

**Experiences and support needs of poverty-stricken
people living with HIV in the Potchefstroom district
in the North West Province**

ANITA FEITSMA

2005

**Potchefstroom Campus
North-West University**

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Bachelor's Degree in Nursing

This study is carried out within the following project: Health care provision to the HIV and AIDS patient in the North West Province in South Africa.

This mini-dissertation is submitted in partial fulfilment of the requirements for the degree Magister Curationis at the School of Nursing Science at the Potchefstroom Campus of the North-West University.

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Language editor:	Mrs. C. van der Walt

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Summary

The majority of the people living with HIV in the North West Province are part of households living in an unfavourable economic situation (Kotze, Roux & Wessels 2001:83). The AIDS pandemic has intensified their poverty situation even more, which is emphasized by Natrass (2004:150) in the following statement: 'The AIDS pandemic is both a cause and effect of poverty.' Adding to this, the majority of the poverty-stricken people living with HIV in the Potchefstroom district do not feel supported after having been diagnosed HIV positive (Pienaar, 2004:55-58). Once there is a clearer understanding of how South Africans experience living with HIV, counsellors, nurses and other health care workers will be better equipped to meet the needs of these people (Coetzee & Spangenberg 2003:216). Therefore, guidelines that can serve as useful tools for professional nurses and other health care workers, including volunteers, who are working with poverty-stricken people living with HIV, were developed in this study in order to address the gap in the support during the HIV infection.

The objective of this research was to explore the experience and to identify the support needs of poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district and to formulate guidelines for effective support for poverty-stricken people living with HIV. A qualitative, phenomenological design was used which enabled the researcher to understand the way in which poverty-stricken people experience living with HIV and to identify their support needs. In-depth interviews, consisting of 24 one-to-one interviews and one focus group were conducted to obtain the data.

The population studied in this research consisted of the poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district in the North West Province, South Africa. Purposive sampling was used to select participants with the assistance of mediators who are working for the Non Governmental Organisations dealing with HIV and AIDS in the Potchefstroom district. The sample size was determined by data saturation, which was reached after 25 interviews.

Data analysis was carried out simultaneously with data collection. In consensus discussions, the researcher and the co-coder reached consensus on the main and sub themes. From the research findings, six main themes were identified. The first two main themes are the facilitative and impeding experiences of poverty-stricken people living with HIV. The remaining four main themes include the needs of poverty-stricken people living with HIV, namely; basic needs, psycho-social needs, cultural-spiritual needs and self-actualisation needs.

It could be concluded that the experience of poverty-stricken people living with HIV in the Potchefstroom district is closely related to their support needs. In order to address these needs holistically and to enhance the quality of life of poverty-stricken people living with HIV, the needs should firstly be addressed individually and according to culture. Following that, the collective needs can be addressed by a support system addressing basic, psychosocial, cultural-spiritual and self-actualisation needs for which an experiences and needs framework and guidelines were formulated.

[Key words: HIV and AIDS, poverty, support, needs, experience, North West Province (South Africa), informal settlements]

Opsomming

Die meerderheid mense met MIV in die Noordwes Provinsie kom uit huishoudings wat in 'n ekonomies ongunstige situasie lewe (Kotze, Roux en Wessels 2001:83). Die Vigs-pandemie het hul toestand van armoede selfs vererger, wat deur Natrass (2004:150) in die volgende stelling benadruk word: 'The AIDS pandemic is both a cause and effect of poverty.' Hierbenewens voel die meerderheid armoedige mense met MIV in die Potchefstroom-distrik dat hulle nie ondersteun word nadat hulle as MIV-positief gediagnoseer is nie (Pienaar, 2004:55-58; Russell & Schneider, 2000:20). Eers wanneer daar duidelike begrip is vir wat Suid-Afrikaners wat MIV-positief is, ervaar, sal beraders, verpleegkundiges en ander gesondheidsorg-werkers beter toegerus wees om aan die behoeftes van hierdie mense te kan voldoen (Coetzee & Spangenberg, 2003:216). Daarom is in hierdie studie riglyne ontwikkel wat as bruikbare instrumente kan dien vir professionele verpleegkundiges en ander gesondheidsorg-werkers, insluitend vrywilligers, wat met armoedige mense met MIV werk met die doel om daadwerklik aandag te skenk aan die gebrek aan ondersteuning tydens MIV-infeksie.

Die doelwitte van hierdie navorsing was om die ervaring van armoedige mense met MIV in die informele nedersettings in die Potchefstroom-distrik te ondersoek en ook hul ondersteuningsbehoefte te identifiseer en om riglyne vir doeltreffende ondersteuning aan armoedige mense met MIV te formuleer. 'n Kwalitatiewe fenomenologiese ontwerp is gebruik wat die navorser in staat gestel het om die wyse waarop armoedige mense dit ervaar om MIV te hê, te verstaan en om hul ondersteuningsbehoefte te kan identifiseer. Met die oog daarop om die data te bekom is indiepte individuele onderhoude asook een fokusgroep-onderhoud gevoer.

Die populasie wat in hierdie navorsing bestudeer is, het bestaan uit die armoedige mense met MIV in die informele nedersettings in die Potchefstroom-distrik in die Noordwes Provinsie, Suid-Afrika. Doelbewuste steekproefneming is toegepas om deelnemers te selekteer met die hulp van tussengangers wat vir die Nieregeringsorganisasies werk wat te make het met MIV en Vigs in die Potchefstroom-distrik. Die steekproefgrootte is bepaal deur middel van dataversadiging wat na 25 onderhoude bereik is.

Data-analise is gelyktydig met data-insameling uitgevoer. Tydens konsensusgesprekke het die navorser en die medekodeerder konsensus bereik met betrekking tot die hoof- en subtemas. Uit die navorsingsbevindings is ses hoofemas geïdentifiseer. Die eerste twee hoofemas is die fasiliterende en belemmerende ervaring van armoedige mense met MIV. Die oorblywende vier hoofemas sluit die behoeftes van armoedige mense met MIV in; basiese behoeftes, psigososiale behoeftes, kultureel-geestelike behoeftes en selfverwesenlikings-behoeftes.

Die gevolgtrekking kan gemaak word dat die ervaring van armoedige mense met MIV in die Potchefstroom-distrik nou verwant is aan hul ondersteuningsbehoeftes. Om hierdie behoeftes holisties onder die loep te kan neem, en om die lewensgehalte van armoedige mense met MIV te kan verbeter, behoort hul behoeftes eerstens individueel en ooreenkomstig hul kultuur aandag te geniet. Daarna kan die kollektiewe behoeftes hanteer word deur middel van 'n ondersteuningstelsel wat basiese, psigososiale, kultureel-geestelike en selfverwesenlikings-behoeftes in ag neem, waarvoor 'n ervarings- en behoeftesraamwerk en riglyne geformuleer is.

[Sleutelwoorde: MIV en Vigs, armoede, ondersteuning, behoeftes, ervaring, Noordwes Provinsie (Suid-Afrika), informele nedersettings]

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1. Overview of the study

1.1 INTRODUCTION AND PROBLEM STATEMENT

The AIDS pandemic in Sub-Saharan Africa not only is a major health crisis, but also an enormous socio-economic threat to the population (Nattrass, 2004:13). In 2003, an estimated 26.6 million people were living with HIV in Sub-Saharan Africa. This is almost 70% of the total number of HIV-infected people in the world (UNAIDS, 2003). What makes the AIDS pandemic in Sub-Saharan Africa more tragic, is that the largest number of HIV-infected people in the world are living in this region, although it is the least equipped region in the world to deal with the AIDS problem (Poku, 2001:191). Partly because of the low access to care, lack of financial and logistical means and the noticeable macro-economic impact that AIDS has in Sub-Saharan Africa, HIV-prevalence is still rising (Report National HIV and Syphilis Sero-Prevalence Survey, 2000; UNAIDS, 2003).

South Africa, which is part of the Sub-Saharan African region, has the highest number of HIV-infected people in the world; more than 5 million people are living with HIV and AIDS and deaths due to AIDS are expected to rise sharply until 2010 (UNAIDS, 2003:19; Nattrass, 2004:13). In the North West Province, HIV prevalence was 29,9% in 2003 (Makubalo, *et al.*, 2004). The HIV/AIDS and STD Strategic Plan for South Africa (2000-2005) clearly indicates that the HIV pandemic is severely affecting the young, black and economically poor populations of South Africa (Kotze, Roux & Wessels, 2001:73). In the same article, it is argued that the majority of the people living with HIV in the North West Province are part of households living in an unfavourable economic situation and the AIDS pandemic has made their poverty situation even worse. Nattrass (2004:150) emphasizes this fact in the following statement: 'The AIDS pandemic is both a cause and effect of poverty.'

In a speech at the 13th International AIDS Conference in Durban in 2000, President Thabo Mbeki stated that poverty is causing AIDS (Mbeki, 2000). This speech was criticised because of the fact that no concrete strategies were offered to combat HIV (Garrett & Susman, 2000). Phatlane (2003:77) also criticises the speech stating that it is a little too easy and simplistic to regard AIDS as a disease only of the poor, and furthermore Nattrass (2004:34) states that reducing poverty alone cannot solve the

AIDS problem. Fact is though that poverty is driving and fuelling the AIDS pandemic (Natrass 2004:34).

Poverty-stricken people are more severely affected by HIV and AIDS for several reasons. The main reasons are that poor people have a lower level of human and financial resources, such as a lower level of education and a low income (Poku, 2001:195). In the North West Province, 40 per cent of the black population is living below the poverty line (Serumaga-Zake & Naudé, 2002:564). Furthermore, poor people generally have a poor health status (Poku, 2001:195). The lack of human and financial resources causing a lower level of education, results in a lower knowledge level concerning health matters, including HIV and AIDS, and a poor health status results in a higher vulnerability to ill health (Phatlane, 2003:78). Impoverished people are also less likely to seek adequate health care and to participate in HIV and AIDS preventive programmes than richer people (Booyesen, 2003:420; Phatlane, 2003:78). In addition to the fact that poor families are more severely affected by the HIV pandemic, they have less capacity to deal with morbidity and mortality (Poku, 2001:196). The loss of a family member due to AIDS results in broken and traumatized families and a loss of income. As a result, poor families affected by AIDS are more socially and financially dependent on the community (Gaffeo, 2003:34). Furthermore, stigmatisation often destroys their community safety networks. Reading the above, it becomes clear how difficult it is to be poor and live with a chronic, terminal and stigmatised disease such as HIV and AIDS without the social and economic support of the surrounding community.

Serumaga-Zake and Naudé (2002:570) found that the number of poor people and the extent of poverty among poor people are higher in the North West Province than in South Africa on average. Considering the above statements and the high HIV-prevalence in the North West Province, the conclusion can be made that there is a need to explore the experience and to identify the support needs for the poverty-stricken people living with HIV in the North West Province in order to assist these people and to enhance their quality of life.

The informal settlements in the townships in the Potchefstroom district in the North West Province are the setting for this research. In these townships, people affected by HIV indicated a gap in the support after having been diagnosed HIV positive (Pienaar, 2004:55-58). Support for people who are living with HIV implies assisting them in handling their HIV infection (Uys, 2002:101). According to Uys (2002:101), support consists of various aspects, such as, emotional, psychological and social support, which is given by counselling, but also physical, material and practical support, depending on the needs of the supported person. For purposes of this project, support is initially interpreted in this wide context, since the more specific needs of support will be explored and described in the course of the study. Pienaar (2004:2-3) states that there is support for the patients before and shortly after the HIV test by means of counselling, but there is minimal continuation in the form of follow-up counselling and other types of support such as support groups or practical support.

The needs of support that poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district have after they are diagnosed HIV positive are not known (Pienaar, 2004:4). Currently, the support mainly consists of home-based care, which only commences when people living with HIV develop physical symptoms (Russell & Schneider, 2000:20). Counselling is carried out predominantly by voluntary lay counsellors who have had limited counselling training and do not have a formal qualification in counselling (Pienaar, 2004:10). In conversations with people in the Potchefstroom district, it was found that the support given by these voluntary lay counsellors is mainly information driven and does not really focus on the individual needs of the people. It tends more towards health education than counselling and it does not include referrals to a multidisciplinary team, which could provide physical and practical support or support from a traditional healer (Pienaar, 2004:5-6).

Various researchers confirm the need that HIV positive patients have for follow-up support after post-test counselling (Coetzee & Spangenberg, 2003:216; Eichler, 2002:945; Green & McCreaner, 1996:260; Van Dyk, 2003:4). Because HIV and AIDS represent a major life crisis being a stigmatised, progressive and chronic disease, support after the HIV diagnosis is of major importance when assisting HIV patients in handling the stress they encounter (Coetzee & Spangenberg, 2003:206-207; Uys & Cameron, 2003: 163). Russell and Schneider (2000:49) describe the overall experience of people living with HIV and AIDS as that of deepening poverty,

isolation, inability to satisfy basic needs such as food and shelter, and rejection by communities and formal services. In their research, they found that patients who participated in care and support programmes experienced clear benefits such as being able to disclose their status and overcome isolation and despair.

Coetzee and Spangenberg (2003:214) stress the fact that there is a lack of research on how South Africans handle living with HIV and AIDS. The main purpose of conducting research in this area is that once there is a clearer understanding of how South Africans experience living with HIV, counsellors, nurses and other health care workers will be better equipped to meet the needs of these people (Coetzee & Spangenberg, 2003:216). The focus of this research is to develop guidelines to address the gap in the support during the HIV infection. Russell and Schneider (2000:20) identify the same gap in the support during the HIV infection in their research. They state that there are not enough support programmes available in South Africa for people after having been diagnosed HIV positive and that there is a lack of guidelines and programme standards in the existing programmes. Van Dyk (2003:9) states that it will be expected from nurses to form the backbone of the HIV and AIDS support services. This is supported by Uys (2002:108) who found that community caregivers, such as voluntary lay counsellors, have proven themselves effective and efficient under the supervision of registered nurses. This supports the relevance of this research project for the nursing discipline.

The researcher has spent some time in the informal settlements in the Potchefstroom district as part of the preparation for her research and confirmed what is stated in the above argumentation; the majority of the poverty-stricken people living with HIV do not feel supported after they are diagnosed HIV positive. This results in the following research problem: 'Poverty-stricken people living with HIV in the Potchefstroom district utter a gap in the support after they are diagnosed HIV positive.' In order to target this problem, the following research questions are answered in the course of this research project:

Research questions

1. How do poverty-stricken people in the informal settlements in the Potchefstroom district experience living with HIV?
2. What do people living with HIV need to feel supported?
3. What can be done to address these needs?

1.2. RESEARCH OBJECTIVES

1. To explore and describe the experience of poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district.
2. To explore and describe the needs of poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district to feel supported.
3. To formulate guidelines for support in order to assist poverty-stricken people living with HIV and to enhance their quality of life.

1.3 PARADIGMATIC PERSPECTIVE

The paradigmatic perspective describes the way in which the researcher views the research material (De Vos, 2003:45). It consists of metatheoretical, theoretical and methodological assumptions as defined by Botes (1995:9). These assumptions are described below.

