THE IMPACT OF SOCIAL SUPPORT ON PEOPLE WITH HIV/AIDS AT VHEMBE DISTRICT

By

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MAY 2005
DECLARATION

I, the undersigned, hereby declare that this thesis is my own original work and that it has not been submitted previously in its entirely or in part to any other university for a degree.

Signed ……………………..    Date …………………..
ABSTRACT

This research investigated the impact of social support on people living with HIV/AIDS. The main aim of the research was to establish the impact that social support or lack thereof has on the lives of people living with HIV/AIDS at Vhembe District in Limpopo Province.

HIV/AIDS is a stigmatised disease and such stigmatisation together with lack of knowledge and unrealistic fears can lead to communities, families and friends of the infected people treating them inappropriately or detrimentally. Infected people can also choose not to disclose their status because of fear of being stigmatised. However, despite all the negativity surrounding HIV/AIDS epidemic, there are those who are brave enough to disclose their status not only to their families but to their communities as well.

In this research ten (10) respondents, both male and females were interviewed by making use of a semi-structured interview schedule. And since HIV/AIDS is a sensitive and personal topic, an availability sampling method was used. The semi-structured interview schedule consisted of both closed and open ended questions.

The researcher used the qualitative method. The findings and responses of all the respondents were analysed and discussed in line with the findings that were described in the literature on HIV/AIDS issues by various authors.

The findings of this research can be used by the department, social workers, families of infected people, home based care workers, doctors and nurses and other professionals who work closely with HIV/AIDS infected people. These findings
can be used to broaden people’s understanding on the importance and impact of social support or lack thereof to those who are HIV/AIDS infected.
ACKNOWLEDGEMENT

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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>CONTENTS</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CHAPTER 1</strong></td>
<td></td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td></td>
</tr>
<tr>
<td>1.1. Introduction</td>
<td>1</td>
</tr>
<tr>
<td>1.2. Motivation for the choice of the subject</td>
<td>2</td>
</tr>
<tr>
<td>1.3. Problem formulation</td>
<td>3</td>
</tr>
<tr>
<td>1.4. Aim/goal and objectives of the study</td>
<td>5</td>
</tr>
<tr>
<td>1.4.1. Literature study</td>
<td>6</td>
</tr>
<tr>
<td>1.4.2. Social support</td>
<td>6</td>
</tr>
<tr>
<td>1.4.3. Department of Health and Welfare</td>
<td>6</td>
</tr>
<tr>
<td>1.5. Research questions for the study</td>
<td>7</td>
</tr>
<tr>
<td>1.6. Research approach</td>
<td>7</td>
</tr>
<tr>
<td>1.7. Type of research</td>
<td>8</td>
</tr>
<tr>
<td>1.8. Research designs</td>
<td>8</td>
</tr>
<tr>
<td>1.9. Research procedures and strategy</td>
<td>9</td>
</tr>
<tr>
<td>1.10. Pilot study</td>
<td>10</td>
</tr>
<tr>
<td>1.10.1. Literature review</td>
<td>11</td>
</tr>
<tr>
<td>1.10.2. Consultation with experts</td>
<td>11</td>
</tr>
<tr>
<td>1.10.3. Feasibility of the study</td>
<td>12</td>
</tr>
<tr>
<td>1.10.4. Pilot testing of semi structured interview schedule</td>
<td>13</td>
</tr>
<tr>
<td>1.11. Description of the research population, delimitation/boundary of the sample and sampling method</td>
<td>14</td>
</tr>
<tr>
<td>1.11.1. Population of the study</td>
<td>14</td>
</tr>
<tr>
<td>1.11.2. Delimitation/boundary of sample</td>
<td>14</td>
</tr>
</tbody>
</table>
1.11.3. Sampling method 15
1.12. Ethical issues 16
  1.12.1. Harm to the respondent 17
  1.12.2. Informed consent 17
  1.12.3. Violation of privacy 17
  1.12.4. Deception of respondents 17
1.13. Definition of key concepts 18
1.14. Contents of research report 20

**CHAPTER 2**

**HIV/AIDS AND ITS IMPACT ON PEOPLE INFECTED WITH AND AFFECTED BY IT**

2.1. Introduction 22
2.2. Overview on HIV/AIDS? 22
  2.2.1. What is HIV/AIDS? 23
  2.2.2. How is HIV transmitted? 23
  2.2.3. How can HIV be prevented? 23
2.3. HIV/AIDS epidemic in South Africa 24
2.4. Factors that make South Africa more vulnerable to HIV/AIDS epidemic 25
2.5. HIV/AIDS impact on children 26
2.6. HIV/AIDS and women 29
  2.6.1. Socio-economic status 29
  2.6.2. Biological factors 32
  2.6.3. Sexual practices and epidemiological factors 33
2.7. Reducing the impact: Priority issues 34
  2.7.1. Accelerate socio-economic development 34
  2.7.2. Improve prevention programmes 35
2.7.3. Establish inter-sectoral coordination 36
2.7.4. Make hard strategic choices 37
2.7.5. Improve workplace programmes 37
2.7.6. Strengthen health sector programmes 38
2.7.7. Reduce HIV/AIDS stigma 39
2.7.8. Support affected people and orphans 41
2.7.9. Improve the status of women 41
2.7.10. Improve information on the epidemic and its impact 42
2.8. Summary 42

CHAPTER 3
SOCIAL SUPPORT

3.1. Introduction 43
3.2. Social support defined 43
3.3. Characteristics of social support networks (as outlined by a report on participatory workshops, 2002: 17) 46
3.4. Barriers to (social) support 47
3.4.1. Fear of rejection 47
3.4.2. Lack of knowledge 48
3.4.3. Financial problems 48
3.5. A continuum of services 49
3.6. Summary 52
CHAPTER 4
PRESENTATION AND INTERPRETATION
OF THE EMPIRICAL STUDY ON THE IMPACT
OF SOCIAL SUPPORT ON PEOPLE WITH HIV/AIDS

4.1. Introduction 53
4.2. Presentation of data 54
4.2.1. Biographical data 54
4.2.1.1. Age of the respondents 54
4.2.1.2. Gender of the respondents 54
4.2.1.3. Educational level of the respondents 55
4.2.1.4. Economic status of the respondents 56
4.2.1.5. Marital status of the respondents 56
4.2.2. Disclosure of status 56
4.2.2.1. Feelings after disclosure 61
4.2.2.2. Reasons for disclosure 62
4.2.3. Social support 65
4.2.3.1. Lack of social support 70
4.2.3.2. Other source of social support 72
4.2.4. Economic status 74
4.2.4.1. Source of income 76
4.2.4.2. Number of dependents 79
4.2.5. Emotions about HIV/AIDS status 80
4.2.5.1. HIV/AIDS stigma 82
4.2.5.2. HIV/AIDS comments by others 83
4.2.5.3. Feelings about negative remarks regarding HIV/AIDS 85
4.2.6. Summary 86
CHAPTER 5
CONCLUSIONS AND RECOMMENDATIONS

5.1. Introduction 87
5.2. Conclusions based on the findings of the study 88
5.3. Recommendations 90
5.3.1. Department of Health and Welfare 90
5.3.2. Social workers 91
5.4. Bibliography 91

FIGURES

Fig. 4.1: Disclosure of status 58
Fig. 4.2: family social support, views on social support and Types of social support 65
Fig. 4.3: Economic status 76

ANNEXURES

Annexure A: Semi structured interview schedule
Annexure B: Consent form
Annexure C: Letter of approval
CHAPTER 1

1.1. INTRODUCTION

HIV / AIDS is a serious and an incurable disease that has become a threat to human kind. The disease has both medical and social implications. For many, being diagnosed HIV positive is like a death sentence. This fear is created mostly by lack of information about the disease. Even though HIV / AIDS is the most talked about disease, there are still a large number of people who are ill informed about it.

The disease does not only affect those infected by it, instead it affects everyone, that is, family, friends, work market and the community at large. Davies, Schneider, Rapholo and Everatt (1998:7) assert that “the HIV / AIDS epidemic affects everyone, every family, every social institution, every organization and indeed every business, big and small”. Contrary to popular belief that HIV / AIDS only infects specific population groups within the society, the disease does not discriminate. It knows no colour, race, gender or religion, which means that anyone can be infected and affected by it.

Given the fact that HIV/AIDS is the most stigmatized disease of all times, people affected by it stand a greater chance of being stigmatized as well. It is because of such actions and behaviours that those infected by it are more often than not, reluctant to disclose their status. According to Kinghorn and Steinberg (1999:27) people with the disease need to be confident that revealing their status will not expose them to prejudice, or financial and other penalties.
1.2. MOTIVATION FOR THE CHOICE OF THE SUBJECT

The researcher is currently employed by the Department of Health and Welfare as a social worker based in Makwarela Welfare office. The researcher started working with HIV / AIDS clients in 2001. One such person passed away while under the care of his mother. There are also some HIV/ AIDS clients who are staying alone, either due to lack of support from families and friends or their partners have passed away as a results of the disease.

This has motivated the researcher to have an interest in establishing the impact that social support has on people with HIV/ AIDS. The researcher strongly believes that knowing and having family and friends who care can play an important role in the lives of people with HIV/ AIDS. Even if they were on the verge of death, such people can die happily knowing that they were cared for, and if they have children, then they will know that their children would be cared for after their death.

Another factor that motivated the researcher has to do with the stigma attached to the disease. The stigma is so serious that people with HIV/ AIDS end up being disowned by their own families and therefore become outcasts of the society. More often than not, people with HIV/ AIDS do not disclose their status because they are afraid of how their families will react to the news. Kinghorn and Steinberg (1999:27) emphasize that it is essential that the current stigma surrounding HIV / AIDS is reduced.
The research has obtained data on HIV/ AIDS from the health section of the Department of Health and Welfare, specifically for the Vhembe District.

According to statistics, the number of HIV / AIDS infected people is growing rapidly. It shows that from January to March 2002, there was a total number of 602 people who tested HIV positive. During April to June 2002, that number has doubled to 1468. Meanwhile the number of infected people has been increasing at an alarming rate as the combined statistics from January to July 2002 shows that 2070 people are suffering from HIV/ AIDS epidemic.

It should however, be borne in mind that the above statistics may not be a true reflection of the actual number of people infected with the disease, as there are those who get sick and die before they are even tested. On the other hand, there are also those who refuse to give consent to voluntary testing. This can only mean that the problem is more serious than statistic shows.

The above statistics motivated the researcher to establish the impact of social support or the lack thereof has on the lives of people with HIV/AIDS at Vhembe district in Limpopo Province.

1.3. PROBLEM FORMULATION

Within a research context, the formulation of a problem introduces the necessity of defining all the concepts used and of determining the variables and their relationships (Bless and Higson- Smith ,2000:26). Meanwhile, Fouché (2002:106) asserts that there are a number of factors about which the researcher must make decisions, resulting in a
formal problem formulation. And these factors are: the unit of analysis, the research goal and the research approach. Based on the above statements relevant to problem formulation, the researcher defines it as one’s knowledge about the proposed area of study based on both personal observation and literature.

HIV / AIDS is the most formidable public health problem facing South Africa today. The epidemic poses a major challenge to everyone and is a problem that requires communities, non-governmental organizations, governmental departments and social institutions to work in collaboration with each other if the disease is to be brought under control. A true partnership is important to face the problem.

Davies et al. (1998:7) point out that in South Africa, it is estimated that as many as 1000 people, mostly young people, are infected everyday. This is an indication that the epidemic is spreading rapidly and people are dying as a result. People infected with HIV/AIDS epidemic need the support of their families and those closer to them. But this can be too much expectation especially in the rural areas, where people are still not yet well informed about the disease. Hence most people infected with HIV / AIDS are less likely to be accepted by their families, friends and relatives.

The issue of sufficient support network for people with HIV/ AIDS is very important. It cannot, therefore, be over emphasized because it has a crucial role to play in the well being of the infected people. Naturally, we all need support when we are going through some difficult times in our lives, and knowing that one has people who care can make all the difference in the world.
The implication of this is that there is a great need to care for people with HIV/AIDS. Jones (2001:10) clearly states that access to care for people with HIV/AIDS is undoubtedly one of the most complex development challenges that the world currently faces, raising ethical, political, economic and social issues that most of us would prefer not to have to face.

