus. Maybe that when the times goes, you are going to be OK. I said, 'I don't think so.' They're laughing at me."* [1:105]

N wants nothing to do with men; she says that she is scared of them. Men must play some role in HIV positive women's experience of social support ranging from no support to supportive. For N she hates men and wants nothing to do with them.