1.3.1 Metatheoretical statements

Metatheoretical statements are not verifiable and describe the researcher's assumptions about human beings and society (Botes, 1995:9). In this research, the metatheoretical assumptions are based upon the holistic approach because this approach is congruent with the researcher's own philosophy. Holism implies that the whole is bigger than the sum of the parts and that human beings are holistic persons with interacting biological, psychological, social and cognitive subsystems (George, 2002:472).

Guided by the holistic philosophy, the following metatheoretical statements are defined within the researcher's view: person, health, illness, environment and nursing.

1.3.1.1 Person

The researcher's definition of a person corresponds with the following statement; a person is a unique and holistic being with interacting biological, psychological, social and cognitive subsystems (George, 2002:472). Furthermore, the researcher considers every person as having unique characteristics and deserving a fair treatment and an unbiased approach.

The poverty-stricken people living with HIV, who are living in the informal settlements in the Potchefstroom district are viewed uniquely and holistically and in constant interaction with their community. They are referred to as 'he', 'him' and 'his' although the participants can be both male and female.

1.3.1.2 Health

According to the researcher's view, health is not the absence of illness, but a condition of physical and psychological well-being. Since persons are holistic beings, the physical health condition cannot be viewed without the psychological health condition and vice versa. According to Leininger (1991:20), every culture has its own specific way of defining, valuing and practising the state of well-being. This is consistent with the researcher's view and therefore the view of the participating population on health is valued in this research.

The focus on physical and psychological well-being and on the cultural aspect of health is important in this study. People living with HIV in the informal settlements in the Potchefstroom district may not show physical symptoms after they have been diagnosed HIV positive, but can be far from a state of well-being because of the psychological stress that is caused by the disease.

1.3.1.3 Illness

The researcher defines illness as a state of physical and/or psychological discomfort due to internal or external influences which an individual is exposed to.

The focus of this study is on the phase after people have been diagnosed HIV positive when physical HIV related symptoms are not likely to be present. Therefore, the focus on the psychological part of illness may be higher than the focus on the physical aspect of illness, but both the psychological and physical aspects are addressed in congruence with the holistic approach.

1.3.1.4 Environment

Human beings are continuously in interaction with and influenced by their internal and external environment. According to the researcher, the internal environment includes the psychological and physical aspects of a person's life while the external environment contains the physical environment, social interactions and the community in which a person lives. The researcher aims to be aware of the fact that the diversity of South Africa's cultures results in a variety of religions and worldviews which influence a person's internal as well as external environment (Mannikam, 1991:69).

This research project is focused on both the internal and the external environment, because the thoughts of poverty-stricken people living with HIV about their experiences and needs to feel supported are shaped within the internal environment and highly influenced by the external environment. The poverty-stricken people living with HIV are depending on their environment and African people generally have a strong community sense. Therefore, the external environment is particularly addressed during this study.

The external environment in this study consists of the community that is living in the informal settlements in the townships in the Potchefstroom district. The informal settlements mainly consist of small houses or shelters which are built out of corrugated iron. This community forms part of the South African population that is influenced by international and national policies, such as the Health Sector Strategic Framework (1999-2004) for South Africa. One of the goals of this framework is to deal decisively with the HIV and AIDS epidemic (Department of Health, 1999:3-22). In the same framework, increasing the use of community and home based care and strengthening the support and referral systems for patients and their caregivers is mentioned as a strategy to achieve this goal. This framework, among others, influences the external environment which the participants are exposed to, and therefore the researcher is aware of these influences during the research project.

1.3.1.5 Nursing

The researcher defines nursing as a service focused on the use of therapeutic interventions to promote health, to prevent and treat illness and to alleviate suffering. In order to fulfil this service, a nurse has to be able to carry out different roles, such as the role of a supervisor, leader, facilitator, consultant and manager. The service should not only be focused on the individual, but should also involve the individual's family and the community and culture in which the individual lives.

In this research project, the focus is on the supervising role in nursing, since it is expected from nurses to form the backbone of the HIV and AIDS support services by supervising voluntary lay counsellors as was mentioned in the introduction (Van Dyk, 2003:9). The research project starts with an exploration of the experiences and the needs of poverty-stricken people living with HIV to feel supported. Once it is clear what these experiences and needs are, guidelines are formulated and at this point, the role of the registered nurse steps in. He or she will be responsible for supervising the implementation of these guidelines to ensure that the guidelines are used efficiently and can help voluntary lay counsellors to assist poverty-stricken people living with HIV and to enhance their quality of life in a manner that is in accordance with their culture.

1.3.2 Theoretical statement

The theoretical statement includes the central theoretical argument and the conceptualisation of the key concepts in this research project, which are described below (Botes, 1995:9). They are based on scientific knowledge and existing theories within the body of knowledge in the nursing discipline as well as related disciplines.

1.3.2.1 Central theoretical argument

Exploring and describing the experience of poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district and exploring and describing their need for support will contribute to formulating guidelines for support in order to assist these people and to enhance their quality of life.

1.3.2.2 Conceptual definitions

The Cultural Care Diversity and Universality theory of Leininger (1991) is used as a guide for the definition of the core concepts in this research because of its congruency with the holistic approach and its applicability to this research. In her Cultural Care Diversity and Universality theory, Leininger states that nurses should have an open appreciation of different cultures because expressions, processes and patterns of caring vary among cultures (George, 2002:502). Considering the importance of the knowledge of culture in HIV and AIDS counselling, which Pienaar (2004) stresses in his research, this theory offers a relevant perspective for my role as a researcher in this research project. The following key concepts are defined within the context of this study;

HIV and AIDS

The acronym AIDS stands for Acquired Immune Deficiency Syndrome (Van Dyk, 2003:4). It is caused by the Human Immunodeficiency Virus or HIV. The HIV virus is highly concentrated in blood, semen and vaginal fluids and it is primarily transmitted through sexual intercourse, mother to child transmission and injected drug use (Van Dyk, 2003:19, 25). AIDS is the final stage of the HIV infection, also called full-blown AIDS (Van Dyk, 2003:40). In this stage, the symptoms of the HIV infection become more acute and untreatable opportunistic infections and cancers begin to manifest. Once people have developed AIDS, they usually die within two years if they are not taking anti-retroviral therapy.

According to Van Dyk (2003:36), the HIV infection cannot be divided into separate phases precisely because they overlap, but a theoretical distinction can be made as follows:

1. the primary HIV infection phase
2. the asymptomatic latent phase
3. the minor symptomatic phase
4. the major symptomatic phase and opportunistic diseases
5. AIDS-defining conditions: the severe symptomatic phase.

This research project is focused on the phase after people have been diagnosed HIV positive; this would include the first two phases as defined by Van Dyk (2003:36). In this phase of the HIV infection, people are not likely to experience any physical HIV related symptoms yet, but it is characterised by psychological symptoms (Van Dyk,

2003:37). The virus remains active in the body during this stage and continues damaging the immune system. This phase can take 1 year up to 10 or more years, depending on the person's life style, health condition and health care seeking behaviour.

Poverty

Poverty can be described as the situation of a low level of human and financial resources, such as low levels of education with an associated low level of literacy, generally poor health status and, as a result, low productivity (Poku, 2001:195). Poor households typically have few financial means and are often restricted politically and socially which leads to coping mechanisms that are likely to expose people to risky sexual behaviours and thus to HIV and AIDS. Evidence from demographic and health surveys in Southern Africa indicate a strong connection between poverty and vulnerability to HIV (Nattrass, 2004:29). Nattrass (2004:150) states that the AIDS epidemic is both a cause and effect of poverty.

In the North West Province, 40% of the black population is living below the poverty line and the poverty gap ratio, which implies the total shortfall of an individual welfare below the poverty line, was twice as high as the South African average in 2002 (Serumaga-Zake & Naudé, 2002:564, 570). Within the North West Province, higher levels of education are associated with lower levels of poverty and larger households have a higher probability of being poor (Serumaga-Zake & Naudé, 2002:570). These poverty-stricken households are more affected by HIV and AIDS, which also is the case in the North West Province where, as mentioned before, the majority of the people living with HIV is part of households living in an unfavourable economic situation (Kotze, Roux & Wessels, 2001:73).

In this study, the term poverty-stricken refers to the poorest people under the poor who are mainly living in the informal settlements in the Potchefstroom district, because they do not have the resources to pay for residence in the formal part of the township.

Support

Support refers to assisting people in handling difficult life situations such as HIV infection. This implies the communication between an HIV positive person and a person who has the strengths and possibilities to productively manage the situation a person living with HIV is in. The assistance can consist of various types of support, such as physical, emotional, social, spiritual, material and practical support, depending on the needs of the supported person (Uys, 2003:101). Physical support for instance, such as relaxation training, meditation or massage, may improve the quality of life during difficult times (Department of Health, 2003:18). Others find spiritual guidance a meaningful and comforting way of support and many people living with HIV need this in addition to other types of support.

The various types of support a person living with HIV may need, can be provided by a support system in which the different types of support and/or referrals to these types of support are present. Russell and Schneider (2000:18) point out that people living with HIV who participate in a support system have expressed the importance and healing effect of being able to share and meet with others. An important part of such a support system is a support group which consist of HIV positive people who meet on a regular basis to talk about their difficulties or simply to relax and enjoy each other's company (Van Dyk, 2003:251). Next to that, they can support one another in emotional, spiritual, physical and psychological aspects of daily living and functioning (Department of Health, 2003:20). However, support groups should no be seen as a substitute for other support interventions. Therefore, referrals to a multidisciplinary team, which can provide physical, social, spiritual, material or practical support and referrals to the formal health sector are important to encounter the different needs of the people living with HIV are essential within a support system (Pienaar, 2004:2-3; Uys, 2003:50). In this study, support is initially interpreted in the wide context that is described above, since the more specific needs of support are explored and described in the course of the study.

Experience

Poverty-stricken people living with HIV have a specific way in which they experience being HIV positive. They have certain thoughts and feelings about their disease resulting in certain needs to feel supported. Therefore, the first objective of this research is to explore and describe the experience of poverty-stricken people living with HIV in order to discover their need to feel supported.

Needs

A need can be described as the discrepancy between what people desire and what people actually have (Klopper, 2000:75). Poverty-stricken people living with HIV have certain needs to be able to live a quality life, which is consistent with their view. Every person has equal basic needs such as being loved by other people, nutrition and comfort. People living with HIV who are studied in this research have these basic needs, but they also have very specific needs in order to be able to cope with their disease. It is essential that these needs are addressed holistically in this study, taking all the different needs poverty-stricken people living with HIV have into consideration.

Counselling

According to Johnson (quoted by Van Dyk, 2003:200) counselling is: 'a structured conversation aimed at facilitating a client's quality of life in the face of adversity'. The World Health Organisation (1990) defines HIV and AIDS counselling as: 'an ongoing dialogue and relationship between a client/patient and a counsellor with the aims of: (1) preventing transmission of HIV infection and (2) providing psychosocial support to those already affected'. In this research, counselling forms part of the support that is given to poverty-stricken people living with HIV, and the way in which the participants experience the counselling activities is addressed.

Voluntary lay counsellors

Voluntary lay counsellors are counsellors with limited counselling training who do not have a formal qualification in counselling. They normally work under the supervision of professional counsellors (Pienaar, 2004:10; Uys, 2002:100).

Potchefstroom district

The Potchefstroom district is situated 115 kilometres southwest of Johannesburg in the North West Province, one of the nine provinces of South Africa (Dikeni, 2002:1).

Informal settlements

Abbot *et al.* (2001:iv) define the term informal settlement as the occupation of land in the absence of (1) legal rights to land, (2) official approval of land use and (3) provision of infrastructure. The land is either occupied through individual action or organised collective action. The informal settlements in the Potchefstroom district are the setting of this research.

1.3.3 Methodological statements

The methodological dimension of research implies the manner in which scientific research should be planned, structured and carried out in order to comply with the demands of science (Mouton & Marais, 1996:16). Methodological assumptions ensure the validity of the research and provide a framework for the research objectives and the research context, which both influence decisions concerning the research design (Botes, 1995:3-9).

Burns and Grove (2001:4) define nursing research as “a scientific process that validates and refines existing knowledge and generates new knowledge that directly and indirectly influences nursing practice”. This research project contains the characteristics of a scientific process by using a systematic approach (Brink, 2002:8). The researcher moves through certain steps in a specific order according to a predetermined plan of action. By exploring and describing the experiences and needs of support of poverty-stricken people living with HIV, new knowledge concerning these experiences and needs can lead to the formulation of guidelines in order to assist these people in handling their HIV infection and to enhance their quality of life. This influences nursing practice, which forms the research area and in this research includes the informal settlements in the townships in the Potchefstroom district, directly and indirectly. Poverty-stricken people living with HIV in this district uttered a gap in the support after having been diagnosed HIV positive, which determines the research problem of this project. Once there is a clearer understanding of how these people experience living with HIV, nurses and other health care workers will be better equipped to meet the needs of these people.

The holistic perspective and Leininger's Cultural Care Diversity and Universality theory (1991) have shaped the metatheoretical and theoretical statements in this study to ensure that this research project is based upon applicable scientific knowledge.

1.4 RESEARCH DESIGN AND METHOD

1.4.1 Research design

The design of this research project was qualitative, considering the fact that it focused on the exploration and description of the experience of people living with HIV (Burns & Grove, 2001:28). Because the goal of this research project was to understand the way in which people experience living with HIV and to identify their need for support, the method was phenomenological (Burns & Grove, 2001:31; Morse, 1995:22). The experiences and interpretations were finally condensed to a central meaning or the common essence of the experiences, which is the ultimate purpose of phenomenological research (Brink, 2001:119; Fouché & Delport, 2003:273; Kvale, 1983:184; Morse, 1995:22). This could be applied to the practice by formulating guidelines for support for poverty-stricken people living with HIV in order to assist these people and to enhance their quality of life.

Exploring and describing experiences involves doing a survey among people who have had practical experience of the studied phenomenon, and providing a reflection of this experience within its practical context (Mouton & Marais, 1992:44). The experiences are studied from the viewpoint of the participants and through their descriptions of these experiences within their specific context (Brink, 2002:119). Therefore, the practical context in this study was captured in its entirety, instead of attempting to control the research context (Brink, 2002:13).

Mouton and Marais (1992:91-92) define research context as the area, time, culture and the individual or community's orientation with regard to the circumstances in which the research takes place. The poverty-stricken people living with HIV in the Potchefstroom district in the North West Province of South Africa uttered a lack of support after having been diagnosed HIV-positive. The majority of these people lives in the informal settlements of the Potchefstroom district, therefore this was chosen as the research area. The informal settlements within the townships Ikageng, Promosa and Mohadin were chosen for this study specifically because they are home to the poorest people in the Potchefstroom district who are addressed in this research. In these informal settlements, people usually live in shelters which are built out of corrugated iron. The researcher spent time within the research context regularly the whole year during which the research took place.

The predominant ethnic group within these informal settlements is the Batswana population, but people from the Xhosa, Sotho and Zulu population are also present in the research area. The views on health and illness and the norms and values of these different cultural groups were taken into consideration during the interviews and data analysis.