During the last stage of the disease, which is characterized by serious sickness, people with HIV/AIDS are always in and out of the hospital. When they are at the hospital, they are cared for by the relevant professionals, but when they are at home, it becomes a different issue because they need special care from their families and other social support systems. But from the researcher’s experience, as related by clients, this is not always the case with all people with HIV/AIDS, as most of them are treated badly by their own families. Sadly, these people have nobody to turn to and to care for them.

Therefore, this research proposes to investigate the importance of social support on the lives of people with HIV/AIDS as well as the kind of support that they expect from their families and friends.

1.4. AIM / GOAL AND OBJECTIVES OF THE STUDY

According to Grinell (1981:47) goals are ultimate values to be achieved. While Webster’s third international dictionary (1961:972, 1556) as cited by Fouché (2002:107) defines both “goal” and “objective” as “the end towards which effort or ambition is directed: aim, purpose.” Fouché goes on to indicate that the terms goal, purpose and aim are thus often used interchangeably. Providing a different
definition is Mouton (1996:101) who states that the research objective or purpose gives a broad indication of what researchers wish to achieve in their research. Based on the above definitions the researcher defines goals and objectives simply as broader and specific ways through which a study wishes to attain.

The main aim and goal of the study is to establish the impact that social support or lack thereof has on the lives of people with HIV/AIDS at Vhembe district in Limpopo Province.

The objectives of the study are:

1.4.1 Literature Study

- To review literature on HIV/AIDS and social support.

1.4.2 Social support

- To conduct empirical study on social support that people with HIV/AIDS receive.

1.4.3 Department of Health and Welfare.

- To arrive at recommendations and suggestions to the Department of Health and Welfare, specifically for social workers who are working closely with HIV/AIDS infected and affected people.
1.5. RESEARCH QUESTIONS FOR THE STUDY

It is important for a researcher to have research questions as they may act as guidelines on what to be studied. De Vos and Van Zyl (1998:267) point out that the research question helps to narrow down the problem to a workable size.

A question to be addressed in this research will be (although not limited to) the following:

- What is the impact of social support or the lack thereof, on the lives of People with HIV/AIDS?

1.6. RESEARCH APPROACH

Fouché (2002:104) indicates that research approach refers to quantitative or qualitative or combined quantitative-qualitative. But Grinnell (1981:183) refers to an approach as a method and defines it as the plan or design for the process of finding a solution to the research problem posed by the investigator.

The researcher used a qualitative research approach since the study was focusing on experiences of respondents. The researcher opted for this approach because the study was focusing on experiences of the respondents about the disease as well as their feelings with regard to social support or the lack thereof, that they received from their families. Thus, involved exploration of feelings. According to Grinnell (1988:186) qualitative research places emphasis on fully describing and comprehending the subjective meanings of events to individuals.
and group caught up in them. Qualitative research is idiographic, thus holistic in nature, and the main reason is to understand social life and the meaning that people attach to everyday life. It basically seeks to understand phenomena within a particular context.

1.7. TYPE OF RESEARCH

The study was an applied type of research as this is a research in which the researcher contributes knowledge in the practice. Applied research is defined by Arkava and Lane (1983:12) as research which addresses immediate problems facing the professional in practice, with the goal of scientific planning of induced change in a troublesome situation. While Bless and Higson–Smith (2000:155) refer to it as social research that has the primary aim of finding solutions to specific concerns or problems facing particular groups of people, by applying models or theories developed through basic research.

More information has been said and highlighted about HIV / AIDS, the study was therefore contributing to what other researchers have also said about the subject.

1.8. RESEARCH DESIGNS

Research design is defined by Mouton (1996:107) as a set of guidelines and instructions to be followed in addressing the research problem. Bless and Higson-Smith (2000:156) provide a closely related definition by referring to it as the set of procedures that guide the researcher in the process of verifying a particular hypothesis and excluding all other possible hypotheses or explanations. On the basis
of these definitions, the researcher defines research design as specific ways on how the researcher will conduct the study.

The study was descriptive in nature. Descriptive research is a social research with the primary aim of describing (rather than explaining) a particular phenomenon (Bless and Higson-Smith, 2000:154). However, Newman (2000:21-22) emphasizes that descriptive research presents a picture of the specific details of a situation, social setting or relationship. It is the researcher's view that the latter definition was more relevant to the topic under study as it focused on how the impact of social support from families and friends or the lack thereof influenced the lives of those infected with HIV/AIDS.

As pointed out by Babbie (1998:91), many qualitative studies aim primarily at description. When using a descriptive design, the main purpose is to describe situations and events.

1.9. RESEARCH PROCEDURE AND STRATEGY

According Grinnell (1981:47) a procedure refers to prescribed specific manner in which the goals are to be achieved. Procedure is also defined by the Oxford College Thesaurus (1998:639) as a course of action, line of action or plan of action. As explained by Fouché (2002:271) the term strategy or strategies will be utilized for the equivalent of research design in quantitative approach. Therefore, the researcher defines research strategy as plan that the researcher develop on how to conduct the study.
The study was conducted in areas that fall under Vhembe District in Limpopo Province. The respondents of the study were clients with HIV/AIDS, that are already being assisted by Welfare offices and hospitals. The researcher made use of a semi-structured interview schedule as a method of data collection. Newman (2000: 512) states that interview schedule is the name of survey research questionnaire when a telephone or face to face interview is used. Greeff (2002:302) emphasizes that semi-structured interviews are especially suitable when the issue is controversial and personal. In this regard HIV/AIDS is both controversial and personal.

The respondents were interviewed in the researcher’s office in order to minimize stigma if they are visited at their respective homes. Since the researcher made use of an interview schedule, a pilot study was conducted with two HIV / AIDS clients.

1.10. PILOT STUDY

Pilot study is defined as the process whereby the research design for a prospective survey is tested in order to find out if people can understand the wording, New Dictionary of Social Work (1995:45).

While Bless and Higson-Smith (2000:155) mention that a pilot study is integrated summary of all available literature relevant to a particular research question. Therefore pilot testing would simply mean carrying out the pilot study. According to Strydom and Delport (2002:337) a pilot study assists, moreover, in estimating the time and costs that may be involved, as well as in pre-empting the problems that may arise during the actual qualitative interviews.
1.10.1 Literature review

Mouton (1996:119) defines literature review as a “map” or “maps” of the terrain. On the other hand Fouché and Delport (2002:127) state that literature review is aimed at contributing towards a clearer understanding of the nature and meaning of the problem that has been identified.

The researcher reviewed the relevant literature on HIV / AIDS to enable her to arrive at important aspects to be included in the literature of the study. Literature was also used to validate the findings from collected data. The researcher utilized the Academic Information Services (AIS), Internet and other relevant sources to obtain more information on the topic.

1.10.2 Consultation with experts

The Pocket Dictionary of Current English (1984:258) defines an expert as someone who is highly practiced and skilful or well informed in the subject. Thus the researcher defines an expert as someone who is more knowledgeable about a particular subject.

The purpose of consultation with experts was to determine that there is really a need for the study to be conducted. The significance of such a consultation can never be over emphasized as it assisted the researcher in terms of themes to be included in the literature review. Sharing the same sentiment is Strydom and Delport (2002:337), who highlight the fact that interviewing experts is important in qualitative research, for the purpose of identifying themes for further investigation in order to do valid literature review with a view of verifying findings.
The researcher interviewed persons who are experts on the subject of HIV / AIDS. The first expert to be interviewed was Mrs T.E. Musandiwa, who is a chief professional nurse based at Tshilidzini Hospital in Limpopo Province.

The second expert was Mrs. A. Nkuna, who is a chief social worker a co-coordinator of Vhembe district HIV/AIDS Malamulele social. She is based at Thohoyandou regional office for Health and Welfare.

The third expert was Ms Florence Nekhubvi of Vhuawelo Community Project, who, together with other women within their community, provide home based care to HIV/AIDS clients.

Ms. Nowazi Gazi from the University of Pretoria Centre for AIDS was also consulted. She used to work as a project manager and is also a psychologist by profession. She has since resigned from this position and is doing other responsibilities.

1.10.3 Feasibility of the study

The term feasibility means practicability, possibility, workability, viability, suitability and expedience, The Oxford College Thesaurus (1998: 289). However, Bless and Higson-Smith (2000:154) refer to a feasibility study as a study designed to determine whether particular strategy or intervention is likely to reach its stated objectives.

It is the researcher’s opinion that it was feasible to conduct the proposed study in terms of the availability of literature, respondents and finance. There is much literature on HIV/AIDS; and in terms of
financial costs, the researcher managed as she was being sponsored by the Canon Collins Educational Trust For Southern Africa and the Department of Health and Welfare in Limpopo Province. The researcher would like to highlight the fact that since some of the potential respondents were in the AIDS stage, some of them died before she had an opportunity to interview them. It was therefore not feasibly possible to interview all available respondents.

A letter of permission was obtained from the Department of Health and Welfare in Limpopo Province on 11 February 2003 to enable the researcher to interview social welfare clients as the respondents for the study.

1.10.4 PILOT TESTING OF THE SEMI-STRUCTURED INTERVIEW SCHEDULE

A pilot study was conducted with two HIV/AIDS clients who were not included as respondents in the main study. It helped the researcher to construct the questions appropriately and to remove some of the questions that did not seem to serve a purpose at all. It also ensured that there was a flow in the way questions were asked.
1.11. DESCRIPTION OF THE RESEARCH POPULATION, DELIMITATION / BOUNDARY OF THE SAMPLE AND SAMPLING METHOD

1.11.1 Population of the study

According to Rubin and Babbie (1997:238) a study population is that aggregation of elements from which the sample is actually selected. Newman (2000:201) refers to study population as a target population and defines it as a specific pool of cases that the researcher wants to study. The researcher therefore defines a study population as a group of units that are chosen to enable the researcher to obtain relevant data.

For the purposes of this study the population was clients with HIV/AIDS in Limpopo Province. The population of the study was HIV/AIDS clients who are receiving social and material support services within Vhembe district social welfare offices as well as at hospitals. This may reduce stigma attached to HIV/AIDS as clients may be reluctant if the researcher just approached them requesting to know their status for the purposes of conducting the research. The fact that they were already service recipients meant that their HIV/AIDS status was already known.

1.11.2 Delimitation / boundary of sample

As it has already been indicated that HIV/AIDS is a stigmatized disease, this can have a negative impact on the study’s sample size. Although there are probably more people infected with AIDS but
because of the stigma attached to it, there are less people coming out and disclosing their HIV / AIDS status.

The researcher interviewed 10 HIV/AIDS respondents, who were male and females of different age groups. The sample consisted of any HIV/AIDS client who stays within and are client of the Vhembe district welfare offices and hospitals.

1.11.3 *Sampling method*

Bailey (1982:91) clearly states that sampling methods can be classified into those that yield probability samples and those that yield non-probability samples. Providing a closely related definition is Bless and Higson-Smith (2000: 84) who indicate that sampling means abandoning certainty in favour of probability. Therefore, the researcher defines sampling method as a technique that the researcher uses to select a sample.

The researcher used availability sampling method. The contributing factor for the choice of this sampling method has to do with stigma attached to the disease. “In non-probability sampling, there is no way of forecasting, estimating or guaranteeing that each element in the population will be represented in the sample” (Leedy ,1993:200). Thus the availability sampling makes no pretence of being representative of a population. Availability sampling makes use of those respondents who are nearest and most easily available. Strydom and Delport (2002:334) indicate that in qualitative studies non-probability sampling methods are utilized. And Denzin and Lincoln (2000: 370) point out
“thus to study the particular is to study the general”. These authors believe that any case will have attributes of the universal.

1.12. ETHICAL ISSUES

The researcher thinks that it is of utmost importance that one comply with professional ethics when conducting a study. Strydom (1998:24) defines ethics as a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employer, sponsors, other researchers, assistants and students. Meanwhile the Webster’s New World Dictionary as cited in Babbie (1998:438) defines the concept “ethical” as conforming to the standards of conduct of a given profession or group. On the basis of the above two definitions, the researcher defines ethics as moral principles and rules that the researcher must adhere to when conducting a research to ensure that respondents are not deceived, harmed in any way or forced to participate in the research process.

1.12.1 Harm to the respondents

The study will not expose respondents to any harm, be it physical, emotional or psychological. It should, however, be taken into consideration that some respondents, especially those who have not yet come to terms with their HIV AIDS status, may become emotional. If they did become too emotional during the interviewing session, the researcher would have suggested a break or would have stopped the
session. Other arrangements would have been made when they would be able to answer the research questions.

1.12.2 Informed consent

Each of the ten respondents read or had the content of the consent form read to them with all the explanations. All of them signed up the form as a way of showing that they are agreeing to be part of the research process.

1.12.3 Violation of Privacy

To ensure privacy, the researcher has taken into consideration issues of confidentiality and anonymity. The study will adhered to the above issues by refraining from mentioning respondents by their names. Since the respondents were already part of the office caseload, they were known to the researcher, therefore there was no way in which their privacy would be violated in this research.

1.12.4 Deception of respondents

The researcher explained to the respondent what the research is all about and how it will benefit them and other people infected with HIV/AIDS. As soon as that has been achieved, they were requested to sign the consent form as a way of accepting responsibility to participate in the study. However, all respondents were also informed that they were under no obligation to participate in the research. This meant that they only participated out of their own free will. “Emphasis was therefore placed on accurate and complete information so that subjects would
fully comprehend the investigation and consequently be able to make a voluntary, thoroughly reasoned decision about their possible participation” Strydom (2000:26).

The researcher reviewed literature on HIV/AIDS, wrote a proposal and after the proposal was approved, she interviewed the respondents. Informed consent for the interview was obtained from the respondents and the principle of confidentiality was adhered to. This was achieved by not requesting the respondents to reveal their names as well as by not referring to their names during the process of analyzing and interpreting data.

1.13. DEFINITION OF KEY CONCEPTS

For the purpose of this study, the following terms are defined as follows:

HIV : Kinghorn and Steinberg (1999:4) defines HIV as the “human immunodeficiency virus”.

: Murray (1999:5) defines HIV as a virus which gets into cells of one’s body and breaks down the body’s resistance to diseases.

: The researcher defines HIV as a virus which weakens the body’s immune system to fight (against) disease, therefore making the body prone to many opportunistic diseases.

AIDS : “Aids stands for acquired immune deficiency
syndrome”, meaning: (a) Acquired-not genetically inherited but due to something in the environment, (b) Immune deficiency –weakness or inadequacy of the body’s main disease fighting mechanism, the immune system and (c) Syndrome- many different symptoms, disease and problems, not just one specific disease, Mbuya (2000:11)

: According to Murray (1999:5) Aids is the name given to the diseases that people get when they are infected with HIV.

: The researcher describe Aids as the final and terminal stage (phase) of infection with HIV.


: According to Oxford Advanced Learners Dictionary of current English (1999:594) impact is a strong impression or effect or the action of one object hitting another.

: The researcher defines impact as the effects, both positive and negative, brought about changes in ones life.

According to Bor and Elford (1994:79) social support is an ‘omnibus term’ referring to a ‘meta-construct’ relating to different aspects of social relationship, including the existence, quality and type of interpersonal relationships, the functional context and the perceived quality of the support. 

Social support is defined by the researcher as an assistance given to HIV/AIDS infected persons by family, friends (the larger society) and the relevant professionals, which they (respondents) then use as a coping resource.

1.14. CONTENTS OF RESEARCH REPORT

The study will consist of 5 chapters that are as follows:

Chapter 1: Introduction and motivation of the study. It includes objectives, research questions, problem formulation, research designs, ethical issues, definitions of operational terms and contents of research report. It also focuses on the population of the study, research respondents, sampling method, research instrument and limitations of the study.

Chapter 2: Literature review on HIV/AIDS, what it is, how it is transmitted, how it can be prevented.

Chapter 3: Literature review on social support and how it benefits HIV/AIDS infected people.
Chapter 4  :  This chapter deals with presentation of raw data, findings and the interpretation thereof.

Chapter 5  :  This chapter provides conclusion and recommendations of the study.
CHAPTER 2

LITERATURE REVIEW

HIV/AIDS AND ITS IMPACT ON PEOPLE INFECTED WITH AND AFFECTED BY IT

2.1. INTRODUCTION

This chapter focuses on reviewing literature on HIV/AIDS but since this is a broad subject the study will concentrate on the impact of the epidemic on the family and its sub-systems.

2.2. OVERVIEW ON HIV/AIDS

HIV/AIDS is one of the most formidable disease facing our society today. It knows no race, colour, sex, age, religion, sexual, orientation or social status and thus does not discriminate. Kinghorn and Steinberg (1999:4) stress that HIV respects no boundaries. Seiglie (2000:8) also indicates that no nation is immune. It would therefore, be naive and extremely dangerous for people in any particular group or race to think that they are immune from the epidemic.

The epidemic affects everyone and not only those who are infected but also the community at large. Despite continuous awareness campaigns, the issue of stigmatisation is still attached to the epidemic. And people’s level of knowledge determines how such people react to issues of HIV/AIDS.
2.2.1. What is HIV and AIDS?

HIV is a virus which causes AIDS and when it is in the body it attacks the immune system (Soul City: living positively with HIV and AIDS, 2000:2). Davies, *et al.* (1998:14) explain that HIV stands for Human Immuno-deficiency Virus, the virus which causes AIDS. They continue to describe AIDS as a phase of HIV-infection when a person becomes sick. Mbuya (2000:9) however regards AIDS, (acquired immune deficiency syndrome), as a sexually transmitted disease which can also be transmitted through blood related activities or from mother to baby.

2.2.2. How is HIV transmitted?

There are three main ways in which HIV is transmitted, and Murray (1999:8), Kinghorn and Steinberg (1999:5) and Davies, *et al.* (1998:16) have identified those ways as:

- Sexual intercourse;
- When infected blood is passed directly into the body;
- From an infected mother to her unborn child during pregnancy, childbirth or breastfeeding.

It is crucial that people realize that one cannot get HIV from shaking hands, sharing cups and plates, using the same toilet, looking after animals, sneezing or coughing, sharing a bath, kissing, taking a bus, hugging and wearing second-hand clothes (Murray, 1999:10-11).
2.2.3. How can HIV be prevented?

HIV infection can be prevented by:

- Saying “no” to sex;
- Staying faithful to your sexual partner;
- Using a condom every time you have sex and
- Preventing direct contact with blood by using gloves, plastic bags or other barriers (Key points about HIV/ AIDS, 1998).

The risk of HIV transmission can be reduced by those in authority attending to some issues such as lack of access to health care services, high unemployment, exploitation of women and lack of accurate information on the epidemic.

2.3. HIV/AIDS EPIDEMIC IN SOUTH AFRICA

When a disease spreads rapidly and affects many people, it is known as an epidemic (It affects us all: know the facts, 2002). According to Evian (1991:15) the total number of HIV infected people in South Africa is expected to increase in the next decade. In 1991, there were approximately 15,000 people known to be HIV positive and about 800 known to have AIDS. However, this number has increased drastically. Jackson (2002:10) highlights that the number of people newly infected with HIV in 2001 was being 5 million with women and children being the most newly infected with the virus. It should be remembered that there are some unknown cases. Therefore, the above figures cannot be viewed as the absolute reflection of the HIV/ AIDS epidemic.
Unless there is a medical break-through in finding an affordable cure for AIDS, most of the infected people will become seriously ill and die within a short space of time. It should also be borne in mind that even if a cure was to be found, it would take some time before it is affordable and available to the poor and needy.

2.4. FACTORS THAT MAKE SOUTH AFRICA MORE VULNERABLE TO HIV/AIDS EPIDEMIC

These factors include the following:

- Disrupted families, communal and high levels of poverty.
- Resistance to the use of condoms, which could be based on cultural and social norms.
- Cultural norms that accept and encourage men to have more than one sexual partner.
- The low status of women in society and in relationships, economic dependency and the threat of physical abuse make it difficult for women to protect themselves from infection.
- Good transport infrastructures and high mobility rates allow for a rapid movement of the epidemic to new communities.
- The issue of cultural norms that frown on open discussion about sexual matters (including sex education at schools) with children.

Jackson (2002:8) outlined additional factors as:

- Population movement, including the military;
- Developed trade and transport routes;
- Gender inequity and inequality;
- Lack of social cohesion in some areas;
- Broad sexual mixing patterns and multiple partnership, including commercial sex;
- Various cultural factors (e.g. Low rates of male circumcision);
- High levels of untreated sexually transmitted infections and reproductive tract infections and
- Relatively low condom use.

2.5. HIV/AIDS IMPACT ON CHILDREN

Since HIV/AIDS epidemic is increasing at an alarming rate and it is likely to infect adults who have children, this means that even the number of orphans will increase as well in the next 5-10 years. The resource book on the emerging HIV/AIDS epidemic in South Africa (2001:11) highlights that orphans are perhaps the most tragic and long-term legacy of the HIV/AIDS epidemic. Having said that, it is estimated that by 2005, the number of AIDS orphans is expected to be around 8 million, rising to more than 19.5 million in 2010. Some of these frightening statistics are quoted by Seiglie (2000:8) who clearly indicates that the number of AIDS orphans can rise as high as 13.5 million and is expected to grow to a staggering 44 million over the next decade. According to Ramsden (2002:2) the problems that children face as a result of HIV/AIDS begin long before their parents die.

Problems may include:

- Living with sick relatives and having to care for them;
- Poverty and loss of income when it is the breadwinner who is ill;
- Being unable to attend school;
- Sorrow and distress when they care for dying parents;
- Being forced to take on the role of a parent, when you are still a child yourself;
- Families breaking down and children being divided among extended family members or fostered by strangers;
- The shame of having to beg for food or other basic needs;
- Unfair treatment and bullying because of the stigma of HIV/AIDS;
- Being forced to do child labour (harmful work) in order to survive and
- More and more children leaving their homes to live and work on the streets.

In addition to the above problems, some of the children may be infected themselves and this increases stigmatization and the risk of them being committed to institutions. Social and health care workers have an important role to play in educating families about the importance of family preservation. The researcher has realized, in her line of duty, that some people think that institutionalization is the answer to HIV infected orphaned children. The pros and cons of such an idea are debatable. It should, however, be taken into consideration that caring for these children is one of the greatest challenges facing South Africa (Kinghorn and Steinberg, 1999:14).

The above authors also indicated that AIDS orphans have severe stresses, even if they do not have AIDS. Some of them are likely to end up in child-headed households. They also have less access to basic needs and are faced with worsening poverty as the number of dependents increase in households that have taken them in.
Due to lack of employment and the long period of illness, most people infected with HIV/ AIDS leave no estate when they die and because of that, their children are left with no financial support. And even if the foster care grant is applied, it is a process that takes some time, even years. The process is delayed because of:

- High caseloads for social workers;
- Lack of co-operation from local child welfare commissioners,
- Lack of necessary documents such as birth and death certificates and affidavits in cases where there are no death certificates or the where- about of the surviving parent is unknown and
- Delayed processing of grants from the social security section.

Sometimes some relatives will foster children with the main aim of benefiting from the foster care grant. This requires that social workers to monitor the grant closely to ensure that it is utilized for the benefit of the children in question.

Stigmatization is still being experienced by HIV/ AIDS infected and affected orphans and as a result they may end up in institutions, especially if family members and relatives are not well informed about HIV/ AIDS issues. More often than not, these relatives seem to be under the impression that the infected orphans will be well off in institutions rather than at home, and they, in turn will not be faced with a burden of caring for infected children. While all of this is perceived as helping the orphans, nobody bothers to think about the negative impact that institutionalization might have in a child’s life. Institutionalization should always be the last resort.
The preservation of the family, with the parents (or other close family members and relatives if both parents have died) has always been and continues to be of primary importance (Information guide for social workers on the practical application of the Child Care Act 74 of 1983, as amended and Regulations, 1998:3).

2.6. HIV/AIDS AND WOMEN

Women are more easily infected by the epidemic. They are at greater risk of getting infected because of biological, social and economic factors. According to Pratt (1995:176) women as a group are more vulnerable to becoming infected with HIV than men for a number of reasons which include:

- Socio economic status,
- Biological influences and
- Sexual practices and epidemiological factors.

2.6.1. Socio-economic status

Women are more likely to be socially and culturally vulnerable to HIV infection because they tend to be economically dependent on men. For example, women who are poor may sometimes have sex in exchange for money or special favours (Soul City: living positively with HIV and AIDS, 2000:4). Due to changes in industrialization and socialization there is an increasing number of women headed families. However, most of these families tend to be poorer than those of their male counter-parts. It is also clearly indicated in the Resource book on the emerging HIV/ AIDS epidemic in South Africa (2000:10) that women
headed households in South Africa tend to be poorer than those headed by men, and therefore have less reserves.