The community living in the informal settlements of Ikageng, Promosa and Mohadin is severely affected by the AIDS pandemic; these informal settlements are part of the North-West Province where the HIV prevalence was 29,9% in 2003 (Makubalo *et al.*, 2004). The poorest people who are living in these informal settlements form part of the population that is most severely affected by HIV and AIDS. In the North West Province, including the Potchefstroom district, 40% of the black population is living below the poverty line and the number of poor people and the extent of poverty among poor people are higher than in South Africa on average (Serumaga-Zake & Naudé, 2002:564-570). These facts result in a community that is affected by poverty and the AIDS pandemic which are influencing one another. The HI-virus is not only causing HIV-infected individuals but also a HIV-affected surrounding community. Infected individuals all belong to households resulting in a large part of the community that is affected by the AIDS pandemic in some way or another (Booyesen, 2003:420). HIV-positive people are mostly cared for by their family members, which often leads to psychosocial distress within the family (Poku, 2001:196). Furthermore, the eventual death of a family member due to AIDS has a significant impact on the family (Booyens, 2003:420). In conclusion, the circumstances in which the research took place were those of poverty and the severe impact of the HI-virus

1.4.2 Research process

In this paragraph, a detailed discussion of the research process within this study is provided which serves as a guide for the research. The sampling method, data collection and analysing and the role of the researcher are described in detail.

1.4.2.1 Population

The population studied in this research consisted of the poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district in the North West Province.

1.4.2.2 Sampling method

Purposive sampling was used to select participants who complied with the sample criteria mentioned below, and who voluntarily agreed to participate. This involved the conscious selection of participants who are typical or representative of the studied phenomenon (Brink, 2002: 141; Burns & Grove, 2001:376). In this way, the understanding of the experiences and needs of the participants was increased because the participants who are dealing with these experiences and needs themselves were selected (Burns & Grove, 2001:376). The sampling was carried out with the assistance of mediators who are working for the Non Governmental Organisations (NGOs) dealing with HIV and AIDS in the Potchefstroom district and who are well known to the poverty-stricken people living with HIV. In this way, the selected sample was more representative of the population because the mediators are part of the support system for people living with HIV. The participants had to comply with the following criteria for inclusion:

Criteria:

They had to:

- be living with HIV;
- form part of the poverty stricken population in the informal settlements of Ikageng, Promosa or Mohadin;
- give consent to participate in the study and agree with the recording of the interviews;
- be able to communicate in Setswana or English.

The mediators were approached by asking for their assistance in the selection of participants in a letter in which the objectives of the research and the sampling criteria were explained (Annex E). When they agreed to participate, a list of participants was obtained and the researcher made sure that these participants met the criteria for inclusion in this study.

When the participants were selected, they were given information concerning the research and on what was expected from them as participants (Annex F). This information provided an explanation of the objectives of the research and ways in which confidentiality was ensured. It also stressed that the interviews were recorded and it included the fact that participation was fully voluntary (Brink, 2002). Having ensured that the participants understood this information, which was checked by asking the participants questions about this information, they were requested to sign a consent form (Annex G).

1.4.2.3 Sample size

The sample size, which is the number of participants who are selected from the population, was determined by data saturation (Morse, 1994:285). The process of purposive sampling in this study continued until a sufficient amount of data of the studied population had been obtained to be able to draw valid conclusions, and new participants were interviewed until no new themes were reported (Rossouw, 2003:113). This implied that interviewing new participants continued until the experiences and needs for support of poverty-stricken people living with HIV were totally clear and a pattern in the data became evident.

1.4.3 Data collection

1.4.3.1 Method of data collection

Data was collected by in-depth interviews that were guided by two central questions. Experts in qualitative research were consulted to validate these questions and a trial run was undertaken to test the questions. The interviews were neither a free conversation nor a highly structured interview; they can be regarded as a 'conversation with a purpose' (Brink, 2002:158; Greeff, 2003:298; Kvale, 1983:174). The purpose was to understand the experience of people and their views on that experience (Greeff, 2003:298).

The interviews were predominantly guided by open-ended questions. Additionally, probe follow-ups were used in order to get the participants to open up and express their experiences and needs (Greeff, 2003:301). When the participants did not express their experiences clearly, they were asked to explain and elaborate on these experiences and the researcher made sure that the participant focused on issues at hand and did not elaborate on irrelevant topics. When 'thin' areas were recognised, the researcher probed for additional information (Greeff, 2003:301). During the interviews, the researcher tried to 'get inside the participant's skin' by fully concentrating on what the participant said in order to capture the experiences from the participant's perspective. Towards the end of the interview, the researcher summarized the major issues and asked whether the participant had any questions. The researcher also made clear that the participant could contact the researcher after the interview when the participant felt the need to do so. The interviews were recorded on a MP3 voice recorder. This is a new technology which records people's voices very clearly, even if background noise is present. The data can be saved on a computer directly from the voice recorder.

1.4.3.2 Trial run

A trial run interview was conducted at the School of Nursing Science in order to evaluate the researcher's interviewing skills and to test the practical aspects of the interviews. After this, a trial run took place within the field, which allowed the researcher to determine whether the relevant data could be obtained from the participants (Strydom & Delpont, 2003:337). It also provided the researcher with practical information on the necessary arrangements and adjustments that were needed to carry out the succeeding interviews effectively. Once the researcher was convinced that the relevant data could be obtained and that the needed interviewing skills were mastered, the interviewing started.

The interviewing procedure, which was tested during the trial run, was as follows:

- The researcher arranged an appointment with the participant, which was confirmed the day before the interview. She arrived at the NGO where the interview took place at the arranged time and was dressed appropriately (Burns & Grove, 2001:421).

- The researcher introduced herself to the participant and clarified what was expected from the participant as explained in the informed consent form. The participant was reminded of the fact that confidentiality was ensured and that the participant should feel free to express his or her ideas.
- When the researcher had confirmed that the participant was ready, the voice recorder was switched on and the interview commenced.
- After approximately one hour, the researcher guided the conversation towards the end by summarizing the most important aspects of the interview and by asking the participant whether he/she had any questions.
- The researcher thanked the participant for his or her assistance in the research and switched off the voice recorder.

After testing this procedure, it was adjusted where necessary and then applied to all interviews. To encourage the participants to open up and express their experiences of living with HIV and their needs of support, the researcher applied verbal as well as non-verbal communication skills. The non-verbal communication skills consisted of an open body language, conveying interest by nodding the head, sitting forward, and maintaining eye contact where culturally appropriate (Rossouw, 2003:144).

The following verbal communication skills were used:

- *Listening*: the participant should be encouraged to do 90% of the talking, therefore listening is a very necessary skill which the researcher applied accurately (Greeff, 2003:293, 295). Non-verbal communication skills and minimal verbal responses such as 'mm-mm' and 'aha' were applied to show the participant that the researcher was listening (Greeff, 2003:294);
- *Clarifying*: this skill was used to get clarification on statements of the participant which were unclear to the researcher (Greeff, 2003:295);
- *Probing*: to stimulate the participant to elaborate on certain issues that were discussed, additional prompting questions were used (Brink, 2002:158);
- *Reflective summarizing*: in order to check whether the researcher had really understood the participant's statements, the researcher summarised the participant's ideas, thoughts and feelings (Greeff, 2003:295).

The researcher wrote down field notes shortly after the interviews, which consisted of observational, theoretical, methodological notes (Schurink, 1998: 285; Morse & Field, 1995:112; Strydom, 1998: 286-287). The observational notes described the who, what, when, where and how of the interview (Schurink, 1998: 285). In the theoretical notes, the researcher interpreted the observational data and added meaning to them (Schurink, 1998: 286). Reminders, instructions and critical comments to the researcher were included in the methodological notes. The field notes were used to supplement and verify the voice recording because a voice recorded interview cannot represent everything that occurs during the interview.

1.4.3.3 Physical setting

The interviews took place in a comfortable room at one of the NGOs dealing with HIV and AIDS where as much privacy as possible for the participant was ensured. The time and setting for the interview were ensured to be convenient for both the participant and the researcher (Brink, 2002:159). When it was impossible for the participant to come to the NGO's office, arrangements were made to carry out the interview at the participant's home. The interview setting was as optimal as possible; care was taken that the participants felt free and comfortable and the room temperature and light condition were ensured to be convenient for the participant.

1.4.3.4 Duration of interviews

There was no set time limit for the interviews, because the length of the interview strongly depended on the specific interview situation. However, the estimated time for the interviews was between one and two hours and the participants were requested to be available for two hours.

1.4.3.5 Role of the researcher

When conducting the research, the researcher applied all the ethical issues as described in paragraph 1.6. The researcher adhered to the Transcultural Care Theory of Leininger (1991) which entails an open appreciation of different cultures because expressions, processes and patterns of caring vary among cultures (George, 2002:502). To commence with the purposive sampling method, appointments were made with mediators who are working for the NGOs that are dealing with HIV and AIDS in the Potchefstroom district. These mediators introduced the researcher to potential participants. Thereafter, the sampling and data collection were carried out as described in paragraph 1.4.3.

1.4.3.6 Data analysis

The interview data that were recorded on the voice recorder were transcribed verbatim. The data analysis began after the first interview and was carried out simultaneously with the data collection. The initial data analysis guided decisions concerning further data collection (Burns & Grove, 2001:66). Open coding, which was carried out manually, was used for analysing the transcribed data and a co-coder coded the data independently (Brink, 2001:192; Burns & Grove, 2001:346; De Vos, 2003:346). In consensus discussions, the researcher and the co-coder discussed the coding themes and consensus was reached on categories in order to ensure the trustworthiness of the data analysis (Polit & Hungler, 1987:359).

A description of the data analysis procedure is given below:

- Shortly after the interview was conducted, the researcher transcribed the interview verbatim on the computer.
- Once the interview was transcribed, the researcher read it several times in order to become familiar with the data and to obtain an overview of the interview as a whole before breaking it up into parts (De Vos, 2003:343). During the reading, the researcher wrote short phrases, ideas and key concepts in the margins of the transcripts.
- In order to classify the information, the researcher took the transcriptions apart and looked for categories and themes of information (De Vos, 2003:343). These categories and themes were coded by giving them an abbreviation (Burns & Grove, 2001:597).
- After this, the code-recode process was applied which involved that the researcher waited at least two weeks after coding a part of the data and then coded the data once again (Krefting, 1990:4).
- Eventually, five or six general themes were identified which provided the researcher with a manageable set of data, which was written into the article (De Vos, 2003:343). Then the researcher started looking for larger opinions on and linkages among the data and identified apparent patterns that were explained and described.
- The final phase of the data analysis involved representing and visualising the data in table form which gave the researcher a brief and clear overview of the identified patterns and allowed the researcher to compare the different patterns (De Vos, 2003:344-345).

The co-coder followed the same procedure independently. A framework for data analysis, which entailed assisting guidelines for coding, was given to the co-coder (Annex J) and appointments were arranged for the consensus discussions. When the researcher and the co-coder met, they discussed their individually reached tables of categories. Similarities and differences in the categories were identified and consensus was reached concerning these categories, after which the table of categories was finalised.

1.5 TRUSTWORTHINESS OF THIS STUDY

To ensure the trustworthiness of this study, the researcher applied Guba's (1981) model for assessing the trustworthiness of qualitative data (Krefting, 1990:2). Compared to other models for trustworthiness, Guba's model is comparatively well developed conceptually and has been used by nurses in conducting qualitative research for a number of years. The model describes four criteria of trustworthiness; credibility, transferability, dependability and confirmability, which were studied and applied to this research. A description of the criteria and the strategies, which were used in this research, is given first, after which an overview of the criteria, strategies and applications to this study follows in Table 1.

1.5.1 Credibility

Credibility establishes the truth of the findings (Krefting, 1990:3). Data in qualitative research should present such accurate descriptions or interpretation of human experience that people who share the same experience would immediately recognise the descriptions.

Within this study, implementing the following strategies that are shortly explained below, ensured credibility:

- **Prolonged engagement with the field:** allows the researcher to check perspectives and allows the participants to become accustomed to the researcher.
- **Reflexivity:** refers to an assessment of the influence of the researcher's own background, perceptions and interests on the qualitative research process.

- **Triangulation:** implies the convergence of multiple perspectives for mutual confirmation of data to ensure that all aspects of a phenomenon have been investigated.
- **Member checking:** is a technique that consists of continual testing the researcher's raw data with participants.
- **Peer examination:** involves the researcher's discussion of the research process and findings with impartial colleagues who have experience with qualitative methods.
- **Interview technique:** the reframing, repetition or expansion of questions on different occasions increases credibility.
- **Structural coherence:** involves ensuring that there are no unexplained inconsistencies between the data and the interpretations thereof.

1.5.2 Transferability

To meet the criterion of transferability, the research findings should fit into other research contexts outside the study situation (Krefting, 1990:4). To ensure this, the sample should be representative of the population. The following strategies were applied to ensure the transferability of the study:

- **Dense descriptions:** includes providing dense background information concerning the participants and the research context and setting to allow others to determine how transferable the findings are.
- **Nominated sample:** implies the use of mediators who are experienced in the research field and therefore can assist in the selection of participants who are representative of the phenomenon under study.

1.5.3 Dependability

Dependability relates to the consistency of the research findings (Krefting, 1990:4). In qualitative research, variability is expected since qualitative research emphasizes the uniqueness of the human situation. Therefore the concept of dependability in qualitative research implies trackable variability that can be ascribed to identified sources (Krefting, 1990:4). Applying the following criteria ensured the dependability of this research:

- **Peer examination:** in relation to dependability, peer examination involves discussing the research plan and implementation with experienced colleagues;
- **Triangulation:** implies the use of alternative data gathering methods in order to compensate for the weaknesses of one method of data collection;
- **Dense descriptions of methodology:** includes an accurate description of the method of data gathering, analysis and interpretation;
- **Code-recode process:** involves an analysis process in which the researcher waits at least two weeks after coding a part of the data and then codes the data once again.

1.5.4 Confirmability

Confirmability is achieved when truth-value and applicability of the research data are established (Krefting, 1990:5). The data should be free of bias. To ensure this, three strategies were used:

- **Confirmability:** keeping field notes consisting of observational, theoretical and methodological field notes and conducting a literature control ensures the confirmability of the research findings;
- **Triangulation:** includes the use of multiple data gathering methods, data sources and theoretical perspectives which test the strength of the researcher's ideas;
- **Reflexivity:** reflexive analysis ensures the researcher's awareness of his or her influence on the data.