Jackson (2002:93) reveals that all over the world women’s human rights are violated everyday. In many societies women do not have control over their sex lives as they must do what their male partners ask them to do and will not ask their partners to use condoms even if they are aware that their partners practise unprotected sex with other women. Having said that, the researcher is of the opinion that people should not be ready to assume the worst about all men and therefore generalize on the basis of such assumptions. As a practitioner, it came as a great shock to the researcher to realise that there are some women who do not want their partners to use condoms, even if the men offer and are willing to use them.

Unemployment is also higher among women than men. This can be attributed to the fact that most women have never been given an opportunity to acquire formal educational qualifications or to work, rather than concentrate on what is perceived as women’s activities such as cooking and taking care of the children at home. Pratt (1995:176) points out that throughout the world, women’s status is always lower than that of their male-counterparts, and have fewer opportunities for education and acquiring financial independence as well as personal freedom. Focussing on similar issues of gender and the inferior status of women is Kisoon, Ceasar and Jithoo (2002:42) who assert that articles in the Women’s Convention which are key protections addressing these issues include the following provisions:
- States should endeavour to modify social and cultural patterns of conduct that stereotype either gender or put women in an inferior position.
- States should ensure that women have equal rights in education and equal access to information.
- States should eliminate discrimination against women in their access to health care, and
- States should end discrimination against women in all matters relating to marriage and family relations.

Due to lack of training and skills, some women may be forced to sell their bodies to earn a living and maintain their children. Widows may become dependent on their husband’s heir for financial support under some customary arrangement and practices, thus, making them more vulnerable to infections. More women face the risk of being abandoned and abused if they disclose their HIV / AIDS status, therefore, the safest thing to do is to keep quiet. According to Kinghorn and Steinberg (1999:14) women and female-headed households are particularly vulnerable to the impact of HIV/ AIDS because of some of the following reasons:

- Cultural, social and economic pressures make women more likely to contract HIV infection than men. Susceptibility is increased by factors ranging from rape, pressure on teenage girls to have relationships with men, and economic dependence on men.
- Women and girls tend to bear the main burden for caring for sick family members but often have less care and support when they themselves are infected.
- HIV/AIDS complications are already the top cause of maternal mortality in South Africa.

2.6.2. Biological factors

Men are reported to be more efficient in transmitting HIV to women than are women to them. In fact, Jackson (2002:87) highlights that gender inequity and inequality are critical factors in the spread of HIV in Africa. Biologically, women are more vulnerable to HIV infection than men because they have more mucosal surface exposed during sexual intercourse. Mazibuko (2002:7) explains that it is easier for women to contract HIV/AIDS during sex because their reproductive organ exposes more tender skin to infection making women more receptive partners during sex.

It is also believed that semen contains a higher concentration of virus than that present in vaginal secretions. For example, engaging in dry sex increases the chance of tearing of the skin, and this in turn increases the chances of infection. If a woman is raped, it is obvious that the rapist will not get her ready for the penetration and such an encounter will result in dry sex, which will result in her delicate sex-organ skin being torn, therefore increasing the risk of infection. It is the researcher’s opinion that there is much to be done in terms of teaching some men how their behaviours impact negatively on the lives of those women they abuse sexually. However, it will be unrealistic for one to think that this can be addressed overnight.

According to Holland, Ramazonoglu, Scott, Sharpe and Thompson (1991:129) AIDS has presented us with an opportunity to reassess
and redefine sexuality. Sexuality is defined as the aspects of gender identity that relate to sex, which includes sexual desire, sexual behaviour and sexual orientation (Jackson, 2002:88). The above author also indicates that men, in many societies are proud of their multiple partners as it shows their sexual prowess. Murray (1999:20) also shares the same view by mentioning that in many societies women are expected to be faithful to their husbands but men are not always expected to be faithful to their wives.

According to Holland, et al. (1991:129) the idea that women are free to choose the most rational form of protection ignores the nature of systematic inequalities in the social relationships between women and men. But contrary to popular belief, there are few men who would never risk and endanger their lives and those of their partners by engaging in unprotected sex. These men would request HIV test and suggest condom protection during sex. Such men are surprised by some female partners’ refusal to use any kind of protection whatsoever.

2.6.3. Sexual practices and epidemiological factors

Women have been victims of violence, including sexual ones over a long period. Jackson (2002:95) suspects that there are four factors that are major determinants of the prevalence of violence against women in societies. These factors are:

- Economic inequality between males and females;
- Use of physical violence to resolve conflicts;
- Low female autonomy and control of decision making in household affairs and,
- Legal restrictions on divorce for women.

It is therefore not surprising that in South Africa, it is a common practice for women to be violated sexually in the form of rape. Sharing the same view is Mazibuko (2002:7) who indicates that a growing number of women experience violence and abuse in their relationships. Some women have sex with men older than themselves, and these men usually have had many sexual partners. Other women also offer sexual favours in return for food, shelter or money. Drug use as a form of sexual enhancer can also increase the risks of HIV infections.

2.7. REDUCING THE IMPACT: PRIORITY ISSUES

HIV/ AIDS impacts negatively on both the individuals infected with and affected by the epidemic, as well as communities and the workplace. HIV prevalence is increasing at an alarming rate and there are still large groups of people who are ignorant and do not have all the facts about HIV/ AIDS. This means that there is still a great need for prevention programmes if the epidemic is to be reduced. Kinghorn and Steinberg (1999:25-28) identify and discuss the following as priority issues:

2.7.1. Accelerate Socio-economic Development

There is a need for increased economic development in our country as poverty and inequality may lead to disruption of stable family and
community life. Thus making people vulnerable to HIV infection as poverty and inequality can increase the impact of HIV/ AIDS. The availability of basic needs is important in enabling families to cope with HIV/ AIDS-related illnesses. Jackson (2002: 5) points out that poverty and malnutrition are increasing, particularly in Southern Africa, worsening HIV infection and spreading its progression to AIDS. The cycle of poverty can be reduced through improved economic development in the form of employment for all and therefore improving the standard of living for the poor.

2.7.2. Improve prevention programmes

It is often said that prevention is better than cure. If HIV is to be reduced, then focus should be on reaching the unreachable and making them aware of the consequences and impact of the epidemic. Some people, especially in the rural areas do not have television sets and radios. This means that it would be even more difficult to reach them. Therefore, it would be naive and wrong for service providers who do radio and television talk shows to address HIV/ AIDS issues on these media, to believe that they are reaching everyone. It is must be ensured that legislation, regulations and attitudes which hinder preventions among those most at risk are challenged and reviewed. All messages communicated through such programmes should be aimed at reducing the stigma of HIV/ AIDS as well as providing information on how to manage the impact of HIV/ AIDS. The programmes must also strive towards assisting people to address their personal, social and economic circumstances.
It is believed that prevention programmes are cost-effective. The costs of delivering prevention programmes can vary widely depending on the strategy used and the nature of the implementing agency. In general, prevention programmes are far more cost-effective than treatment (Resource book on the emerging HIV/AIDS epidemic in South Africa, 2000:21).

2.7.3. Establish inter-sectoral co-ordination

The White Paper for Social Welfare (1997:17) has principles on partnership and inter-sectoral collaboration. The above paper indicates that welfare policies and programmes can be developed and promoted in partnership with organizations in civil society, the private sector and government departments. Meanwhile, an inter-sectoral approach will guide the design, formulation, implementation and monitoring of anti-poverty strategies.

HIV/AIDS is not a “one person” problem; it requires all to be involved. All sectors must work together in the fight against HIV/AIDS. It is clear that no one sector alone can make a significant inroad into the fight against the epidemic. A true partnership involving the government, the private sector and the community is essential to face the problem (Davies, et al, 1998:7). HIV/AIDS issues cannot simply be seen as the responsibility of the public or health sectors alone. Therefore:

- Sectors need to collaborate to build capacity for appropriate responses to HIV among their employees.
- Many of the needs of people with HIV/AIDS will be linked to broader developmental issues such as financial security for their households.
- Inadequate responses by any sector will have a detrimental knock-on effect on other sectors.
- Coordinated strategies are required to ensure that available resources are used in the most effective way to meet the needs of people affected by HIV/AIDS, and that any other important objectives are not unduly compromised.

2.7.4. Making hard strategic choices

At all levels, HIV/AIDS needs are far greater than the resources to satisfy them. However, it is crucial to remember that HIV/AIDS is just one of the many problems facing South Africans. There are still other problems that are of a threat to the country. However, immediate decisions must be made on adequate allocation of resources to HIV/AIDS. And within the available resources for meeting HIV/AIDS specific needs, priorities must be established.

2.7.5. Improve workplace programmes

HIV/AIDS is undoubtedly a major problem facing South African industry. For employers to show that they care about the well-being of their employees, they must develop and improve on workplace programmes. Private and public sector employers have a crucial role to play in reducing HIV/AIDS impact as they have resources, and can direct incentives to make a contribution in combating HIV/AIDS.
HIV/ AIDS educational programmes should be continuous projects rather than annual training courses. Programme directors or managers must make sure that such programmes are not too brief and infrequent. Employees should be constantly reminded of HIV/ AIDS. There should be HIV/ AIDS posters everywhere in the workplace and management should demonstrate its commitment to addressing HIV/ AIDS issues in the workplace.

The support of organized labour for HIV/ AIDS programmes is essential. According to Evian (1991:39) managerial commitment and the allocation of adequate resources for training and AIDS education are essential if programmes are to be sustained. Programmes must balance financial and other cost implications for employers, employees and the broader community.

2.7.6. Strengthen health sector responses

It is indicated that in years to come, HIV/ AIDS will be the single biggest health care issue. Resources will be limited unless HIV/ AIDS is fully integrated into all aspects of both public and private health care sectors. It is a well known fact that South African health care is mainly characterized by two distinct funding avenues, that is, public and private sectors. It is predicted that both public and private sectors will be seriously affected by the HIV/ AIDS epidemic, with seroprevalence levels in the population reaching 13% and 9% respectively by 2010.

It is believed that the effects on the private sector is more likely to be delayed compared to those on the public sector. Projections show that the cost of public sector health care by year 2010 will be R45 000-00
per year while in the private sector it will cost R300 000 -00 per year by 2010. All these costs include all acute in-patient and outpatient care but exclude prevention activities, long stay and rehabilitation activities, and administration and management. Therefore, plans based on projections must be made early to develop capacity for care that meets HIV/ AIDS needs in an affordable and cost effective manner. But most importantly, health workers must be given skills and knowledge to effectively care for HIV/ AIDS people.

2.7.7. Reduce HIV/ AIDS Stigma

Stigmatization is defined as negative thoughts about a person or group based on a prejudiced position (Advocacy for Action on Stigma and HIV/AIDS in Africa, 2001: 1). HIV related stigma and discrimination is widespread. An infected person will refrain from disclosing his/her status because of fear of being stigmatized. The stigma attached to HIV/ AIDS is a major barrier deterring parents from talking openly about sex with their children (Jackson, 2002: 274).

People living with HIV/AIDS (both women and men), their families and those negatively associated with the epidemic (e.g. homosexuals, sex workers, migrants and foreigners) still face stigmatization and discrimination (HIV/AIDS in South Africa, 2003: 21). One of the reasons why stigmatization arises is because HIV/AIDS programmes appear to suggest that some categories of people are more likely to get HIV/AIDS than others. For example those infected with HIV/AIDS may be seen as promiscuous people. But this is not always true as it can also be contracted through other means than sex.
In a study that was done by Fesko (2001: 240), it shows that in discussing their reasons for not disclosing their HIV status, several individuals mentioned the stigma that they felt was associated with the disease. Several women in the study said that they had not told people about their status because of the stigma associated with the disease. From the information mentioned above, it is evident that stigma can be a barrier in offering support to HIV/AIDS infected people, as they may be afraid to disclose their health status.

HIV/AIDS has always been a stigmatized disease. The stigma occurs because HIV/AIDS has long been associated with sex, blood, death, disease and behaviours that may be illegal or seen as immoral. For example, pre-marital sex, extra-marital sex, sex work, men having sex with men and injecting drug users. Jackson (2002:346) stresses that in addition to the stigma itself, HIV/AIDS poses genuinely difficult issues around the rights of people with HIV, the rights of those without, and rights of those whose status are unknown.