Table 1: Strategies to ensure trustworthiness

STRATEGY	CRITERIA	APPLICATION
Credibility	Prolonged engagement within the field	- the researcher has 6 months working experience and 3 years of voluntary work experience within the field of HIV and AIDS care and prevention - 25 interviews were conducted - the researcher spent considerable time with the participants to ensure understanding of their situation
	Reflexivity	- by having consensus discussions with a co-coder and by planning and discussing the research process with experts, the influence of the researcher's own background on the study was minimised
	Triangulation	- the interview data were interpreted by a co-coder and cross-checked in consensus discussions
	Member checking	- the chances of misrepresentation of the data were decreased by testing the raw data with the participants
	Peer examination	- the research process was discussed with impartial, experienced colleagues
	Interview technique	- credibility was increased by reframing, repetition or expansion of questions
	Structural coherence	- deviant cases and rival explanations were discussed in the interpretation of the interview data
Transferability	Nominated sample	- purposive sampling by use of mediators who are well-known to the field was carried out in order to ensure a representative sample
	Dense descriptions	- dense background information concerning the participants and the research context was provided
Dependability	Peer examination	- methodological experts checked the research plan, method and implementation, which was discussed with the researcher
	Triangulation	- data was gathered by in-depth interviews - verbatim transcribed interviews and field notes were used in data analysis - the open coding method was used
	Dense descriptions of methodology	- the method of data gathering, analysis and interpretation was described carefully and as accurately as possible
	Code-recode process	- the researcher and a co-coder coded the data independently and consensus discussions were held on the coding themes and data analysis
Confirmability	Confirmability	- field notes were kept, consisting of observational, theoretical and methodological notes after every interview and during the entire research process and a literature control to verify the data was conducted
	Triangulation	- multiple data sources, such as relevant literature and recent studies and theoretical perspectives were used to test the strength of the researcher's ideas
	Reflexivity	- reflexive analysis took place during the whole research process

1.6 ETHICAL ISSUES

During this research project, the principles defined by Brink (2001:38-49), DENOSA (1998) and the International Council of Nurses (2000) were used as a guide to ensure that the rights of the participants were protected. According to Brink (2001:39), the principles of justice, respect for people and beneficence form the basis of the protection of human rights.

1.6.1 Confidentiality and privacy

This research project could have been especially threatening to human rights due to the high stigmatisation of HIV and AIDS in South Africa (Sana Loue, 1995:1). Since this also applies to the Potchefstroom district, a primary concern in this research was confidentiality. The interviews took place in a room, preferably at one of the NGOs dealing with HIV and AIDS in the Potchefstroom district where the privacy of the participant was ensured. The identity of the participants was kept confidential. All data, which was collected honestly and correctly on the voice recorder and in field notes, was kept private by locking it away in a safe place in the School of Nursing Science at the Potchefstroom Campus of the North-West University. The data was protected from being shared with people who did not form part of the research team.

1.6.2 Informed consent

Participation in this research project only took place when informed consent, preferably in written form, was ensured (Brink, 2001:42; Burns & Grove, 2001:206; DENOSA, 1998:3). Therefore, the participants were provided with sufficient understandable information concerning their voluntary participation in the research, adjusted to the language and knowledge level of the poverty-stricken people in the Potchefstroom district (Brink, 2001:42; Burns & Grove, 2001:208). The essential information was written on an informed consent form which the participants were requested to sign. When obtaining written consent was not possible, the information was given verbally and the participants were asked to sign the consent form or to give verbal consent when understanding was ensured. This was done by asking the participants questions on the presented information verbally.

1.6.3 Fair treatment and protection from discomfort and harm

The positive values of the research as well as the harm that might be inflicted during the research actions was considered during all research steps in order to ensure a balance between the benefits and risks of the research project (Brink, 2001:45). At all times, the participants were protected from physical or psychological discomfort (DENOSA, 1998:6). To give the participants the opportunity to discuss difficulties they could have encountered during the interviews, an experienced psychiatric nurse was available to support the participants after the interview. By obtaining the permission from the Research Committee of the School of Nursing Science and the Ethics Committee of the Faculty of Health Sciences of the North-West University, the researcher ensured that the research was scientifically and ethically justified. The researcher adhered to the ethical aspects linked to this research and the project was carried out with integrity and in a scientifically honest fashion.

1.7 LITERATURE CONTROL

Following data collection and analysis, the research findings were related to the existing body of knowledge in the HIV and AIDS research field (Fouché & Delpont, 2003:268). In this way, a full exploration of the experiences and needs of support for people living with HIV was obtained and the collected data was confirmed by comparing them with relevant literature. The new findings obtained in this research were highlighted as unique findings.

1.8 GUIDELINES

From the research findings and conclusions, guidelines were formulated for support in order to assist poverty-stricken people living with HIV and to enhance their quality of life.

1.9 REPORT OUTLINE

The report was written in article format, including the following elements:

1. Overview of the study.
2. The research findings have been written in the format of an article with the title: 'Experiences and support needs of people living with HIV in the Potchefstroom district.' The article has been prepared for submission to the international journal 'AIDS' (see page 31).
3. Conclusions, recommendations, shortcomings and guidelines for effective support for poverty-stricken people living with HIV in the Potchefstroom district.

1.10 AUTHORS' CONTRIBUTIONS

This study has been planned and carried out by four researchers from the School of Nursing Science at the North-West University, Potchefstroom Campus. Every researcher's contribution is listed in the table below:

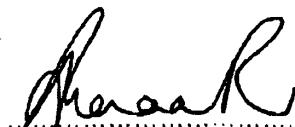
Miss A.T. Feitsma	Master's student, responsible for exploring relevant literature, conducting the interviews and writing the text
Prof. M.P. Koen PhD. Professional Nursing	Project leader, supervisor and critical reviewer of the study.
Dr. A.J. Pienaar PhD. Health Sciences	Co-supervisor, co-coder, advisor and critical reviewer of the study.
Mrs.C.S. Minnie M. Cur Obstetric and Neonatological Nursing Science	Assistant supervisor and critical reviewer of the study.

In the following statement, the co-authors confirm their role in this study and agree with including the article in this dissertation:

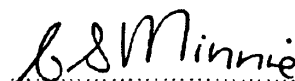
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Prof. M.P. Koen



Dr. A.J. Pienaar



Mrs. C.S. Minnie

2. Article

Full title: 'Experiences and support needs of people living with HIV in the Potchefstroom district.'

Short title: 'Support needs of for people living with HIV.'

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Guidance for Authors on the Preparation and Submission of Manuscripts to AIDS

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Acknowledgements

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Supplements:

Goulis J, Burroughs AK. Role of vasoactive drugs in the treatment of bleeding oesophageal varices. *Digestion* 1999; **60(Suppl 3)**:25–34.

Letter/Abstract:

Ozsoylu S, Kocak N. Naloxone in hepatic encephalopathy [Letter]. *Am J Dis Child* 1985; **139**:749–750.

Lankisch PG, Assmus D, Pflichthofer D.: The burden of pancreatic disease in a well-defined population [Abstract]. *Gastroenterology* 1998; **114**:A24.

Books

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Whitehead WE, Schuster MM, *Gastrointestinal Disorders. Behavioral and Physiological Basis for Treatment*. Orlando: Academic Press; 1985.

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Abstract:

Objective: To explore the experience, identify the support needs and formulate guidelines for effective support for poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district.

Design: A qualitative, phenomenological design.

Setting: The informal settlements in the Potchefstroom district in the North-West Province in South Africa.

Methods: In-depth interviews guided by two central questions, a total of 25 interviews (24 one-to-one interviews and a focus group).

Results: The first central question that was asked during the interviews focused on the experience of living with HIV. The response to this question resulted in two of the main themes that were identified after data-analysis: the facilitative and impeding experiences of poverty-stricken people living with HIV. The response to the second question, which addressed the support needs, resulted in four main themes; basic needs, psycho-social needs, cultural-spiritual needs and self-actualisation needs.

Conclusions: The experience of poverty-stricken people living with HIV in the Potchefstroom district is closely related to their support needs. In order to address these needs holistically and to enhance the quality of life of poverty-stricken people living with HIV, the needs should firstly be addressed individually. Following that, the collective needs can be addressed by a support system addressing basic, psychosocial, cultural-spiritual and self-actualisation needs for which guidelines were formulated. Further studies are needed to implement these guidelines and to evaluate their effectiveness.

Key words: HIV and AIDS, poverty, support, needs, experience, North-West Province (South Africa), informal settlements

Introduction

South Africa has the highest number of HIV-infected people in the world; more than 5 million people are living with HIV and AIDS, and deaths due to AIDS are expected to rise sharply until 2010 [1,2]. In the North West Province, the province in which the Potchefstroom district is situated, HIV prevalence was 29,9% in 2003 [3]. The North West Province is one of the nine provinces of South Africa, and the Potchefstroom district is situated 115 kilometres southwest of Johannesburg [4]. The poorest people in this district form part of the population that is the most severely affected by HIV and AIDS. This is confirmed in the HIV/AIDS and STD Strategic Plan for South Africa (2000-2005), which clearly indicates that the HIV pandemic is severely affecting the young, black and economically poor populations of South Africa [5].

In the Potchefstroom district, 40% of the black population is living below the poverty line and the number of poor people and the extent of poverty among poor people is higher than in South Africa on average [6]. Kotze, Roux and Wessels [5] state that the majority of the people living with HIV in the North West Province are part of households living in an unfavourable economic situation and the AIDS pandemic has made their poverty situation even worse. Natrass [2] emphasizes this fact in the following statement: 'The AIDS pandemic is both a cause and effect of poverty.'

Furthermore, the majority of the poverty-stricken people living with HIV in the Potchefstroom district do not feel supported after having been diagnosed HIV positive. This became clear in previous research in this district and in relevant literature on this topic [7,8]. The researcher could confirm this statement after

spending some time in the research field as part of the preparation for this study. Pienaar [7] has carried out his doctorate study concerning an HIV/AIDS counselling approach for Africans in the North West Province, including the Potchefstroom district. He states that there is support for the patients before and shortly after the HIV test by means of counselling, but there is minimal continuation in the form of follow-up counselling and other types of support such as support groups or practical support. Russell and Schneider [8] also identify a gap in the support for people living with HIV. They state that there are not enough support programmes available in South Africa for people who have been diagnosed HIV positive and that there is a lack of guidelines and programme standards in the existing programmes.

Therefore, the focus of this study was to develop guidelines to address the gap in the support during the HIV infection. Coetzee and Spangenberg [9] emphasize the fact that there is a lack of research on how South Africans handle living with HIV. They mention that once there is a clearer understanding of how South Africans experience living with HIV, counsellors, nurses and other health care workers will be better equipped to meet the needs of these people [9]. Van Dyk [10] states that it will be expected from nurses to form the backbone of the HIV and AIDS support services. This statement is supported by Uys [11] who found that community caregivers, such as voluntary lay counsellors, have proven themselves effective and efficient under the supervision of registered nurses. This supports the relevance of this research project for the nursing discipline.

The above argumentation resulted in the following research problem: 'Poverty-stricken people living with HIV in the Potchefstroom district utter a gap in the support after having been diagnosed HIV positive.' The following research questions were formulated in order to target this problem:

Research questions

- How do poverty-stricken people in the informal settlements in the Potchefstroom district experience living with HIV?
- What do people living with HIV need to feel supported?
- What can be done to address these needs?

These research questions led to the following objectives for this study:

Objectives

- To explore and describe the experience of poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district.
- To explore and describe the needs of poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district to feel supported.
- To formulate guidelines for support in order to assist poverty-stricken people living with HIV and to enhance their quality of life.

Methods

The research method in this study consisted of sampling, data collection and data analysis. The determination of a paradigmatic perspective preceded the execution of the research method.

Paradigmatic perspective

In the initial phase of the study, a paradigmatic perspective was determined, which implies the way in which the researcher views the research material [12]. The paradigmatic perspective for this study was based upon a holistic approach and on Leininger's [13] Cultural Care Diversity and Universality theory, which is also influenced by holism [14]. This research project contains the characteristics of a scientific process because a scientific, systematic approach was used [15].

Sampling method

The population studied in this research consisted of the poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district in the North West Province, South Africa. Purposive sampling was used to select participants who complied with the sample criteria mentioned below, and who voluntarily agreed to participate. The sampling was carried out with the assistance of mediators who are working for the Non Governmental Organisations (NGOs) that are dealing with HIV and AIDS in the Potchefstroom district and who are well known to the poverty-stricken people living with HIV. In this way, the selected sample was more representative of the population because the mediators form part of the current support system for people living with HIV.

When the participants were selected, they were given information concerning the research and about what is expected from them as participants. The participants were provided with sufficient understandable information concerning their voluntary participation in the research. This information was adjusted to the language and knowledge level of the poverty-stricken people in the Potchefstroom district [15,16]. It also included an explanation of the objectives of the research, the ways in which confidentiality was ensured and the voice recording of the interviews. After ensuring that the participants understood this information, which was checked by asking the participants questions concerning this information, they were asked to sign a consent form.

Sample size

The sample size was determined by data saturation [17]. The process of purposive sampling in this study continued until a sufficient amount of data of the studied population was obtained to be able to draw valid conclusions, and new participants were interviewed until no new themes were reported [18]. This implied that interviewing new participants continued until 25 interviews were conducted, after which the experiences and needs of support of poverty-stricken people living with HIV were totally clear and a pattern in the data had become evident.

Data collection

Congruent with the qualitative, phenomenological research design that was chosen for this study, data was collected by in-depth interviews with poverty-stricken people from the Potchefstroom district. The interviews were conducted from October 2004 until April 2005. A voice recorder was used to record the interviews which all lasted between 25 and 45 minutes. The interviews were predominantly guided by two open-ended questions.

Additionally, the researcher used probes in order to get the participants to open up and express their experiences and needs [19]. The two open-ended central questions were:

- How does it feel for you to live with HIV?
- What do you need to feel supported?

Experts in qualitative research were consulted to evaluate these questions and a trial run within the field was undertaken. The interviews took place in a comfortable room at one of the NGOs dealing with HIV and AIDS in the Potchefstroom district or at the participant's home. There was no set time limit for the interviews, because the length of the interview strongly depended on the specific interview situation. After the interviews, field notes which were used to supplement and verify the voice recording were written down as soon as possible.

Data analysis

After having recorded the interviews on a voice recorder, they were transcribed verbatim. The data analysis commenced after the first interview and was carried out simultaneously with the data collection. The initial data analysis guided decisions concerning further data collection [16]. Open coding was used for analysing the transcribed data and an experienced co-coder coded the data independently [15,16,12]. During consensus discussions, the researcher and the co-coder discussed the coding themes and consensus was reached on the main and sub-categories in order to ensure the trustworthiness of the data analysis [20].

Trustworthiness

To ensure further trustworthiness of this study, the researcher applied Guba's (1981) model for assessing the trustworthiness of qualitative data [21]. Compared to other models for trustworthiness, Guba's model is comparatively well developed conceptually and has been used by nurses in conducting qualitative research for a number of years. The model describes four criteria of trustworthiness; credibility, transferability, confirmability and dependability, which were applied to this research. The researcher had an engagement with the field for one and a half years, which allowed the researcher to check perspectives and the participants to become accustomed to the researcher. Once the researcher had built a trust relationship within the research field, participants came to the researcher on their own initiative because they were willing to participate. This increased the credibility of the research, which was also ensured by reframing, repetition and expansion of the interview questions. Furthermore, the interpretation of the data by an experienced co-coder and the cross-checking of the data in consensus discussions enhanced the credibility of the research findings. The previously discussed purposive sampling method contributed to the transferability of the study and the fact that the researcher kept observational, theoretical, methodological and personal field notes ensured the confirmability of the research findings. Peer examination by discussing the research process with experienced experts in qualitative research increased the dependability of the study. These experienced experts did not express concerns about the trustworthiness of the findings.