It is apparent that people living with the disease need to be confident that knowing and revealing their status will not expose them to prejudice, or financial and other penalties.

Thus if the disease is to be reduced so should the issue of stigma. A case in point is that of Gugu Dhlamini who was killed in December 1999 by members of her community after she had disclosed her health status (Jackson, 2002: 347). The community felt afraid of her living amongst them and that her presence would adversely affect their neighbourhood.
2.7.8. Support affected people and orphans

It is crucial that people infected with and affected by HIV/AIDS must be supported. As the disease continues to affect more people, the number of orphans will increase as well. Therefore, there should be affordable ways to provide financial and other support to infected and affected people. Communities must be made aware about the availability of government grants such as disability, care dependency, child support and foster care grants. Procedures must be clearly spelled out as well as policies that inform them on how to apply for these grants.

2.7.9. Improve the status of women

Changing the social and economic status of women could be a major contribution to reducing the spread of HIV infection and increasing the ability of households to cope with its impact. Most women tend to be economically dependent on their male counterparts. In some cultures women are expected to be obedient to their male partners and do as they are told. This results in lack of assertiveness on their part. Therefore, empowering women educationally and economically becomes a crucial and key element in reducing their dependency on their male partners who put them at risk. Jackson (2002:93) emphasizes that the short term priorities to assist girls and women to avoid HIV infection should include:

- Sexual and reproductive health and life-skills education at school and for out-of-school females and males. This should (include
developing self-esteem, and negotiating and other communication skills, especially among girls);
- Peer education strategies;
- Widespread youth friendly sexual and reproductive health services including voluntary HIV counselling and testing;
- Wide availability of condoms for boys and girls who are sexually active;
- Helping girls in particular to stay in school and not be drawn out because of poverty or for family care needs;
- Promoting economic security for females and their families;
- Encouraging shared care roles in the family by males as well as females and
- Promoting the rights of widows and orphans around inheritance issues.

2.7.10. Improve information on the epidemic and its impact

Resources must be identified to ensure that studies and monitoring systems provide improved information on the impact of HIV AIDS. It has often been indicated that HIV/ AIDS data in South African is scarce and most of the available data is obtained from ante natal clinics. This means that the problem might be even more serious than we are led to believe.

2.8. SUMMARY

This chapter provided an overview on HIV/ AIDS issues as well as concentrating on how the disease affects people’s lives, particularly children and women.
CHAPTER 3

LITERATURE REVIEW

SOCIAL SUPPORT

3.1. INTRODUCTION

This chapter will focus on social support, and provides definitions of what it is. It also looks into a continuum of services to people infected with and affected by HIV/AIDS. Another aspect to be explored in this chapter is the causes of barriers to social support.

When one is infected with HIV/AIDS, it is essential that their families and friends are supportive as social support seeking is a common strategy for coping with personal crisis. Reaching out to those closer to you during the time of a crisis is an indication that you are unable to help yourself. Therefore, lack of social support can be a devastating experience.

3.2. SOCIAL SUPPORT DEFINED

This concept was first articulated by Cassel and Caplan in the early 1970s. Social support has been variously defined since then. Roberts, Cox, Shannon and Wells (1994:159) highlight the fact that some studies have typically conceptualized social support in one of two ways, either from the perspective of social network size and function,
or from the perspective of perceived adequacy of support. Based on this, they defined social network as the social connections provided by the environment in terms of structural (size, density, multiplicity) and functional (provision of information, comfort, emotional support and material aid) dimensions. While they refer to perceived social support as the impact that network has on the individual, based on his or her subjective appraisal.

Ell (1984:134) as quoted by Hurdle (2001:73) note social-services as the emotional support, advice, guidance and appraisal, as well as the material aid and services that people obtain from their social relationships.

Kleinman, Kaplan & Weiss (1984:202-203) indicated that ‘social support’ suggests a stable and reliable interpersonal scaffolding that sustains an individual’s morale, well being or functioning. The term social support is misleading. In its broadest sense, ‘social support’ refers to optimum personal and social integration and may include the following elements:

- Supportive religious and other rituals;
- Supportive values and beliefs by which individuals and families are comforted;
- Supportive shared norms that provide “meaning”;
- Social networks that supply supportive needs;
- The fit between the role(s) of the bereaved and the meeting of acute dependency needs at death and recovery time;
- The availability and supply of nurturing others;
- The availability of supply that “protects” the self;
The function of self supports, in terms of the ability to seek and get support;

- The availability of supportive others who “permit” or elicit emotional release and
- Structural supports such as community work and the like;

The above authors have in addition identified four aspects of social support. These are:

- Enhancing self-esteem and a feeling of being loved;
- Problem-solving;
- Networking and;
- Providing relationship resources for meeting life cycle transitions

According to Roberts, et al. (1994:159) there are five types of social support:

1. Expression of positive affect or caring;
2. Agreement with one’s beliefs or feeling;
3. Encouragement of open expression of beliefs and feelings;
4. Provision of material aid and;
5. Inclusion in a network of mutual or reciprocal help.

Some authors focus on support systems holistically and not specifically on social support. For example, Moutinho (1990:22) explains that support systems can be divided into two broad categories, namely formal and informal support systems. The formal support network includes provincial hospitals, HIV clinics, local authorities and primary
care practitioners (these would be doctors, social workers, nurses and other health care workers).

The informal support network meanwhile consists of partners, family, friends and support groups. Chinkanda (1990:14) has divided the informal network into primary and secondary levels. The primary level is family and next of kin, and the secondary one includes a priest, friend, employer and medicine man. The distinction between familial and non-familial sources of support is considered important because different populations may rely on or benefit to different extents from these separate sources of support (Roberts, et al. 1994:159).

3.3. CHARACTERISTICS OF SOCIAL-SUPPORT NETWORKS (AS OUTLINED BY A REPORT ON PARTICIPATORY WORKSHOPS, 2002:17)

The report shows that the following social support networks are particularly important:

- Positive peer networks can play an important protective role as they give a sense of social acceptance, identity and values. Peer networks are particularly important when other protective factors are not available, such as the case of children orphaned by HIV/AIDS.
- Role models beyond the family can be another important protective factor. Research has pointed to teachers as having especially important role here.
- Family, friends, extended family, neighbours and other local community contacts can also provide a supportive network. The
more children can turn to trusted others in the community, the more able they are to cope with difficult life situations.

Save the Children (UK) conducted a research on “The Role of Stigma and Discrimination in Increasing the Vulnerability of Children and Youth Infected with and affected by HIV/AIDS”. Participatory research methods were used as a method of data collection. The participatory workshops took place in three sites:

- East Rand, Gauteng
- Bloemfontein, Free State
- Ingwavuma, Kwazulu Natal

The aim of the study was to understand stigma and discrimination from the point of view of those most affected by it, that is, children and adults.

3.4. BARRIERS TO (SOCIAL) SUPPORT

3.4.1. Fear of rejection

If someone who is HIV positive is not sure about how family and friends will react to their health status, they may be afraid to disclose their HIV status. Possibilities are also high that they might disclose their HIV status and seek assistance from a professional person. Motang (1990:16) asserts that all individuals with AIDS and many of those closely associated with them are experiencing extreme rejection and isolation due to the public's fear of contamination. Mbuyu (2000:65) agrees with the above author by emphasizing that many
people are unable to tell relatives or friends of their HIV diagnosis for fear of stigma and rejection.

In a study conducted by Goggin, Catley, Brisco, Engelson, Rabkin and Kotler (2001:85) it shows that about 7 percent of women in the study talked about their fear of being rejected because of their HIV positive status. While on the other hand, the White Paper for Social Welfare (1997:89) clearly points out that the combination of material, social and emotional stresses caused by stigmatisation and discrimination make it extremely difficult for people living with HIV/ AIDS to mobilise effectively what is an already limited set of support mechanisms.

3.4.2. Lack of Knowledge

Knowledge is power and without it we perish. How can those close to HIV/ AIDS infected person(s) be of assistance to the victims if they themselves are ill informed about the disease? It is therefore, imperative that people are well informed about HIV/ AIDS issues. According to Kinghorn and Steinberg (1999:7) poor people usually have less access to information about HIV/ AIDS and therefore are less able to protect themselves from infections.

3.4.3. Financial Problems

Sometimes even if there are some family members who may be willing to support those infected with HIV/ AIDS, they may be prevented from doing so because of financial problems. Thus while many families appear to be willing to care for those with AIDS and to nurture and socialize orphans, some are not able to do so owing to financial strains
and poor living conditions. Where these problems may not exist there may be an or absence of close relatives to provide the necessary care and support (White Paper for Social Welfare, 1997:89). Highlighting the same problem is Ramsden (2002:23) who asserts that the burden of care for “orphaned” children can be too great for a poor family, and they may need help in getting financial support.

3.5. A CONTINUUM OF SERVICES

People and families infected with and affected by HIV/ AIDS have the right to receive a wide range of supportive services. These services should be provided in their normal environment consistent with both the child's and family’s strengths, needs and resources. Provision of such services would reduce institutionalization of AIDS orphans and improve the lives of those infected by the disease, thus being cost-effective.

Barth, Pietzak and Ramlex (1993:225) maintain that while the following list is by no means exhaustive, it gives a fair representation of the types of services families with an HIV-infected parent and child might need.

- Specialised medical care, preferably provided at the same facility and at the same time, for the child and other infected family members to help them deal with the effects of HIV infection.
- At a minimum, primary health care from practitioners trained in HIV treatment for the child and other infected family members, preferably primary health care, including prenatal care for pregnant women and for the whole family.
- Comprehensive, family oriented early services for HIV-infected children under the age of 5, including family support and education services.
- Increased access to clinical trials integrated into the comprehensive care and treatment centers to assure up-to-date therapy and therapeutic research benefits for all HIV infected adults, children and youth.
- Early childhood special education programmes for infected children between ages of 3 and 6, and regular special education services for children over the age of 6, including family support services.
- Developmentally supportive child care for the infected child as well as for the non infected children in the family.
- Babysitting and respite from child care.
- Home health and home maker support.
- Readily available and accessible drug treatment programmes, including those designed for women.
- Emotional support for the family, such as grief and bereavement counselling for family members, support groups and counselling for uninfected brothers and sisters, and opportunities for family to provide social support.
- Environmental and social support for the family, such as housing assistance, food stamps and other nutrition programmes, employment assistance, when possible, and legal assistance when necessary.
- Specialised foster care for children or for mother and child care when the biological family is unable to care them.
- Adoption services for both infected and uninfected children when family members are unable to care for them or when they are orphaned by both parents’ death.
- Expedited procedures for extended families to obtain legal guardianship of orphaned children.
- Enhanced efforts to recruit culturally appropriate foster families.
- Small, developmentally supportive, nurturing-group homes to provide transitional or long-term care for those children who are in hospitals for non medical reasons and for whom foster care, adoption or other permanent home arrangements are not immediately possible.
- Subsidized transportation to allow families to use available services.
- AIDS education and prevention programmes for the entire community with a special outreach programmes for persons most at risk, including teenagers, intravenous drug user and sexual partners of intravenous drug users.
- Home based hospice services for the child and family, as well as residential programmes for both the infected parent and child.
- Health and social services for undocumented aliens who are parents of HIV infected children.
- Life skills training and supported employment for those adults capable of working.

The National Department of Social Development needs to develop a policy with regard to assessments of HIV/ AIDS disability grant applications. As a social worker who serves HIV/ AIDS clients, the researcher is alluding to the above issues because of the experiences that she has had regarding clients’ disability grants applications. These are:

- Clients have to wait for months before they go through hospital assessment panels to have their applications completed and
approved. Sometimes even after they would have waited for sometime, their applications can still be disapproved on the basis that they are still healthy. Then they will be referred to the social worker’s office for food parcels.

- If and when their applications are finally approved, they go to social security offices or section to apply for the grant. But there is a problem of the waiting period that ranges between 3-6 months. And if there are in the final stage of the disease, they can die before the grant is paid out to them. The researcher has had clients who died before receiving their grants.

3.6. SUMMARY

The chapter focused on some of the important issues that must be taken into consideration regarding HIV/ AIDS when dealing with and assisting people infected with and affected by the disease. Service providers need to be aware of the role that a family as a system plays. Thus realizing that mobilizing for social support should start at family level.