Ethical issues

By obtaining the permission from the Research Committee of the School of Nursing Science and the Ethics Committee of the Faculty of Health Sciences of the North-West University, Potchefstroom Campus, the researcher ensured that the research was scientifically and ethically justified. This study could have been especially threatening to human rights due to the high stigmatisation of HIV and AIDS in South Africa [22]. Since this also applies to the Potchefstroom district, a primary concern in this research was confidentiality. Privacy for the participants was ensured at both types of venues and the identity of the participants was kept confidential at all times. Because all participants had the right to know what participating in this study entailed and to voluntarily participate, informed consent was ensured before all interviews [15,16,23]. The participants were protected from physical or psychological discomfort and an experienced psychiatric nurse was available to support the participants after the interviews when needed [23]. The researcher adhered to the ethical aspects linked to this research and the project was carried out with integrity and in a scientifically honest fashion.

Results

The research findings of the experience of poverty-stricken people living with HIV and their needs of support were related to the existing body of knowledge in the HIV and AIDS research field [24]. In doing so, a full identification of the needs of support for poverty-stricken people living with HIV was obtained and the collected data was confirmed by relating them to relevant literature.

A need can be described as the discrepancy between what people desire and what people actually have [25]. Poverty-stricken people living with HIV have certain needs, consistent with their view, to be able to live a quality life. Every person has equal

basic needs such as nutrition, comfort and being loved by other people. People living with HIV who were studied in this research have these basic needs, but they also have specific needs in order to be able to cope with their disease. Next to this, a person's need is influenced by that person's culture, because the perception of a need is based on the learning and the standards of a culture [26]. The needs of poverty-stricken people were addressed holistically in this study, by respecting the participant's culture and by taking all the various needs poverty-stricken people living with HIV have into consideration.

After data-analysis and consensus discussions with the co-coder, six main themes were identified in the research findings. The first two themes are the facilitative and impeding experiences of poverty-stricken people living with HIV. The response to the first guiding question asked in the interviews: 'How does it feel for you to live with HIV?' resulted in these themes and they include a diversity of experiences which are described in the following paragraph. The second guiding question asked in the interviews: 'What do you need to feel supported?' resulted in a response that is captured in the following main themes: basic needs, psychosocial needs, cultural-spiritual needs and self-actualisation needs. The main themes are discussed and confirmed by relating them to relevant literature.

1. Facilitating experiences of poverty-stricken people living with HIV

The research findings reflected a diversity of experiences of poverty-stricken people living with HIV. The facilitative experiences, which contribute to the quality of life of people living with HIV, are addressed in the first main theme. Experiences of acceptance, disclosure and feeling strong were expressed, which are described below.

- *Acceptance and disclosure*

The majority of the participants stressed acceptance of the HIV positive status and disclosure as very important. They expressed to be feeling strong after accepting and disclosing their status: *"He doesn't have any problem because he has accepted his status before, he feels strong."* *"It's about accepting herself, then you will have control and you will cope and cope and cope."* *"There was a meeting somewhere there, I don't know what came to me, I just disclosed. And then after that I got that power, till now."* *"I am fine with my status and the more I talk about it, the more I feel free."* This is confirmed by Russell and Schneider [8] who point out that stigmatisation and discrimination resulting in denial and secrecy, which are the opposites of acceptance and disclosure, limit the ability to deal with the impact of HIV on individuals and families. This implies that when a person is accepting and disclosing, he or she will have a stronger ability to deal with HIV. Furthermore, Pienaar [7] indicates that people living with HIV who have accepted their status have a 'fuller' life; accepting enables them to live life to the full. The facilitative experiences relate to needs that are already fulfilled and have contributed to a person's quality of life. Therefore these experiences can support people who still have the need to accept or disclose their status.

2. Impeding experiences of poverty-stricken people living with HIV

This second main theme includes the impeding experiences of poverty-stricken people living with HIV such as poverty, stigmatisation, stress and loneliness. They represent the limited possibilities poverty-stricken people living with HIV experience due to their HIV positive status.

- *Poverty*

The following quotes indicate the experience of deepening poverty: *"We struggle; we don't have anything at home at this present moment."* *"Another time we are sleeping like this, we don't have nothing."* *"I told them one day there is no food, let us sleep. We pray and sleep."* Russell and Schneider [8] confirm this experience of deepening poverty in their study on Community-based HIV/AIDS care and Support Programmes in South Africa. As indicated in the introduction, the majority of the people living with HIV in the North West Province are part of households living in an unfavourable economic situation and the HIV and AIDS epidemic has made their poverty situation even worse [5].

- *Stigmatisation*

Stigmatisation was felt by many participants and expressed as a main problem. *"They don't believe that it's HIV, but they can see that I am HIV and that they really don't love me."* *"They see AIDS as a demon or something like that and my family think that's something to do with those Satanism."* *"They are killing us. It hurts when somebody starts to ignore you, to be afraid of you because of you told the person that you are positive."* Especially during the first period of the HIV infection it affected some of the participants so severely that they attempted to commit suicide. *"But again when I am alone, I don't want to lie. I tried to commit suicide twice."* *"It was very, very hard. I tried to kill myself and my baby."* Van Dyk [10] confirms that there is a significantly higher risk of suicide among HIV-infected individuals. Stigmatisation

also makes it difficult for HIV-positive people to accept their status: *"A stigma to persons who are HIV doesn't work; if you criticise that people and remark their mistakes, that person could not accept that he is having this, you see?"* Russell and Schneider [8] confirm this experience; they mention that the experience of people living with HIV is one of isolation and rejection by the community and formal services. Van Dyk [10] also points out that it is the fear of rejection and isolation that causes people living with HIV the greatest pain.

- *Stress and loneliness*

Many participants indicated that they felt stressed and very lonely, especially shortly after having been informed about their HIV-positive status: *"But the first time I know my status, I was having the stress." "I was alone and I feel like everything it's, you see, like I can't cope anymore."* One participant said that she ran away from home after receiving the results: *"After the test, they call me, I ran away from home. I was just alone for the first time."* The Department of Health in South Africa [27] also states that people living with HIV often feel lonely and experience the first period following the diagnoses as very stressful. These impeding experiences are directly related to needs because each impeding experience results in the need to stop the limitations that the specific experience is causing. The experience of poverty for example results in the need to find a job or to apply for a grant.

The experiences of poverty-stricken people living with HIV were described as the facilitating and the impeding experiences because they both influence the need for support. Facilitative experiences can support people who still struggle to fulfil the need for acceptance and disclosure and who are still not coping with their HIV positive status. Impeding experiences directly result in certain needs of support in

this study. Therefore, the impeding experiences play an essential role in the following four main themes that address the need for support.

3. Basic needs

The four remaining main themes that were defined after data-analysis and consensus discussions consist of basic, psychosocial, cultural-spiritual and self-actualisation needs. The basic needs that were stressed in the interviews are discussed first. They could be subdivided into hygiene needs, nutritional needs, need for physical well-being, need for treatment and financial needs.

- *Hygiene needs*

The need for hygiene is evident in the following statements: *“Because another people, when they are sick they don’t want to wash themselves. You can’t take a tooth brush and wash your mouth, you wait for somebody must told you, you must wash yourself, you must wash your mouth, whatever.”* *“I want if somebody come at my house, he must get all the time that it’s clean, I am clean, my children are also clean.”* It was remarkable how clean the houses were in which some of the interviews were conducted. The houses were all small and it was evident that the participants had little means, but the floors were always shining. Not being able to clean the house due to illness, was expressed as stressful: *“The problem is; she is stressing because she cannot clean her house at the moment.”* This was also mentioned in another statement: *“So if she gets ill, she gets annoyed to herself because she can’t do the things by herself.”* Uys [28] confirms the relation between illness and hygiene by stating that one might need more hygienic care due to symptoms such as extensive sweating, and the ability to take care of personal hygiene might be limited by the illness. Furthermore, she points out that most people feel more comfortable when they are clean and well cared for [28].

- *Nutritional needs*

The participants expressed their nutritional needs by mentioning the need for healthy food which is a priority for the success of both the antiretroviral treatment (ART) and the Cotrimoxazol. The following quotes from the research findings represent these nutritional needs related to the treatment: *"Yeah, nutrition is very much important to me to keep my body fit."* *"Yeah, she thinks it is possible to get those nutrition, yeah. To boost your body so that those drugs when they come, you feel strong, yeah."* It was also stressed that one of the side-effects of both the antiretroviral and the antibiotic treatment is an increased appetite: *"This tablets that we are eating Anit, you drink that tablet now, after 15 minutes you are hungry, you eat. After 15 minutes again you are hungry."* The need for adequate, sufficient and healthy nutrition is represented in the following quotes: *"I've one day read from the other book that sugar is the thing that causes this mouth ulcer. If I use brown sugar, or syrup, I don't have that problem."* *"If you eat healthy, do some exercise, no sugar, limit the sugar, limit the fish oil, limit the salt, keep yourself busy, you life long."* Van Dyk [10] stresses the importance of these nutritional needs by pointing out that there is a strong correlation between malnutrition and immune depression. Some participants mentioned that they were given this information: *"Then they told us we must eat the food that has vitamins and minerals."* A healthy diet, vitamin and mineral supplementation may enhance the immune response to HIV infection and the resistance to opportunistic infections [29].

- *Need for physical well-being*

During the interviews, it became clear that the participants were or have been suffering from physical pain and discomfort and they strive for a feeling of physical well-being. In the following quote, it is evident that physical discomfort is leading to limited possibilities for other kinds of support: *"I couldn't come to the support group because my foot was hurting so much, I couldn't walk."* *"She is interested in the*

support group but she is too weak to come.” These participants are struggling with their health which results in the fact that they cannot take part in the support group. Furthermore, it was mentioned that physical discomfort results in fear and stress: *“And when I, like maybe something happens to me like I have a headache or pain inside in the stomach, I start thinking that this is it, I am going to die.”* Uys [28] defines physical well-being as the absence of pain or discomfort and living in harmony with one’s physical environment. As people living with HIV encounter feelings of pain and discomfort, it is important to identify and treat physical problems at an early stage and to promote their general health [10].

- *Need for treatment*

The participants expressed treatment as an evident need for support. The participants in this study, who are using the public health system in South Africa, only qualify for the anti-retroviral therapy (ART) when they have a CD4 cell count below 200 cells/mm³. They get Co-trimoxazole as long as their CD4 cell count is above 200 cells/mm³. The participants highlighted the treatment as essential: *“My problem is to find the medication, the cure to stay healthy. That is all I can say.”* *“I am getting the treatment from the clinic and getting better each and every day.”* The following quotes make clear that the participants feel the necessity to stick to their treatment: *“So if it can happen those medication maybe is, it’s, maybe, let me see, it disappear maybe. What am I going to do? We are going to die or what?”* *“But most of the thing is the medication, yeah. He musn’t have a shortage of drugs.”* *“She must drink her medication at 7 o’clock in the morning and 7 o’clock at night.”* This necessity is confirmed by Van Dyk [10] who mentions that it is absolutely essential for the patient to adhere strictly to the ART therapy. Although there is still no cure for AIDS and HIV, the ART can keep the viral load as low and the immune system as healthy as possible.

- *Financial needs*

Financial needs are directly related to the experience of poverty as discussed in the paragraph on experiences. A general opinion was that the disability grant which is currently ZAR 740,- or \$114,20 (at current exchange rate of \$ 6,48) a month is not sufficient for those who have a family: *"There's some they have kids and they cannot provide with that 740."* *"Ooh, for my child it's not easy because we are living just with our grants, his daddy has passed away."* Adding to this, problems with applying for the grant were stressed: *"They didn't write me the letter, I fill the forms again then they told me they are still busy with the papers."* Even misuse of the grant by family members was expressed by some of the participants: *"They make HIV like they supposed to get money from that. Because I am getting 740, my child will also get HIV and get 740 also."* *"Some receive grants and their family misuses their grant."*

These basic needs formed a clear pattern and were often mentioned as the most important needs by the participants. This is confirmed by Maslow [26] who indicates that basic needs, including physiologic needs, such as air, nutrition, water, hygiene and shelter, are the needs which are crucial for survival. If these needs are not met, a person's quality of life is seriously limited.

4. Psychosocial needs

The fourth main theme represents the psychosocial needs, which could be subdivided into self-concept needs, interpersonal relation needs and emotional needs.

- *Self-concept needs*

A healthy self-concept is important to people living with HIV. It was pointed out that accepting oneself is essential in how one copes with the HIV infection. The need for self-concept is closely related to stigmatisation in this study; the more people feel

stigmatised, the more problems they have accepting themselves. It was stressed as very important to believe in oneself and to respect oneself: *“So the first medication is to believe in yourself. You can drink the medication well, but if you don’t accept, you are not going to be fine.”* *“And she respects herself, welcomes herself that she is still a person.”* It also became clear during the interviews that feeling supported starts with accepting yourself: *“Even the friends giving you support, but you are the only person to sit down and accept this problem and say: ‘This virus lives inside of me and I am going to fight’.”* Furthermore, it was mentioned by several participants that they feel like normal people and want to be treated that way: *“I am just a normal person, like other persons who doesn’t have diseases.”* *“I want people to treat me like an ordinary person, it’s not in my heart.”* *“I just live a normal life, you see? Like each and every person who is normal. Sometimes I forget that I am positive, I forget.”* Uys [28] states that every person has a need for an accurate, clear and realistic self-concept. Self-concept is closely related to ‘self-esteem’, which refers to feelings of independence, competence and self-respect [26]. In Maslow’s Needs Theory [26] it is indicated that individuals, including poverty-stricken people living with HIV, need both self-esteem and esteem from others implying recognition, respect and appreciation. Esteem from others is closely related to the next discussed needs: the interpersonal relationship needs.

- *Interpersonal relationship needs*

Interpersonal relation needs were stressed as highly important by the majority of the participants. Especially support groups for people living with HIV where they can share as peers were experienced as very supportive: *“Support from support group. Meeting people discuss and share, then she forgets she is HIV positive finding herself a normal person.”* *“Support group that we are starting now is supporting too much for me.”* *“It think that support group is the best, you see?”* This is confirmed by the statement that support groups for people living with HIV have been recognized

for their value in providing emotional relief and support to individuals [27]. People living with HIV experience benefits from support groups such as having social contact with others who are experiencing similar feelings, sharing valid information and ways of dealing with HIV. Talking and sharing is what most participants expressed as a need: *“Talking makes you forget about the disease and focus on life.” “To teach and to learn and to share with this, with some people that are like her.”* Russell and Schneider [8] also found that people living with HIV verbalise the importance and healing effect of being able to share and meet with others.

- *Emotional needs*

The participants uttered various emotional needs in the interviews of which counselling was expressed as the most important: *“He said he don’t have anyone to sympathy him, to, to counsel him.” “At home there is nobody to comfort him, counsel him. He said he need that particular help.” “I need someone to talk to, maybe I don’t have anything to talk to, I mean about this, my problem.”* The following quote makes clear that sufficient counselling results in coping: *“I used a lot of counselling so I am O.K., I don’t have a problem.”* Since the diagnosis and disclosure of an HIV positive result is an extremely stressful event, counselling can help people living with HIV to manage their problems, to cope and empower people to become self-helpers [27,10].

5. Cultural-spiritual needs

Cultural as well as spiritual needs are included in the fifth main theme and were expressed by the participants as important in feeling supported. The cultural needs were evident in the need for traditional healing.

- *Traditional healing*

It was mentioned that clinics work with traditional healers: *“The clinic they are working like with the traditional healers.”* but the participants stressed that they are

not allowed to mix the traditional medicine with the ART: *"I am a traditional healer, but I don't use my things. I am also taking the ARV. Because they told us: 'If you mix, it's up to you'." "If they give you the 'muti' (traditional medication), they are going to tell you that you don't have to drink the 'muti' and the medication at the same time."* Participants expressed that they were told that their ART will be cancelled if the clinics discover that they mix it with the type of traditional medicine which is harmful to the success of the ART. A participant who is taking the Cotrimoxazol from the clinic expressed that the traditional healer supports her additionally: *"And the family, she knows the sangoma (traditional healer) there and she is going to be all right, she still has a support."* Van Dyk [10] mentions that 80% of the people in Africa, including South Africa, rely on traditional medicine for many of their health care needs. Traditional Africans believe that every illness has a specific cause and for them to understand illness, the questions 'why' and 'who' are very important [30]. This confirms that people living with HIV experience the need for additional support from traditional healers who address the 'why' and 'who' of the HIV infection. Adding to this, Pienaar [7] stresses that people living with HIV support the idea of integrating the strengths of both the Western and African traditional health system to serve their needs. The harmful effects that may occur by using traditional healing can be reduced by educating traditional healers as to these harmful effects [10]. Research has shown that traditional healers abstain from dangerous practices when they are educated about them.

- *Spirituality*

The participants uttered the need for spirituality and expressed they feel supported by their religious beliefs: *"I have friends and I have my Lord and that's why I say I can beat it."* *"She says it's only God, I must have to say you have to be strong to deal with this virus."* *"Then she pray always to God. And she realised that she has a time, she has another chance to live."* It is confirmed in literature that many people find comfort

and support in spiritual guidance and may seek this kind of support [27]. Uys [28] also highlights that spirituality assists people in dealing with uncertainties of life and that suffering, which occurs in HIV infection, brings certain spiritual needs to the fore.

6. Self-actualisation needs

The last main theme addresses the need for self-actualisation. This theme could be subdivided into learning needs, the need to disseminate and practice values and the need for activity and stimulation.

- *Learning needs*

The need for poverty-stricken people to develop their abilities and qualities was very obvious in the research findings: *"I have to organise for them for the workshop and all those stuff and to get trained."* *"That's very much important: the training and the skills."* *"I want to go to the course also, I must know something."* The participants uttered that they feel the need to get information and to learn. They also expressed that it makes them feel strong to teach others: *"When I tell people who don't know, I feel that I am strong."* Another participant said it is her greatest need to be an example to others: *"I want to be example for, at the clinic, to speak with people who are living with HIV."* Uys [28] states that in some cultures people are expected to understand their treatment and to take their own decisions. Others demand dependence on and trust in others: *"But what I need now for them to support, like people from the university."* *"They just need that help to get, if somebody can come and say: 'Just sell this thing' it is going to be good."* In the interviews this differed strongly from participant to participant; some participants went out of their way to gather all possible information and skills, while others wait for people to come and tell them what to do.

- *Practice and disseminate values*

During the interviews, the participants highlighted the values which they believe in and which they want to disseminate within the community: *"To share with them and to learn, to teach the youth about this virus."* *"There are some people, that are HIV-positive, but they are still sleeping around. To share with them if you got this virus, you have to do this and this and this."* *"That is why he don't sleep around and spreading this disease and having a child'.* Van Dyk [10] confirms that values that are important for the survival of others should be included in HIV and AIDS education. It was very important for the participants to correct the idea that someone will immediately die when he or she is HIV positive: *"Most people they believe that this being HIV positive kills. It will kill you if you believe that."* *"Actually HIV and AIDS don't kill. You kill yourself when you don't speak out."* *"No, it doesn't mean that if you are HIV, you are going to die."* This is confirmed by Van Dyk [10] who points out that it is important for people living with HIV to focus on life beyond infection.

- *Activity and stimulation needs*

The majority of the participants expressed the need to be busy, to work and to be active: *"I want to work and do something, be active to keep me busy."* *"I don't say: 'No, I am sick, I must just sit like this'."* *"I wanted to do something if I hear that I still have power."* This is confirmed by Uys [28] who mentions that activity and stimulation are essential for human beings and that a lack of activity can cause disorientation and confusion. Van Dyk [10] also states that HIV-infected people should be encouraged to make decisions for themselves and be assured that they can still be productive in economic, intellectual and social spheres for many years. These activity and stimulation needs are also closely related to the experience of poverty: *"I really need to work, cause I can't afford, I have two children, I really can't afford."* *"So when the CD4 count is above 200, our money is going to be stopped. So I don't know if it's true or false. That's why I am saying I want to have a job."* Russell

and Scheider [8] also stress the need for jobs for people living with HIV, especially for those who are still in the asymptomatic phase.

From these results that were subdivided into six main themes, it is clear that the experiences that were expressed by the participants are very closely related to and determine their needs for support. Although the facilitating and impeding experiences were described separately as themes one and two, they were also evident in themes three to six that addressed the basic, psychosocial, cultural-spiritual and self-actualisation needs for support. It can be concluded that it is essential to focus on how poverty-stricken people living with HIV experience living with the HIV positive status before focussing on their needs for support. Once the experience is clear, the main needs for support can be identified and addressed holistically.

Discussion

Experiences and needs framework

After data analysis, coding and consensus discussions, it was found that the research findings could be directly applied to Maslow's Needs Theory [26] and the division of human needs in related to nursing by Uys [28]. As these two different divisions of needs were merged and related to this research, it became clear that they are very applicable to the needs that were found in this study. The data started taking on a structure and were enriched by relating them to these needs divisions.

When Maslow's [26] and Uys' [28] view on human needs were merged and applied to this study, the experiences and needs framework in Table 1 arose. While the framework was developed, the researcher found that especially the impeding

experience of poverty-stricken people living with HIV directly determines their support needs. The existing body of knowledge could not confirm this finding and it should therefore be highlighted as a unique finding. Facilitative experiences also relate to needs and are important in supporting people who still have impeding experiences, but in this study, the participants regarded these needs as already fulfilled. Therefore they are not included in the framework, but they are included in the guidelines for support for poverty-stricken people living with HIV, which follow after the framework in Table 1.

The impeding experiences are depicted in the left hand column in the framework and directly linked to the needs resulting from that experience in the right hand column. The experience of a lack of food for example, results in nutritional needs and poverty relates to financial needs. The experience of different types of stress relates to both psychosocial and cultural-spiritual needs, therefore stress is covering these two levels of needs in the framework. There are people who search for spiritual help when they are stigmatised, but others will rather discuss this with peers, which is part of the interpersonal relationship needs.

Although the framework links the experiences and needs which are most likely to relate, the lines in the framework should not be seen as fixed and it should be applied individually to each and every individual. This leads to the conclusion that the needs of poverty-stricken people living with HIV are determined by their experience and therefore highly individual. Once the individual needs are assessed, one can address the collectiveness of these needs compared to the needs of other people living with HIV by applying a support system in which collective needs can be met. Since a person's perception of a need is based on the learning and the standards of that person's culture, respecting a person's culture is a prerequisite in addressing a person's needs [26].

Table 1: Experiences and needs framework for poverty-stricken people living with HIV

IMPEDING EXPERIENCES	NEEDS
Basic problems:	Basic needs:
<ul style="list-style-type: none"> • lack of hygiene; 	<ul style="list-style-type: none"> • hygiene needs;
<ul style="list-style-type: none"> • lack of food; 	<ul style="list-style-type: none"> • nutritional needs;
<ul style="list-style-type: none"> • physical problems; 	<ul style="list-style-type: none"> • need for physical well-being;
<ul style="list-style-type: none"> • lack of (info about) treatment; 	<ul style="list-style-type: none"> • need for (info about) treatment;
<ul style="list-style-type: none"> • poverty. 	<ul style="list-style-type: none"> • financial needs.
Stress:	Psychosocial needs:
<ul style="list-style-type: none"> • stigmatisation; 	<ul style="list-style-type: none"> • self-concept needs;
<ul style="list-style-type: none"> • loneliness; 	<ul style="list-style-type: none"> • interpersonal relationship needs;
<ul style="list-style-type: none"> • fear of death, disclosure, anxiety. 	<ul style="list-style-type: none"> • emotional needs.
	Cultural-spiritual needs:
	<ul style="list-style-type: none"> • traditional healing;
	<ul style="list-style-type: none"> • spirituality.
Necessity of life:	Self-actualisation:
<ul style="list-style-type: none"> • lack of knowledge, eagerness to learn; 	<ul style="list-style-type: none"> • learning needs: knowledge, insight, skills;
<ul style="list-style-type: none"> • negligence of values; 	<ul style="list-style-type: none"> • practise and spread values;
<ul style="list-style-type: none"> • lack of activity, unemployment. 	<ul style="list-style-type: none"> • Activity and stimulation needs.

Guidelines

In congruence with the objectives of this study, guidelines for effective support for poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district were formulated. The guidelines were based on the experiences and needs framework in Table 1. It should be stressed that, as was previously stated, one should firstly assess the individual needs whereafter the collectiveness of these needs can be addressed by comparing them to the needs of other people living with HIV. The guidelines that follow represent a support system in which these collective needs can be met. Nevertheless, it is the individual's responsibility to express the needs at the NGOs and other relevant services so that they play an active role in addressing their needs themselves and are encouraged to make their own decisions [10]. As was stated in the introduction, it is expected from registered nurses to fulfil the supervising role in the HIV and AIDS support services [10]. Therefore, these guidelines are to be implemented and supervised by registered nurses who should form the backbone of the support system. Furthermore they should empower community caregivers who have proven themselves effective and efficient under the supervision of registered nurses Uys [11].

- Registered nurses can address the need for hygiene, adequate nutrition, physical well-being and treatment by creating awareness for these needs among their colleagues and patients and within the community. This can be done by distributing HIV and AIDS pamphlets and posters, facilitating HIV and AIDS workshops and training for health-care workers and people living with HIV at the health-care services in the Potchefstroom district. HIV positive people who have experience with and knowledge concerning these needs should be involved in this awareness process because they know exactly what a person living with HIV goes through.

- The need for obtaining nutrition and the financial needs can be met by registered nurses through skills development, which can enable HIV positive people to find a job, to establish vegetable gardens and to successfully follow the application procedure for welfare grants. Next to this, registered nurses can improve the system for the distribution of food parcels by identifying the organisations that are responsible for the distribution and assessing their distribution procedure.
- Registered nurses can meet the need for a healthy self-concept and emotional needs by creating more awareness of HIV and AIDS in the community through HIV and AIDS workshops, pamphlets and organising activities in which AIDS education is integrated, such as sports activities. In this way, stigmatisation, rejection and discrimination are forced back. Furthermore, registered nurses should act as role models in creating awareness by showing their own support and responsibility in the care for people living with HIV [10]. Nevertheless, the people living with HIV should play a major role themselves in educating and motivating their peers.
- Interpersonal relationship needs can be met by registered nurses through establishing more support groups and by creating a system for supervision of these support groups [11]. Registered nurses should also assess the needs of the members of the support groups. This allows them to give information on certain topics or skills which are felt as a need.
- Cultural and spiritual needs can be met by integrating traditional healing and spirituality in the current health-care system for people living with HIV. Registered nurses should encourage religious organisations and churches to be more open about HIV and AIDS and churches should offer supporting facilities to which counsellors at the health clinics can refer their patients [10]. Next to that, traditional African beliefs should be recognised and registered

nurses should advise people living with HIV to consult traditional healers who can identify the ultimate cause of the disease which is very important in the African believe system [30,10]. Registered nurses and other health care workers from the clinics should also meet with the traditional healers regularly, so that the traditional practices that enhance the quality of life of people living with HIV can be identified and encouraged.

- Registered nurses can address the need for self-actualisation of people living with HIV by encouraging and fulfilling their learning, stimulation and activity needs through by workshops and trainings on HIV and AIDS and other relevant subjects. The own initiative of the people living with HIV should be encouraged here by registered nurses who should act as role models in this matter. People living with HIV should for example apply for sponsorship for their support group themselves. Furthermore, people living with HIV should be encouraged and should encourage others to disseminate correct values related to HIV and AIDS within the community.

Although this study provides a rich discussion of how poverty-stricken people experience living with HIV and what their support needs are, there are some limitations to the study that should be noted. Firstly a relatively small sample was included in the study, which cannot fully represent all the poverty-stricken people living with HIV in the Potchefstroom district. Secondly, further research to implement the developed framework and guidelines is necessary in order to test whether they are effective. The researcher has discussed this with the School of Nursing Science at the North-West University, Potchefstroom Campus. A Master's student will be appointed for implementing the results from this study. Finally, the research findings are solely based on interview data. Observations of experiences and needs of poverty-stricken people living with HIV could be helpful in order to verify what the participants expressed during the interviews.

In conclusion, it can be stated that the experiences and needs framework and the guidelines that were developed in this study can serve as useful tools for people who are working with poverty-stricken people living with HIV. They can guide and empower professional nurses and other health care workers, including volunteers, in the Potchefstroom district in assisting poverty-stricken people living with HIV and in enhancing their quality of life in accordance with their culture. The framework and guidelines can also be applied to other comparable settings in other parts of the world because human needs are universal [26]. Further research studies to implement the guidelines that were formulated in this study and to evaluate whether these guidelines are effective would be useful.

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3. Conclusion, recommendations, shortcomings and guidelines for effective support for poverty-stricken people living with HIV in the Potchefstroom district

3.1 INTRODUCTION

In the article, the research findings, which consist of the experiences and support needs of poverty-stricken people living with HIV were discussed. Direct quotes supported the findings, which were related to and confirmed by relevant literature. This eventually led to the development of guidelines for support in order to assist poverty-stricken people living with HIV and to enhance their quality of life. In the following paragraphs the conclusions and shortcomings of the study are discussed. Recommendations for nursing education, research and practice are described and finally, the guidelines, which were developed in this study, are discussed.

3.2 CONCLUSIONS

The objective of this study was to explore the experience, identify the support needs and formulate guidelines for effective support for poverty-stricken people living with HIV in the Potchefstroom district. This objective was achieved by obtaining data in in-depth interviews, analysing them and relating them to relevant literature. After data analysis and consensus discussions with the co-coder, six main themes, namely: facilitating experiences, impeding experiences, basic needs, psychosocial needs, cultural-spiritual needs and self-actualisation needs, were identified. The conclusions that could be drawn from these main themes, are described below.