Due to the nature of the epidemic, it requires vast range of services and these services should be readily available. But in communities where there are no services, people must work together to establish community based services. Thus the availability of such services will ensure that those infected and affected by HIV/AIDS get effective service delivery. One stop centers should also be established so that the infected and affected people do not travel from one point to another before they have access to service.
CHAPTER 4

PRESENTATION AND INTERPRETATION OF THE EMPIRICAL STUDY ON THE IMPACT OF SOCIAL SUPPORT ON PEOPLE WITH HIV/AIDS

4.1. INTRODUCTION

In this chapter, the empirical data is presented as is. Data will be presented in the sequence in which questions were asked in the data collection instrument. The researcher interviewed 10 HIV positive respondents who are receiving material and social assistance from Makwarela Welfare Office.

The semi structured interview schedule consisted of 5 sections, which are outlined as follows:

- Section 1: Biographical data
- Section 2: Disclosure of status
- Section 3: Social support
- Section 4: Economic status
- Section 5: Emotions about HIV/AIDS status
4.2. PRESENTATION OF DATA

SECTION 1

4.2.1. Biographical data

4.2.1.1. Age of the respondents

The ages of the respondents ranged from 19 to 58, but the majority of the respondents were between the ages of 29 to 38. The above data reveals that HIV/AIDS is more likely to affect people who are at childbearing age. Women and female headed households are particularly vulnerable to the impact of HIV/AIDS (Kinhorn and Steinberg, 1999: 14). Again this also highlights that there will be more orphans as a result of the above.

The age factor also has an impact on the economy of the country as well as household incomes since HIV/AIDS is more likely to affect people at the working age.

4.2.1.2. Gender of the respondents

A large number of the respondents were women. According to data collected half of the respondents were single and none was married. Two were separated, one widowed and the last two divorced.

Murray (1999: 20) states that the number of women with HIV is increasing sharply, as already more than half of the HIV infections in Africa are women. And this is extremely serious because women can pass on the disease to their unborn babies when they become pregnant. Kisoon, et al. (2002: 40) ask “what is it that makes women
more vulnerable to HIV/AIDS? There are a number of reasons why women are vulnerable and those persons were discussed in literature review.

The findings of this study revealed that only a small number of respondents were males. However, limited number of male respondents in this study may have to do with the fact that men in many societies are socialised to be self reliant, not to show emotions, and not to seek assistance in times of need or stress.

Such socialization is more likely to lead to expectations that men should protect themselves from potential infections and therefore encourages the denial of risk. The researcher strongly believes that men need to be re-socialized in learning that they are emotional beings, and that it is fine to show one’s feelings when one is hurt(ing)

4.2.1.3. Educational level of the respondents

It has been established in this study that although all the respondents had been to school up to certain level, majority of them never got to grade 12, let alone tertiary education. Lack of education is double edged. On the one hand it leads to lack of financial independency, while on the other hand it decreases one’s chances of getting a job.

However, it is just as important to consider that some of the respondents may not have attended school up to grade 12 because they were living in poverty. The issue of teenage pregnancy may have contributed, as falling pregnant during primary or high school may lead to one dropping out of school for good.
4.2.1.4. Economic status of the respondents

Findings of this study indicate that half of the respondents were employed, others were disability grants recipients, while some were dependent on piece jobs. Only a single respondent was neither employed nor receiving a grant.

4.2.1.5. Marital status of the respondents

This study has clearly shown that being single does not protect anyone from contracting the virus, as long as one is involved in a sexual relationship, then one is prone to infection.

SECTION 2

4.2.2. Disclosure of status

The findings from the study shows that mothers (women) are the most accessible carers who bear many responsibilities to both their children, partners and other family members. Women traditionally provide care to the terminally ill, and girl children in particular may be required to provide care especially in single parent households or when one parent has already died. Sometimes girl children provide care in cases of child headed families or when both parents have passed away. More often than not the elder girl child assumes the responsibility of a parent.
“Since much of the care and support for people affected by HIV/AIDS falls on women’s shoulders, a major task is to find ways of lessening women’s extra workload” (HIV/AIDS in South Africa, 2003: 22). Men should share tasks and responsibilities with women.

Despite the fact that most respondents were able to disclose their status, there were still a small number of those respondents who did not disclose their status. Those respondents who did not disclose had different reasons for not disclosing. Some of those reasons were:

“I was afraid that people would discuss my status as I did not trust anyone and I was scared of being stigmatised because of my status”.

“Afraid that the person(s) I disclosed my status would tell others. But I had been informed at the hospital that if anyone who is aware of my status discloses it to other people without my consent, I could lay a charge against them”.

“People would stigmatisme and that will hurt me”.

“I do not trust my family members or any person, because they can use my status against me especially if we may have differences in the future”.

It is evident from the above responses and findings that there are still some people who would prefer keeping their status a secret, and this may sometimes endanger the lives of those around them. HIV/AIDS is a stigmatised disease, and this can be a major issue that prevent
people from disclosing their status. Poor family relations can also contribute. However, even though these respondents did not disclose their status to their family members, all of them did disclose to the social workers and nurses or doctors and community home based care workers. For the researcher, this means that the respondents felt more comfortable and secure to disclose their status to a professional person, whom they know would keep their status confidential.

It is said that confidentiality must be fully protected at all times (Davies, et al. 1998: 47). It must however, be taken into consideration that there is no absolute confidentiality, especially when one's actions and behaviour may put other people's lives in danger. Not disclosing has its disadvantages, for example, it can lead to social isolation. Sometimes it creates problems in one getting support and being able to explain when one is having a bad day.

**Figure 4.1. Disclosure of status**

<table>
<thead>
<tr>
<th>Respondent</th>
<th>How respondents disclosed status</th>
<th>Reactions of the person to disclosure of status</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>I disclosed to both my mother and brother that I was HIV positive. I informed them immediately after I was diagnosed and I was pregnant at the time.</td>
<td>Supportive, caring, non-judgemental and encouraging me at the same time.</td>
</tr>
<tr>
<td>B</td>
<td>After I was informed that I was positive, I informed my mother first then I informed my father.</td>
<td>They were all surprised and wanted to know whether or not I was sure of my status. And my parents promised to take me to a doctor but unfortunately they have not done so.</td>
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<td></td>
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<tr>
<td>---</td>
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<td>---</td>
</tr>
<tr>
<td>C</td>
<td>I disclosed my status to my younger sister after I was discharged from the hospital. She then informed community based care workers who came to my place to do my laundry and they referred me to the social worker’s office.</td>
<td>My younger sister was scared and afraid because she only associated the disease with immediate death.</td>
</tr>
<tr>
<td>D</td>
<td>After a doctor has informed me that I am positive I then informed my mother and said to her I cannot believe that I am positive. She told me to pray and believe in God.</td>
<td>My mother was hurt but said I should change my lifestyle.</td>
</tr>
<tr>
<td>E</td>
<td>I spent three days after I was diagnosed with the virus without telling anybody. On the fourth day I informed my sister by writing my diagnosis on a piece of paper. My sister replied verbally and we started talking about it. She wanted to know why I did not tell her earlier so I informed her that I was scared of how she would react. She therefore informed my uncle’s wife about my status, who then informed my maternal grand mother.</td>
<td>They all reacted okay and seem to have accepted my status.</td>
</tr>
<tr>
<td>F</td>
<td>I called my mother and sat her down and I explained everything. I wanted her to know my status so that she should not be surprised when I get sick constantly.</td>
<td>My mother cried and I could see that she was hurting but at the same time she had accepted me.</td>
</tr>
<tr>
<td>G</td>
<td>I have not yet disclosed to anyone but do intend doing so.</td>
<td>Not applicable</td>
</tr>
<tr>
<td>H</td>
<td>I have not yet disclosed to anyone at home except to the social worker, nurse and a doctor.</td>
<td>All professionals were helpful and did not say anything to hurt me, instead they encouraged me to take care of myself and informed me on how to do that. The social workers counselled me.</td>
</tr>
<tr>
<td>I</td>
<td>I have never told anyone at home. It is my secret.</td>
<td>Not applicable.</td>
</tr>
</tbody>
</table>
I informed my wife that I had my blood tested and was diagnosed with HIV. My wife acted normal but acknowledged that she may be infected as well.

Data in this study revealed that a vast majority of the respondents had disclosed their HIV/AIDS status to their family members, a social worker, nurse or community home based care workers.

It is vital that HIV positive persons get all social support they need. Having someone to trust when it comes to disclosing one’s status is just as important. The researcher strongly believes that disclosing one’s HIV/AIDS status is a coping mechanism and a way of asking for assistance. Fesko (2001: 236) agrees by asserting that individuals who have begun to accept the diagnosis may disclose their HIV status as a coping mechanism to regain control over their lives and relieve the stress of not disclosing. In this study, some of the respondents said that they disclosed their status because they could not keep it a secret anymore. And that shows that one is more likely to feel depressed, sad and scared by not disclosing one’s status.

The above responses clearly show that people presented with different reactions and emotions. One can see that some people were in denial, others blaming the respondents but there were also those who were caring, supportive and accepting. It is the researcher’s view that sometimes people react the way they do because of lack of knowledge. People need to be educated about HIV/AIDS issues so that they can be supportive.
Kadushin (1999: 199) has noted that family members may have little knowledge about HIV/AIDS. Thus, lack of knowledge may act as a barrier to support.

One respondent stated that her parents wanted to take her to a medical doctor. It appears as if for them, the (problem) HIV status, could be fixed by the doctor, then everything would be fine. This may also be a sign of denial, hoping and wishing that their child does not have the virus and once she sees the doctor she will be fine.

4.2.2.1. Feelings after disclosure

When responding to the question on how they felt after the disclosure, the respondents who disclosed their status revealed that they presented with the following feelings and emotions:

“I felt relieved as I could not eat or do anything before but after the disclosure I felt different”.
“I felt relieved, unlike before I informed them, I was always thinking about my HIV status”.
“I felt good that she accepted me as I am. This also helped me to accept my situation as well”
“I felt relieved that she was able to tell other family members”.
“I have suspected for sometime that I may be HIV positive, so I felt relieved and better about knowing my status”.
“I felt free that at least someone in my family knows”.
“I felt relieved and better that I was sharing my problem with someone in my family, but at the same time scared of what might happen”.


“I felt better because I knew that those professionals will keep my status a secret and will not tell anyone”.

From the above highlighted emotions, one can only conclude that the results of disclosing are far more rewarding than those of not disclosing. It is just as crucial to be empathic to the situations of those who disclose because it is not an easier thing to do. In a study done by Fesko (2001: 240) individuals who disclosed their HIV status reported feeling more relaxed because they did not need to keep a secret. It therefore, goes without a saying that keeping one’s HIV status a secret can actually take a toll on one’s physical and mental health.

4.2.2.2. Reasons for disclosure

As it has already been indicated that disclosing one’s HIV status is a difficult task, it means that a supportive and enabling environment should be created so that people feel free to disclose. From data collected in this study, respondents were prompted to disclose their status because of different reasons, which are highlighted below:

‘I needed my family’s support since they are the closest people to me and I also wanted to make sure that they take necessary precautions when they care for me. I could not keep it a secret because then I would have more explaining to do. For example I would have had to explain why I was not breast feeding’.

“I wanted them to know my status, as I did not want to die without any of them being aware of the cause of my death. Again I hoped
that my younger sister would learn something from my experience and not get herself infected instead, she must be protecting herself”.

“I could not keep it to myself and because I care and wanted my wife to decide whether or not she still wanted to stay with me even after I have disclosed my status”.

“I wanted to share my pain with someone else and I was glad that she accepted me”.

“Wanted her (mother) to be aware of my status. I did not want her to waste her money when I am sick, trying to get me cured, as this disease does not have a cure. She should be using the money for the benefits of my children”.

“I thought it would be better if I informed them (family members) as they would eventually know even if I did not tell them about it since I am more likely to get sick regularly and would lose weight and I wanted them to help me in anyway they can”.

“The realisation that there was nobody else I could tell and if I did not tell anyone, it will always be troubling me”.