3.2.1 Facilitating and impeding experiences

The first two main themes that were identified resulted from the first guiding question that was asked in the interviews: 'How does it feel for you to live with HIV?' The participants expressed a variety of experiences, which could be subdivided into facilitating and impeding experiences. The facilitative experiences relate to needs that are already fulfilled and have contributed to a person's quality of life. The impeding experiences represent the limited possibilities poverty-stricken people living

with HIV encounter due to their HIV positive status. Both the facilitating and impeding experiences influence the support needs. Facilitative experiences can support people who still struggle to fulfil the need for acceptance and disclosure and who are still not coping with their HIV positive status. Impeding experiences directly result in certain needs of support in this study. Therefore, the impeding experiences played an essential role in the following four main themes that address the support needs.

3.2.2 Basic, psychosocial, cultural-spiritual and self-actualisation needs

The second guiding question in the interviews: 'What do you need to feel supported?' resulted in the remaining four main themes: basic, psychosocial, cultural-spiritual and self-actualisation needs.

The basic needs formed a clear pattern and were often mentioned as the most important needs by the participants. This is confirmed by Maslow (*in*: Kozier, Erb & Berman, 2000:191) who indicates that basic needs, including physiologic needs, such as air, nutrition, water, hygiene and shelter, are the needs which are crucial for survival. If these needs are not met, a person's quality of life is seriously limited.

Accepting oneself, wanting to be treated as a normal person, support groups and counselling were mentioned as the most important psychosocial needs by the participants. It was confirmed in the literature that every individual needs recognition and respect, to share and meet with others in interpersonal relationships and counselling in order to cope with stressful events such as HIV infection (Department of Health, 2003:14; Kozier, Erb & Berman, 2000:191; Russell and Schneider, 2000:18; Van Dyk, 2003:201). HIV positive people in this study especially felt these needs because the stigmatisation which they are exposed to causes loneliness.

Cultural-spiritual needs were expressed by the participants as important in feeling supported. The cultural needs were evident in the need for traditional healing which was experienced as relevant additional support by the participants. Relevant literature confirmed this by pointing out that traditional healers play an important role in addressing the 'why' and 'who' of the HIV infection which is important for traditional Africans (Van Dyk 2003:126). The participants also expressed the need to feel spiritually supported which was confirmed by Uys (1999:395-396), who stresses that spirituality assists people in dealing with uncertainties of life and that suffering brings certain spiritual needs to the fore.

The last main theme addressed the need for self-actualisation. The participants mentioned learning needs, the need to disseminate and practice values and the need for activity and stimulation. The majority of the participants expressed the need to develop their abilities and qualities, to be busy and to work. This could be confirmed by Van Dyk (2003:262) who states that HIV-infected people should be encouraged to make decisions for themselves and be assured that they can still be productive in economic, intellectual and social spheres for many years. The participants also highlighted the values which they want to disseminate within the community which could also be confirmed by the fact that values that are important for survival should be included in HIV and AIDS education (Van Dyk, 2003:158).

From these results it became clear that the experiences that were expressed by the participants are very closely related to and determine their needs for support. Although the facilitating and impeding experiences were identified as separate themes, they were also evident in the themes that addressed the basic, psychosocial, cultural-spiritual and self-actualisation needs for support. It can be concluded that it is essential to focus on how poverty-stricken people living with HIV experience living with the HIV positive status before focussing on their needs for support. Once the experience is clear, the main needs for support can be identified and addressed holistically.

3.3 SHORTCOMINGS

Although this study provides a rich discussion of how poverty-stricken people experience living with HIV and what their support needs are, there are some limitations to the study that should be noted. Firstly, a relatively small sample was included in the study, which cannot represent all the poverty-stricken people living with HIV in the Potchefstroom district. Secondly, only one focus-group interview was conducted during the study. More focus-group interviews would have allowed the researcher to compare the focus-group with the one-to-one interviews which would have further enriched the data. Finally, the research findings are based solely on interview data. Observations of experiences and needs of poverty-stricken people living with HIV could be helpful in order to verify what the participants expressed during the interview.

3.4 RECOMMENDATIONS

In this paragraph, recommendations for nursing education, nursing research and the health-care practice are given.

- Nursing education should aim to include the findings of this study in their curriculum. The relevance of firstly addressing the individuality of the needs of poverty-stricken people living with HIV and secondly focusing on the collectiveness of these needs should be stressed in nursing education.
- Further research to implement the developed framework and guidelines is necessary in order to test whether they are effective. The researcher has discussed this with the School of Nursing Science at the North-West University, Potchefstroom Campus. A Master's student will be appointed for implementing the results from this study. Fellow researchers who are interested in further research on this topic are warmly invited to contact the authors of this study.
- The health-care practice and especially registered nurses should play a major role in implementing the guidelines formulated in this study with the goal to enhance the quality of life of poverty-stricken people living with HIV.

3.5 GUIDELINES FOR EFFECTIVE SUPPORT FOR POVERTY-STRICKEN PEOPLE LIVING WITH HIV IN THE POTCHEFSTROOM DISTRICT

3.5.1 Experiences and needs framework

When Maslow's (*in*: Kozier, Erb & Berman, 2000: 191) and Uys' (1999) view on human needs were merged and applied to this study after data analysis and consensus discussions, the experiences and needs framework in Table 2 arose. Both these views on human needs are very applicable to the needs that were found in this study and the data started taking on a structure and were enriched by relating them to these needs divisions. The framework formed the basis for the guidelines for effective support for poverty-stricken people living with HIV that were developed in this study.

While the experiences and needs framework was developed, the researcher found that especially the impeding experience of poverty-stricken people living with HIV directly determines their support needs. The existing body of knowledge could not confirm this finding and it should therefore be highlighted as a unique finding. Facilitative experiences also relate to needs and are important in supporting people who still have impeding experiences, but in this study, the participants regarded these needs as already fulfilled. Therefore they are not included in the framework, but in the guidelines for support for poverty-stricken people living with HIV, which follow after the framework in Table 2.

The impeding experiences are depicted in the left hand column in the framework and directly linked to the needs resulting from that experience in the right hand column. The experience of a lack of food for example, results in nutritional needs and poverty relates to financial needs. The experience of different types of stress relates to both psychosocial and cultural-spiritual needs, therefore stress is covering these two levels of needs in the framework. There are people who discuss their stigmatisation experiences with peers, which is part of the psychosocial needs, while others rather search for traditional healing or spiritual help when they are stigmatised.

Although the framework links the experiences and needs which are most likely to relate, the lines in the framework should not be seen as fixed and it should be applied individually to each and every individual. This leads to the conclusion that the needs of poverty-stricken people living with HIV are determined by their experience and therefore highly individual. Once the individual needs are assessed, one can address the collectiveness of these needs compared to the needs of other people living with HIV by applying a support system in which collective needs can be met. Since a person's perception of a need is based on the learning and the standards of that person's culture, respecting a person's culture is a prerequisite in addressing a person's needs (Kozier, Erb & Berman, 2000:192).

Table 2: Needs and experiences framework for poverty-stricken people living with HIV

IMPEDING EXPERIENCES	NEEDS
Basic problems:	Basic needs:
<ul style="list-style-type: none"> • lack of hygiene; 	<ul style="list-style-type: none"> • hygiene needs;
<ul style="list-style-type: none"> • lack of food; 	<ul style="list-style-type: none"> • nutritional needs;
<ul style="list-style-type: none"> • physical problems; 	<ul style="list-style-type: none"> • need for physical well-being;
<ul style="list-style-type: none"> • lack of (info about) treatment; 	<ul style="list-style-type: none"> • need for (info about) treatment;
<ul style="list-style-type: none"> • poverty. 	<ul style="list-style-type: none"> • financial needs.
Stress:	Psychosocial needs:
<ul style="list-style-type: none"> • stigmatisation; 	<ul style="list-style-type: none"> • self-concept needs;
<ul style="list-style-type: none"> • loneliness; 	<ul style="list-style-type: none"> • interpersonal relationship needs;
<ul style="list-style-type: none"> • fear of death, disclosure, anxiety. 	<ul style="list-style-type: none"> • emotional needs.
	Cultural-spiritual needs:
	<ul style="list-style-type: none"> • Traditional healing;
	<ul style="list-style-type: none"> • spirituality.
Necessity of life:	Self-actualisation:
<ul style="list-style-type: none"> • lack of knowledge, eagerness to learn; 	<ul style="list-style-type: none"> • learning needs: knowledge, insight, skills;
<ul style="list-style-type: none"> • negligence of values; 	<ul style="list-style-type: none"> • practise and spread values;
<ul style="list-style-type: none"> • lack of activity, unemployment. 	<ul style="list-style-type: none"> • Activity and stimulation needs.

3.5.2 Guidelines

In congruence with the objectives of this study, guidelines for effective support for poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district were formulated. The guidelines were based on the experiences and needs framework in Table 2. It should be stressed that as was previously stated, one should firstly assess the individual needs whereafter the collectiveness of these needs can be addressed by comparing them to the needs of other people living with HIV. The guidelines that follow represent a support system in which these collective needs can be met, but they should not be regarded as all inclusive. There may be a need for other kinds of support that are not included in the guidelines, which makes the individual assessment of the needs essential. Nevertheless, it is the individual's responsibility to express the needs at the NGOs dealing with HIV and AIDS and other relevant services so that they play an active role in addressing their needs themselves and are encouraged to make their own decisions (Van Dyk, 2003:262).

As was stated in the overview of this study, it is expected from registered nurses to form the backbone of the HIV and AIDS support services by supervising voluntary lay counsellors and other health-care workers in the community (Van Dyk, 2003:9). This study resulted in guidelines for effective support for poverty-stricken people living with HIV and the role of the registered nurse, who will be responsible for supervising the implementation and evaluation of these guidelines, should now step in. Registered nurses should ensure that the guidelines are used efficiently and can empower health care workers to assist poverty-stricken people living with HIV and to enhance their quality of life in a manner that is in accordance with their culture. The guidelines are given to the Department of Health in the Potchefstroom district from where they will be distributed to the registered nurses in the different health clinics in the district. It is expected from the Department of Health to fulfil the overall supervising role in implementing these guidelines.

- Registered nurses can address the need for hygiene, adequate nutrition, physical well-being and treatment by creating awareness for these needs among their colleagues and patients and within the community. This can be done by distributing HIV and AIDS pamphlets and posters and facilitating HIV and AIDS workshops and training for health-care workers and people living with HIV at the health-care services in the Potchefstroom district. Registered nurses can involve HIV positive people who have experience with and knowledge concerning these needs in this awareness process because they exactly know what a person living with HIV goes through.
- The need for obtaining nutrition and the financial needs can be met by the registered nurses through skills development, which can enable HIV positive to find a job, to establish vegetable gardens and to successfully follow the application procedure for welfare grants. Awareness campaigns within the community that stress the need for nutrition and finances can help creating a broad support network for poverty-stricken people living with HIV. Next to this, registered nurses can improve the system for the distribution of food parcels by identifying the organisations that are responsible for the distribution and assessing their distribution procedure. In this way, the experiences of poverty, unemployment and a lack of food and activity can be addressed which were stressed as severely impeding experiences.
- Registered nurses can meet the need for a healthy self-concept and emotional needs by creating more awareness of HIV and AIDS in the community through HIV and AIDS workshops and pamphlets and by motivating others to organise activities in which AIDS education is integrated, such as sports activities. In this way, the experiences of stigmatisation, rejection and discrimination can be forced back and psychosocial and cultural-spiritual needs can be met as depicted in the framework. As HIV and AIDS counsellors, registered nurses can address the self-concept and emotional needs by establishing a trust relationship, being non-judgemental and conveying their skills (Van Dyk, 2003:207). In this way, people living with HIV are given the opportunity to be open and express their feelings. This is closely linked to the next guideline on interpersonal relationship needs. Furthermore, registered nurses should act as role models in creating awareness by showing their own support and responsibility in the care for

people living with HIV (Van Dyk, 2003:95). Nevertheless, the people living with HIV should play a major role themselves in educating and motivating their peers.

- Interpersonal relationship needs can be met by registered nurses through identifying the need for establishing more support groups and by creating a system for the supervision of these support groups (Uys, 2002:108). Registered nurses should also assess the needs of the members of the support groups. This allows them to give information on certain topics or skills which are felt as a need. Support groups can play an important role in reducing the experience of fear of death, disclosure and anxiety because they enable people living with HIV to share and discuss these experiences with peers and professional nurses.
- Cultural and spiritual needs can be met by integrating traditional healing and spirituality in the current health-care system for people living with HIV. Registered nurses should encourage religious organisations and churches to be more open about HIV and AIDS and churches should offer supporting facilities to which counsellors at the health clinics can refer their patients (Van Dyk, 2003:311). In this way, the experiences of stigmatisation and loneliness can be minimised. Next to that, traditional African beliefs should be recognised and registered nurses should advise people living with HIV to consult traditional healers who can identify the ultimate cause of the disease which is very important in the African believe system (Van Dyk, 2001:5; Van Dyk, 2003:315). Registered nurses and other health care workers from the clinics should also meet with the traditional healers regularly, so that the traditional practices that enhance the quality of life of people living with HIV can be identified and encouraged.
- Registered nurses can address the need for self-actualisation of people living with HIV by encouraging and fulfilling their learning, stimulation and activity needs through workshops and trainings on HIV and AIDS and other relevant subjects. This can address the lack of knowledge and the eagerness to learn which are experienced by people living with HIV in this study. The own initiative of people living with HIV should be encouraged by the responsible registered nurses who should act as role models in this matter. People living

with HIV should for example apply for sponsorship for their support group themselves. Furthermore, people living with HIV should be encouraged and should encourage others to disseminate correct values related to HIV and AIDS within the community.

3.6 CONCLUDING REMARKS

In conclusion, it can be stated that the objective of exploring the experiences and identifying the support needs of poverty-stricken people living with HIV in the Potchefstroom district was met and led to the formulation of guidelines for support for these people. The experiences and needs framework and the guidelines that were developed in this study can serve as useful tools for people who are working with poverty-stricken people living with HIV. They can guide and empower professional nurses and other health care workers, including volunteers, in the Potchefstroom district in assisting poverty-stricken people living with HIV and in enhancing their quality of life in accordance with their culture. The framework and guidelines can also be applied to other comparable settings in other parts of the world because human needs are universal (Kotze, Erb & Berman, 2000:192). Further research studies to implement the guidelines that were formulated in this study and to evaluate whether these guidelines are effective, would be useful.

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Appendix A

Request for permission to conduct research

Dear Sir/Madam,

My name is Anita Feitsma and I am an M.Cur. student at the School of Nursing Science at the North-West University, Potchefstroom Campus. I would like to ask your permission for conducting the following research project:

Experiences and needs of support of poverty-stricken people living with HIV in the North West Province.

The poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district have uttered a gap in the support after having been diagnosed HIV positive. There is support for these people before and shortly after the HIV test by means of counselling, but there is no continuation in the form of follow-up support such as support groups or practical support. Often patients only receive support again when they are in need of home-based care.

As part of the preparation for my research, I have spent some time in the informal settlements in the Potchefstroom district and confirmed what is stated above; the majority of the poverty-stricken people living with HIV do not feel supported. This results in a need to explore the experiences and needs of support of poverty-stricken people living with HIV so that guidelines can be formulated to assist these people in handling their HIV-infection and to enhance their quality of life. This is the focus of the research project for my Master's Degree in Nursing Science. The research proposal for this project has been approved by the Research Committee of the School of Nursing Science and by the Ethics Committee of the Faculty of Health Sciences.