“Since I contracted the disease during rape and was taken to a hospital for examination I had to disclose to other professionals as others knew through my blood test and in some I needed material support”.
All of the above responses show that respondents disclosed their HIV status for different reasons, all of which are genuine. It is interesting to note that some respondents chose to disclose their status because they did not want to go through the pain of being HIV positive alone, instead, they wanted to share their pain with someone. Others disclosed their status because they care so much about their family members and they do not want them to contract the virus unknowingly. It has been revealed in this study that people with HIV have certain needs that arise because they are positive. Goggin, *et al.* (2001: 81) state that there are five primary life concerns for people who are HIV positive and these are:

- The impact of stigma associated with HIV/AIDS,
- Child care concerns and care taking roles,
- Social support needs,
- Concerns about death, dying and despair, and
- HIV/AIDS information needs.

However, the researcher has observed that most respondents were more concerned about the impact of the stigma associated with the disease than they were with death and dying. For the researcher, this implies that respondents were scared of facing their own death and dealing with their imminent death. Not talking about it does not necessarily mean they are not thinking about it. It is revealed in the study that all respondents took sometime to disclose their status and this is an indication that they (respondents) went through these stages although some of them may not have gone through them all.
### SECTION 3

#### 4.2.3. Social support

**Figure 4.2: Family social support, views on social support and types of social support**

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Family social support</th>
<th>Views on social support</th>
<th>Types of social support</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>My family assists me with my child and also take care of me when I am sick.</td>
<td>I feel good because I was scared that they would not be supportive.</td>
<td>Emotional and sometimes financial support.</td>
</tr>
<tr>
<td>B</td>
<td>My family have not changed because of my status, they are still the same.</td>
<td>I feel better because I can get help.</td>
<td>When I am in need they help me, emotionally and financially.</td>
</tr>
<tr>
<td>C</td>
<td>They take care of me when I am sick</td>
<td>I appreciate my mother’s efforts and support and I am very grateful for her.</td>
<td>Physical and emotional support.</td>
</tr>
<tr>
<td>D</td>
<td>My mother encourages me to take my medication regularly and timeously.</td>
<td>I feel good because my mother is the one that I disclosed my status to and she has never let me down. She always wants me to be well informed about HIV/AIDS issues. If she hears about any HIV/AIDS product being sold that helps fight the disease she encourages me to buy and use it.</td>
<td>My mother provides me with emotional and moral support since she cannot help me financially. I appreciate her support because she did not disown me on the basis of my status.</td>
</tr>
<tr>
<td>E</td>
<td>When I am sick and cannot walk, my family is always there to give me physical care.</td>
<td>I appreciate their help and support. And I am grateful for their support.</td>
<td>Physical and emotional support. Sometimes when I am sick my sister baths me and changes my bedding.</td>
</tr>
<tr>
<td></td>
<td>Statement</td>
<td>Response</td>
<td>Support Provided</td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>---------------------------------------</td>
</tr>
<tr>
<td>F</td>
<td>When I am without food, my mother gives me some. And sometimes when I want to go to a doctor before I get paid from my job, she gives me money for consultation.</td>
<td>I feel loved and it shows that her love is unconditional. She could have disowned me but she accepted me.</td>
<td>Financial and emotional support.</td>
</tr>
<tr>
<td>G</td>
<td>My children help me with all household tasks, they cook and do the laundry because they know that I am sick.</td>
<td>I feel happy that my children are helping me.</td>
<td>Emotional and physical support.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No financial support since they are just children.</td>
</tr>
<tr>
<td>H</td>
<td>My mother still treats me like she would under any circumstances and have accepted that I cannot change my situation.</td>
<td>I feel good and appreciate her support a lot. Before she was aware of my status, she always accused me of sleeping around and that made my condition worse and she said all those things when she was drunk.</td>
<td>Emotional support.</td>
</tr>
<tr>
<td>I</td>
<td>My mother assists me by taking care of my baby and me when I am sick.</td>
<td>Feel thankful because I can get things that I would not have under normal circumstances.</td>
<td>Financial support as my mother assists me in meeting the basic needs of my family</td>
</tr>
<tr>
<td>J</td>
<td>My wife provides me with physical care.</td>
<td>I feel proud and I can see that she cares for me.</td>
<td>Moral, physical and emotional support.</td>
</tr>
</tbody>
</table>
Data presented above reveal that the respondents felt good, better and supported and they really appreciated their families’ efforts in supporting them during those difficult times. Although the vast majority of the respondents felt good and happy about the way their families were supporting them, there were others who were scared and afraid that they may be abandoned and such fears are realistic. Some fears are general, while others are highly specific.

The need for social support can never be over emphasised. Previously there was less information on social support and its impact on people who are terminally ill, but recently more research have been done in that area. And most of these research show that social support plays an important role in helping the people concerned cope with their illnesses. In Stewart, Hart and Mann's (1995: 1101) view, integration into a social network and the ability to draw support resources from the network can maintain health and facilitate physical recovery from illness. Meanwhile, Reilly, Thom, Woo and Grace (2004: 1) propose that social support can be best understood as the relationships and interactions that provide individuals with assistance or feelings of attachment. Furthermore, they indicated that social support includes social networks, reports of supportive behaviours and perceptions of support adequately.

General fears concern developing AIDS, the stress of coping with uncertainty about one’s future health and loss of control over a future orchestrated by an unseen virus. Specific fears include that of becoming ill, anticipation of pain and disfigurement and concern about
the possible loss of supportive relationships, whether personal or social (Van der Walt and Mckay, 1991: 46-47).

It is not surprising that some of the respondents felt the way they did, and their feelings are normal given their situation. However, it must be borne in mind that people going through similar experiences will always react differently.

Social support assumes many forms and can encompass a variety of relationships and behaviours (Reilly, et al. 2004:4). This was confirmed in this study. Meanwhile, Friedlan, Renwick & McColl (1996:4) define social support as the feeling of being cared for and loved, valued and esteemed, and able to count on others should the need arise. When responding to the issue of the kind of social support provided by their families, most respondents revealed that they were receiving emotional support, followed by financial, physical and moral support.

The researcher believes that the kind of social support that one receives from one's family depends on one's needs, economic status, stage of the disease and the relationship with others. For example, a person who is unemployed is more likely to need financial support than the one who works.

HIV/AIDS is often accompanied by some distress at some point in time over the course of the illness. Therefore, all people who are infected need any kind of social support to help them cope with their situation. It seems as if there is a close link between social support and the psychological well being of people with HIV. And those who are
satisfied with their social support have a greater ability to cope. Reilly, et al. (2004: 1) have identified three types of support:

- Social embeddedness, which is the connections people have to others in their environment.
- Perceived social support, an individual’s cognitive appraisal of connection to others.
- Enacted or received support, behaviours and actions performed by others as they express their support.

Adding on to the above types of social support are those that have been identified by Stewart, et al. (1995: 1108) which are:

- Instrumental support, which is relevant to problem focused coping.
- Emotional support for emotion focused coping.
- Informational support for cognitive reappraisal and redirection of maladaptive coping strategies.

It has already been highlighted that social support will differ and vary according to individual needs. For example, a person who has been diagnosed with HIV is more likely to need informational support than the one who may have developed AIDS. When most people are diagnosed with HIV, they only think about the “here and now”, meaning that they think they will just die within a short space of time. Therefore, this necessitates the needs for such persons to be well informed about HIV/AIDS issues and how they can take care of themselves to prolong their lives.
4.2.3.1. Lack of social support

We all need to have support networks at one stage in our lives and we often get it and sometimes we may even go to the extent of taking it for granted. However, there are some people who lack social support from their families. In this study it was revealed that some respondents were not getting the support they needed from their families and lack of social support brought out emotions such as:

“I am scared that my mother will go to stay with my sister, and my concern is when I will be unable to meet my children’s needs”.

“Getting social support”.

“One respondent commented that “The disease worsens when no one is there for you”.

It was difficult for the researcher to establish whether or not all those respondents who were not receiving any social support were actually not receiving it because their families were unsupportive or because they did not disclose their status; therefore, there is no way that their families would have known that they are HIV positive and subsequently be supportive. One of the dangers of not disclosing one's HIV status is that it can be a hindrance to support. Understanding barriers to social support in the form of network density, disclosure or relationship satisfaction is especially important given the beneficial contribution of social support to the overall health and well being of HIV positive persons. Serovich, Bruker and Kimberly (2000: 2) provide the burner theory and highlight that it includes:
- Lack of family members,
- Lack of acceptance,
- Lack of intimacy,
- Negative interactions,
- Feeling smothered and
- Wanting to protect family members.

Either way, it is crucial not to overlook the fact that barriers can have a negative impact on people with HIV. These authors noted that “under normal circumstances, social support helps individuals to mobilise their psychological resources and master their emotional burdens as well as providing money, materials, skills, and cognitive guidance to handle situations optimally”.

Since HIV positive people rely on both informal and formal social support services, it means that if they do not have a strong informal social support networks, social workers must intervene to ensure the active involvement of HIV positive individuals in the development and maintenance of support networks. It is therefore, important that social work intervention include roles of advocates, brokers, mediators and planners. Having said that does not necessarily mean that social workers must work alone in helping HIV positive people, instead, they must also involve other relevant professionals to ensure proper and efficient assistance.

All these intervention can assist people who are HIV positive to identify alternative support networks, which in turn will enable them to cope.
4.2.3.2. Other source of social support

This study indicates that besides social support that some respondents were getting, there were other sources of social support, which they were also receiving, and these were:

“My brother assist by buying food for me”.
“Getting paid from my job and being able to consult a doctor”.
“Home based care workers and some community members as well as from friends”.
“Hospital (staff members)”
“My brother also provides social support. He calls me regularly and sometimes send me medications”
“None”
“Friends, colleagues and my manager”.
“My uncle’s wife is a nurse, she gives me the relevant medication and my maternal grand mother visits us regularly”.
“None because my extended family members are unaware of my status”.

Having an extra source of social support is like having a back-up plan, if the first one fails then one can always consider and make use of the back up plan. Again for people whose families are not supportive, they can benefit from having an extra source of social support. Other sources of social support are likely to come from friends, community members, home based care workers, colleagues and others. All these sources play a significant role in the life of a person who is HIV positive.
4.2.3.3. Formal social support

A large number of respondents get their formal social support mainly from social workers. However, since they also need regular medical care, they mentioned nurses and doctors as their other sources of formal social support. Having access to formal social support can be beneficial for the person who is HIV positive. For example, different professionals have specific roles to play in order to assist the person concerned. Presently the Department of Health and Welfare in Limpopo Province is providing special food parcels and other food supplements to those who are HIV positive. Those who have reached the terminal stage of the disease also qualify for disability grant.

Although all people are diagnosed either at their local clinics or hospitals, they are always referred to their area social workers for counselling and material assistance. It must be remembered that most people come from rural areas where there is a problem of poverty and unemployment and as a result such people do not eat nutritious and well balanced meals. This can, to some extent, aggravate their illness. Having said that, the researcher thinks that it is important that professional persons must be well aware of all these issues so that they can help those infected accordingly.

Sometimes formal social support network may be the only form of social support that a person has, meaning that professionals must treat those who are HIV positive in a way that would ensure that those people have faith and confidence in them and their services.
For example, they must inform them to practice health promoting behaviours which are identified by Gielen, McDonnell, O’Campo and Faden (2000: 5) as:

- Eating a healthy diet,
- Getting adequate sleep,
- Engaging in regular exercise,
- Keeping stress level down and,
- Taking vitamins.

SECTION 4

4.2.4. Economic status

People who are HIV positive, have got basic needs just like anybody else. And the findings in this study revealed that the respondents met their basic needs through the following ways:

“Dependent on disability grant and also sells fruits and vegetables”.

“Both my wife and I do piece jobs and we also receive food parcels from welfare office once per month”.

“I use my salary to meet some of the basic needs; unfortunately I am unable to meet them all”.

“I use my salary to meet the basic needs and sometimes my sister and I assist each other to buy food and other necessary
needs. We also receive food parcels from welfare office and that help us a lot”.

“Since I am employed I use my salary to meet my needs and those of my children”.

“I earn money by commission but I get a minimum of R600.00 per month”.

“Although I am receiving a disability grant, my mother also assists me from time to time”.

“Not applicable”

This study shows that half of the respondents depend on their salaries, others on their disability grants, while some rely on their piece jobs to make a living and meet their basic needs and those of their families. Others also depend on their extended family members for financial support. Dependency and financial social support from extended family members means that lack of money does not necessarily mean those who are HIV positive would go to sleep on a hungry stomach.