The study is based on the following objectives:

1. To explore and describe the experience of poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district.
2. To explore and describe the needs to feel supported of poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district.
3. To formulate guidelines for support in order to assist poverty-stricken people living with HIV and to enhance their quality of life.

The research will focus on these objectives by conducting a qualitative research project in which in-depth interviews will be conducted. Mediators who are working for the NGOs dealing with HIV and AIDS in the Potchefstroom district and who are well known to the poverty-stricken people living with HIV will be approached for assistance in obtaining participants. The criteria for inclusion for the participants in this study are as follows:

They must:

- be living with HIV and form part of the poverty stricken population in the informal settlements of the Potchefstroom district;
- have given consent to participate in the study and agree with the recording of the interviews;
- be able to communicate in Setswana or English.

Confidentiality will be a primary concern in this research; the identity of the participants and the collected data will be kept confidential at all times.

Attached, please find a copy of the research proposal which includes more detailed information concerning the study.

Hope to hear from you soon.

Yours sincerely,

Anita Feitsma

(M.Cur. Student)

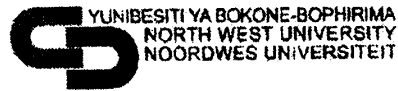
Cellphone: 082-5304085
E-mail: 13115626@puknet.puk.ac.za

Prof. M. Greeff	Prof. M.P. Koen	Mr. A.J. Pienaar	Mrs. C.S. Minnie
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(Project leader)	(Supervisor)	(Co-supervisor)	(Assist. supervisor)
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Appendix B

Permission to conduct research from the North-West University, Potchefstroom Campus: Academical Administration



Akademie Administrasie
Privaatsak X6001
POTCHEFSTROOM 2531
Tel (018) 299-2840
Faks (018) 299-2443
E-Pos akaemd@puk.ac.za

11 Oktober 2004

Mej AT Feitsma
Rissikstraat 96
POTCHEFSTROOM
2531

Geagte Mej Feitsma

REGISTRASIE VAN TITEL: M.CUR (VERPLEEGKUNDE)

Die Fakulteitsraad van Gesondheidswetenskappe het op hul jongste vergadering u titel soos volg goedgekeur:

Experiences and needs of support of poverty-stricken people living with HIV in the North-West Province

Let asseblief daarop dat bogenoemde titel glad nie mag verander word sonder dat u daarvoor met u studieleier oorleg gepleeg het en die goedkeuring van die Dagbestuur verkry is nie.

U moet asb. drie maande voor u beplan om in te dien, ondergetekende skriftelik kennis gee.

U aandag word gevestig op die volgende publikasie:

Handleiding vir nagraadse studie.

Hierdie handleiding is by die *Van Schaik-boekwinkel* beskikbaar en bevat uitgebreide riglyne en wenke ten opsigte van skripsies, verhandelinge en proefskrifte.

Die volgende paragrawe in bogenoemde publikasie het veral betrekking op administratiewe aspekte wat deur u nagekom moet word:

1.9 Indienings- en eksamineringsprosedure

U word aangeraai om ook weer die volgende A-regulasie in u Jaarboek na te gaan om te verseker dat vereistes op u van toepassing is, nagekom word:

Regulasie A 11

Eksaminatore is benoem.

'n Voorspoedige studietydperk word u toegewens.

Die uwe

Mev. EM DANILATOS

n. DIREKTEUR: AKADEMIESE ADMINISTRASIE



POTCHEFSTROOMKAMPUS
Privaatsak X6001, Potchefstroom, Suid-Afrika, 2520
Tel: (018) 299-1111 • Faks: (018) 299-2799
Internet: <http://www.nwu.ac.za>



Appendix C

Permission to conduct research North-West University, Potchefstroom Campus: Ethics Committee



Miss A Feitsma
Postal Cubicle 520
North-West University
(Potchefstroom Campus)

Research Support
Tel (018) 299 2558
Fax (018) 297 5308
Email drvealn@puk.ac.za

23 May 2005

Dear Ms Feitsma

APPROVAL FOR EXPERIMENTING WITH HUMAN SUBJECTS (QUALITATIVE)

Approval has been granted on 15 October 2004 for your project "*Experiences and needs of support of poverty-stricken people living with HIV in the North West Province*". The reference number is 04K12. Please quote this number in all correspondence regarding your project. According to a decision by the Senate (4 November 1992, Art. 9.13.2) approval of a project is valid for a period of five years. There after you have to re-apply.

A report regarding ethical aspects of this project, as well as possible publications resulting from this study, has to be submitted during June of each year. Such document will be forwarded during May 2005.

Wishing you every success

Yours sincerely

Estelle le Roux
SECRETARIAT : ETHICS COMMITTEE



HEAD OFFICE
Private Bag X6001, Potchefstroom, South Africa, 2520
Tel: (018) 299-4900 • Fax: (018) 299-4910
Internet: <http://www.nwu.ac.za>



In accordance with section 23(1) of the Higher Education Act, 1997 (Act No. 101 of 1997), as amended, the Potchefstroom University for Christian Higher Education and the University of North-West merged to form the North-West University on 1 January 2004. In accordance with section 24(1) of the Higher Education Act, 1997 (Act No. 101 of 1997), as amended, the staff and students of the Sebokeng Campus of the Vista University were incorporated into the North-West University on 7 January 2004.

Appendix D

Permission to conduct research Department of Health, Potchefstroom sub-district

**DEPARTMENT OF HEALTH
LEFAPHA LA PHOLO
POTCHEFSTROOM SUB-DISTRICT**



Private Bag X1253
POTCHEFSTROOM
2520

2 Gerrit Maritz Street
Dassierand
POTCHEFSTROOM
2531



Republic of South Africa

Republic ya Africa Borwa

Telephone: (018) 2975061/2/3
Fax: (018) 294 4509/ 297 3389
E-mail: Amohutsioa@nwpg.gov.za



Enquiries: Mrs. M A Mohutsioa

Reference:

"Celebrating Ten Years of Democracy and
A Celebrated Health Service Delivery"

"Celebrating Ten Years of Democracy and
A Celebrated Health Service Delivery"

The North West University
School of Social Studies and Governance
Private bag X6001
Potchefstroom
2520

To: Anita Feitsma
Cc: Prof. M Greef
Prof. M P Koen
Mr. A J Pienaar
Mrs. C S Minnie

Permission to conduct research

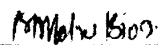
This letter confirms that the management team of the Potchefstroom sub-district of health has received your letter requesting permission to conduct research.

The management team would therefore like to inform you that permission is rightfully granted for you to conduct your research proposal within the sub-district.

However we would like you to share the results with our office so that we are able to identify as to whether the health service is equitable, accessible and acceptable to the community and improve where there is a need.

Wishing you the best of luck in your studies

Thank you,


MOIPOLAI ANNAH MOHUTSIOA
ACTING SUB-DIRSTRICt MANAGER
26. OCTOBER 2004

Appendix E:

Request for assistance of mediators

Dear Sir/ Madam,

My name is Anita Feitsma and I am an M.Cur. student at the School of Nursing Science at the North-West University, Potchefstroom Campus. I would like to request your assistance in the following research project for my Master's Degree:

Experiences and support needs of poverty-stricken people living with HIV in the Potchefstroom district.

The research proposal for this project has been approved by the Research Committee of the School of Nursing Science and by the Ethics Committee of the Faculty of Health Sciences. As we have already discussed in several meetings, my research project will be focused on poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district because they have uttered a gap in the support after having been diagnosed HIV positive. In order to formulate guidelines to assist these people in handling their HIV infection and to enhance their quality of life, there is a need to explore the experiences and needs of support of poverty-stricken people living with HIV.

The study is based on the following objectives:

1. To explore and describe the experience of poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district.
2. To explore and describe the need of poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district to feel supported.
3. To formulate guidelines for support in order to assist poverty-stricken people living with HIV and to enhance their quality of life.

The research will focus on these objectives by conducting a qualitative research project in which in-depth interviews will be conducted. The criteria for inclusion for the participants in this study are as follows: They must

- be living with HIV and form part of the poverty-stricken population living with HIV in the informal settlements of the Potchefstroom district.;
- have given consent to participate in the study and agree with the recording of the interviews;
- be able to communicate in Setswana or English.

Confidentiality will be a primary concern in this research; the identity of the participants and the collected data will be kept confidential at all times. Attached, please find a copy of the research proposal which includes more detailed information concerning the project.

Hope to hear from you soon.

Yours sincerely,

Anita Feitsma
(M.Cur Student)

Cellphone: 082-5304085
E-mail: 13115626@puknet.puk.ac.za

Prof. M.P. Koen	Mr. A.J. Pienaar	Mrs. C.S. Minnie
(Supervisor)	(Co-supervisor)	(Assist. supervisor)

Appendix F

Information for participants and request for participation

Information concerning the participation in the following research project:

Experiences and needs of support of poverty-stricken people living with HIV in the North West Province.

Dear Mr/Ms/Mrs,

Hereby I would like to request you to participate in this research project on living with HIV. I am a Master's student at the School of Nursing Science at the North-West University in Potchefstroom. The objective of my research project is to explore and describe your experiences of living with HIV and your support needs. When your experiences and support needs are known, ways of giving you the support you need can be developed, so that you can be better assisted. The Research Committee of the School of Nursing Science and the Ethics Committee of the Faculty of Health Sciences at the North-West University have approved the study.

Your participation will include that we meet for an interview, which will be recorded on a voice recorder and will last about one and a half hours. The interview will take place in a comfortable room where your privacy is ensured. Your name will neither be on the voice recorder nor in the research report or publication and all the information you give me will be kept strictly confidential by locking it away in a safe place to which only I have access. A psychiatric nurse will be available to support you after the interview, if needed. Your participation in this study is totally voluntary.

If you have any questions concerning the study or on your participation in this study, please feel free to ask me at any time. I would very much appreciate your assistance, because your input will be extremely valuable to my research.

You are kindly requested to sign the attached consent form or to give verbal consent to confirm that you are willing to participate in this research.

Appendix G

Informed consent form

Research title:

Experiences and support needs of poverty-stricken people living with HIV in the North West Province

The researcher:

I have discussed the risks, benefits and obligations involved in this research project with the participant, and in my opinion, the participant understands this information.

.....

.....

Researcher

Date

The participant:

Hereby I give consent to voluntarily participate in the above research project. I agree with participating in an interview and with the tape-recording of that interview. I understand that my participation is voluntary and that I may refuse to participate or withdraw from the research project at any stage.

.....

.....

Participant

Date

Appendix H

Field notes

Observational notes:

The participant was a 40-year-old poverty-stricken woman living with HIV. The participant's appearance gave the impression that she was taking good care of herself. She has overweight and had little pimples in her face. The researcher had met the participant at the hospice clinic and at a later stage at the Bambanani Youth Project. As the researcher approached the participant with the request to participate in an interview, she immediately agreed. One of the Bambanani caregivers translated the participant's answers from Setswana into English, but the participant understood most of the questions in English. The interview took place on a Thursday morning, the 28th of April 2005, from 9:00 until 9:40. The venue was a 'private room' at the office of the Bambanani Youth Project.

Theoretical notes:

The participant was really willing to talk and told the researcher very personal things, such as the story that her boyfriend left her and that he never told her he had a family. The participant was struggling at home because she doesn't have a job at present and her mother is not supporting her. But she is searching for help in any way she can and she said she feels strong, even though she is struggling. Like the participant said herself; there are people who don't believe that she is HIV-positive because she is always happy. The participant seemed most worried about her 5 year old child who will be taken away from her if she does not care for her properly. Therefore she inquired about the food parcels from Bambanani during the interview; she is struggling to obtain food every day.

Methodological notes:

People from the project were disturbing during the interview even though the researcher and interpreter had made very clear that they were having a private conversation. People who entered the office were very loud, but it seemed to disturb the researcher much more than the participant herself who just kept on talking. Otherwise, the room and the manner in which the participant, interpreter and researcher were sitting around a table, made the atmosphere very comfortable.

Appendix I

Part of a transcription of an interview

- R: Can you tell me something more about the support, what is important for you? You said family, friends, support group, what is the thing, which makes you feel supported?
- P: There are many things we talk ne, like the basics of support group. Like today we are going to, I don't know whether it is going to be all right, but this things (P. holds a piece of paper on which she has written some things) it's going to be for you.
- R: Mmm, mmm.
- P: In our support group we need many things. We are running short of many things like (P. reads from her paper) the transport, eco-gardening in our yards, support sponsorship, groceries for those who don't get the grant.
- R: Yeah.
- P: So if we are in a support, we are going to support each other.
- R: Mmm, mmm.
- P: Maybe someone will come with something intelligent. Like this one of eco-garden, if he or she plants something in the yard, then she starts selling, at least she is going to earn something, you see?
- R: Yeah, yeah.
- P: So I see to start with a support group is too much better than sitting at home thinking, stress yourself.
- R: Yeah. It is difficult when you are alone?
- P: Ee, it is difficult. So we try to start this thing last year, but only to find out, we were only 2 and this other girl, she is not staying permanent in Potch.
- R: Ah, ha.
- P: So I stayed. And for the 2nd time I met S. (P. in interview 17), so S. give me strength, I give her strength, so we start this thing.

Appendix J

Framework for data analysis

The focus of this study is:

1. To explore and describe the experience of poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district.
2. To explore and describe the need of poverty-stricken people living with HIV in the informal settlements in the Potchefstroom district to feel supported.
3. To formulate guidelines for support in order to assist poverty-stricken people living with HIV and to enhance their quality of life.

Data collection:

To explore the experience of poverty-stricken people living with HIV and their needs to feel supported, the following two central questions were asked in the in-depth interviews:

- Can you tell me your story, how does it feel for you to live with HIV?
- What are your support needs?

Data analysis:

A description of the data analysis procedure is given below:

- The interviews are read several times in order to become familiar with the data and to get an overview of the interview as a whole before breaking it up into parts (De Vos: 2003:343).
- The transcripts are divided into three columns. The far left column is for concepts, the middle column contains the data and the column to the right is for personal perceptions and ideas.
- The shortest or most interesting interview is chosen and read again.
- The transcript is re-read and spoken words and sentences, which will be used as units of analysis, are underlined.

- The underlined words and sentences are written in the far left column as categories and the perceptions or ideas that come up are written in the column to the right.
- By reading the categories in the far left column, the main and sub-categories become clear and are identified.
- These main and sub-categories are coded by giving them an abbreviation (Burns & Grove, 2001:597);
- Eventually, a manageable set of data is obtained by identifying five or six general themes, which are written into the article (De Vos, 2003:343). Now the researcher starts looking for larger opinions on and linkages among the data and identifies apparent patterns, which are explained and described.
- Following this, the data are represented and visualised in table form, which indicates the main and sub-categories. Hereby, a short and clear overview of the identified patterns is given and the different patterns can be compared (De Vos, 2003:344,345).
- Finally, the table is re-read and finalised by refining the categorisation where necessary.

These steps are repeated for the rest of the transcripts.