It was also established in this study that there were some respondents who were receiving double or more grants, for example, respondents may be receiving their own disability grant, and if they have a child under the age of 14, they also receive child support grant. And those with children with disabilities also receive care dependency grant.
4.2.4.1. Source of income

The findings of the study indicate that half of the respondents have their salaries as their main source of income. Meanwhile, the other half had their disability, care dependency and child support grants as their sources of income.

One respondent indicated that she earned her salary based on commission meaning that the respondent does not have necessary qualifications which can enable her to get a better paying job.

Figure 4.3: Economic status

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Sufficiency of income</th>
<th>How respondents survive</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Not sufficient</td>
<td>I also receive food parcels from welfare office.</td>
</tr>
<tr>
<td>B</td>
<td>I use my disability grant and my mother also assists me financially whenever she has money.</td>
<td>We try our best to survive with whatever we have.</td>
</tr>
<tr>
<td>C</td>
<td>Both my disability and care dependency grants are insufficient in meeting the basic needs as we spend most of the grant money towards medical expenses and sometimes we have to consult a doctor more than once per month.</td>
<td>We survive with the little things we have.</td>
</tr>
<tr>
<td>D</td>
<td>Not at all</td>
<td>When my sister and I get paid we try to buy whatever is needed, but the situation is difficult.</td>
</tr>
<tr>
<td>E</td>
<td>Not applicable</td>
<td>We are entirely dependent on welfare office for food parcels.</td>
</tr>
<tr>
<td>F</td>
<td>Not sufficient</td>
<td>Get assistance from my mother as well as food parcels from welfare office and all of these augment my salary.</td>
</tr>
<tr>
<td>---</td>
<td>----------------</td>
<td>------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>G</td>
<td>Not sufficient.</td>
<td>I augment my disability grant by selling sweets, biscuits and achaar. I am able to get ± R10.00 per day.</td>
</tr>
<tr>
<td>H</td>
<td>Not sufficient.</td>
<td>By trying to stretch the little salary that I earn and my mother also assists me by buying some things for my son.</td>
</tr>
<tr>
<td>I</td>
<td>Yes, although the grant is too little, I am able to meet basic needs of my family.</td>
<td>Not applicable</td>
</tr>
</tbody>
</table>

Being HIV positive places financial burden on those who are infected that they would not normally feel. It is for this reason that most of the respondents explained that their incomes are insufficient to meet their basic needs and those of their families. Responses from the respondents clearly indicated that they are faced with financial hardships despite the fact that some are employed and others are receiving more than one grant.

For those who are presently employed, they may be better off now that they are still working, than those who are receiving disability and other grants. But when they reach the final stage of the disease and are experiencing much pain due to opportunistic diseases and are always in and out of the hospital, they are more likely to experience more financial burden than their counterparts who were only receiving grants. This is based on the fact that once they reach the final stage, it may not be possible for them to apply for the disability grant, but if they
do apply, chances are high that they may die before the grant is processed and paid out to them.

The issue of a waiting period is a problem because sometimes people do not receive their grants even after the waiting period. It therefore means that they have to re-apply.

“The length of the waiting period for disability benefits could have a significant impact on the relative costs of providing death and disability benefits. The longer the waiting period for disability benefits, the more members will die before they become eligible for a disability grant” (Davies, et al. 1998: 92).

On the other hand, if someone is already receiving the grant and they become too sick to go to the pay point to collect their grant money, they can nominate somebody from their family and give that person power of attorney so that they can go and collect the grant money on their behalf.

Since it was revealed that most respondents are getting far too little to be able to meet their basic needs and those of their families, it means that they need extra financial support so that they can cope with their needs.

The above responses clearly demonstrate that the respondents know how to survive despite the hardship they are faced with. Surviving with what they have and trying to stretch what they have seem to be no longer an option but a must. Food parcels from social workers’ office also play a significant role in assisting respondents to have nutritious
and well balanced meals. Again this provides strong evidence that almost all the respondents were living in poverty, some with no visible means of income whatsoever. For example, there were some respondents who said they are entirely dependent on the welfare office for food parcels, but there are times when there are no food parcels at the office, which means that they would have nowhere to go except to their understanding neighbours.

4.2.4.2. Number of dependents

From data collected, it was established that more than half of the respondents had between 1 to 3 children. Only a quarter of them had between 4 to 6 children, and one (1) respondent has no children. The researcher strongly feels that for those who are HIV positive, having children places an extra burden on them, since children have needs of their own. More often than not “women traditionally shoulder the major care giving burden” (Stewart, et al. 1995: 1101) which means that they are more likely to put the needs of their children ahead of theirs.

Although most respondents were employed and some were receiving grants, they are unable to meet their families needs and their own because they are not using the money for themselves alone, they also have other people in their lives whom they must consider and provide for.

The impact of HIV/AIDS on the economy will be so enormous, and it will affect everyone, not necessarily the individuals and their households but the entire economy of the country. The above argument is based on the following:
- Loss of skilled labourers,
- Individual dependency on the government, for example disability grants, and
- Loss of income.

According to Whiteside (1993: 10), the disease will have an impact at all levels of society and on all aspects of the economy.

SECTION 5

4.2.5. Emotions about HIV/AIDS status

Dealing with one’s feelings about being HIV positive is one issue but coming to terms with it and eventually accepting one’s status is completely a different story. It has been established in this study that all the respondents have accepted their HIV/AIDS status. However, they made it clear that that did not happen overnight as they experienced many emotions at first. Some of the feelings and emotions expressed about their HIV/AIDS status were:

“I feel like any other person but there are some things that I know I must not do in order to prolong my life, for example, I must not engage in unprotected sex and drink alcohol”.

“When I first heard about my status, I was hurt, but other people encouraged me and I have since accepted my situation. Others informed me that being HIV positive does not necessarily mean it
is the end of the world as long as one knows how to take care of oneself”.

“I have accepted my (HIV/AIDS) status, therefore, I have no problem”.

“Although I have accepted my status, I still feel hurt, as the disease is problematic and I envy those who are HIV negative”.

“I have accepted what I am and have told myself that if our neighbours were to find out about my status and react in an unbecoming manner, I will just keep quiet and will ignore them until they are tired”.

Despite the fact that respondents have accepted their status, deep down they still have many emotions to deal with. Just like in mourning, they initially experience shock, disbelief, bargaining, and denial until they eventually accepted their status. According to Van der Walt and Mckay (1991: 49) denial is a useful coping mechanism as it reduces emotional stress but the long term danger is that it (denial) precludes behavioural changes to prevent further HIV transmission or further exposure to the virus.

It was established in this study that some of the respondents, despite having accepted their status, are tormented by fears of their neighbours finding out about their status and treating them unfairly.

Most respondents were more concerned and afraid of being stigmatized than of the disease itself. Therefore, they would do
anything to ensure that their neighbours do not find out about their status. This simply implies that the respondents’ fears are realistic and can easily come true.

4.2.5.1. HIV/AIDS stigma

HIV/AIDS has always been linked with stigma, which is one of the main reasons that prevent people who are infected from disclosing their status. In responding to whether or not they have been stigmatized on the basis of their status, the respondents indicated the following:

- None.
- I have never experience any stigma at all. However, people do make remarks, unaware of my status.
- One of my friends knows that I am sick but does not know that I am HIV positive, so they do not stigmatise me.
- Sometimes when I go to parties, people do not want me to touch the plates. They also give me the look that says they do not want me there and it is not nice.
- Being rude and saying hurtful things and spreading the rumour to the rest of the village.
- Not applicable since no one is aware of my status except for home based community workers, social workers, nurses and doctors.
- I have not had any such experience ever since I was diagnosed.

Sometimes people can be insensitive to those who are HIV positive by making hurtful remarks and such remarks may have negative impact on those who are infected. They are likely to feel isolated, rejected
and socially withdrawn. During this time, they need more social support to help them work through the variety of emotions. Social support is associated with less depression. Shernoff (1998) mentions that “Although in the second decade of AIDS, there is still considerable stigma attached to a diagnosis of being HIV positive”. The results of this study also highlight the significant role that community home based care workers play in the lives of those infected with HIV/AIDS.

4.2.5.2. HIV/AIDS comments by others

From data collected, it shows that the comments people generally make about HIV/AIDS include but not limited to the following:

“It kills”

“Infection people should not use condoms so that they do not die alone”

“It is non-existent”

“Blaming infected people of promiscuity”

“Infection people always lose weight, and losing weight is always linked with HIV/AIDS”

“Other people claim that they would kill themselves if they were HIV positive”

“Blaming birth control methods as the cause of the virus” and “Others do not care whether it exists or not”.

Most of the above comments reveal ignorance, lack of caring and knowledge. These also indicate some of the myths that people have about the virus, for example, there are some people who still believe that HIV/AIDS does not exist. Such comments simply means that
people still need more information on HIV/AIDS as lack of information can lead to an increased spread of the disease. It is important to note that it is not like information is not reaching people, even though information is reaching them people are still ignorant while others think that HIV/AIDS is just a foreign disease that can never affect them. Having said that, one cannot help but try to imagine how such people would react if they were to contract the disease.

Blaming the infected people of promiscuity implies that HIV/AIDS will always be a stigmatised disease. Those who are ill informed seem to think that the only way one can contract the disease is through having sexual intercourse. Furthermore, for someone to claim that they would commit suicide if they were HIV positive, clearly illustrated lack of problem solving and coping skills.

4.2.5.3. Feelings about negative remarks regarding HIV/AIDS

It is apparent that being subjected to all of the above stated remarks can do more harm than good for those who are HIV positive. In responding to how they feel about negative remarks regarding HIV/AIDS the respondents explained that they experience some of the following emotions:

- I have no problem as they are only making comments and do not point at me.
- It is sad and hurting but I have accepted my status and I feel that I do not owe them any response.
- I feel bad, sad and rejected and it is unfair to be treated that way. I have as a result learnt to stay away from socializing.
- I do not have a problem but I normally respond by saying that anyone can contract the disease.
- Presently I consider myself as if I do not have the disease. Concentrating on my health. I am no longer involved in a sexual relationship and I am not interested. I am scared that if I get involved, some men do not want to use condoms, so I may have to explain to him why he should use a condom.
- It does not hurt anymore.
- I am not hurt or depressed by all these comments as I have accepted myself.
- Such remarks prove to me that one cannot disclose one’s status to everybody.
- I feel sorry for them because they lack knowledge, but I will always try to advise them even though I do not disclose my status to them.
- I feel sorry for them because they do not know their status and I do not think they would repeat any of the things they say if they were to be diagnosed positive.

All of the above responses highlight different emotions that people infected with HIV/AIDS encounter and have to face on a daily basis. This seems to have led to some of the respondents saying, “It does not hurt anymore”. Chances are very high that they may have heard hurtful remarks far too often to care anymore or even to feel depressed.
4.2.6. SUMMARY

This chapter dealt with the presentation and discussion of the empirical study. And from data collected, it is apparent that HIV/AIDS is still such a stigmatised epidemic and some people are still not yet well informed about the facts surrounding HIV/AIDS issues.
CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1. INTRODUCTION

This chapter focuses on conclusions based on the findings of the study. It also provides recommendations to different stakeholders who form part of service delivery to people living with HIV/AIDS.

The main aim and goal of the study was to establish the impact that social support or lack thereof has on the lives of people with HIV/AIDS at Vhembe District in Limpopo Province.

The objectives of the study were:

Firstly, to review literature on HIV/AIDS and social support.

Secondly, to conduct an empirical study on social support that people with HIV/AIDS receive.

Thirdly, to arrive at recommendations and suggestions to the Department of Health and Welfare specifically for social workers who are working closely with HIV/AIDS infected people.
5.2. CONCLUSIONS BASED ON THE FINDINGS OF THE STUDY

The following conclusions are based on the findings of the research.

Lower level of education affects financial independency of the respondents because even those respondents who are working were earning less. For example, none of the working respondents was earning above R1000.00 per month. And some solely depend on different state grants for survival.

Women of childbearing age were found to be the most infected with HIV/AIDS. However, HIV/AIDS also affects everybody, especially those who are at the working age. This study has revealed that the ages of the respondents ranged from 19 to 58 and these are people who are actively involved in the labour market and largely contributing to the economy of the country.

Getting and receiving social support of any kind has proved to be an important element to those who are infected with HIV/AIDS. Most respondents revealed that they were receiving emotional support such as financial, physical and moral support. However, lack of social support can bring fears and negative emotions. Again, it can act as a barrier to disclosure of status.

Most people are still misinformed about issues of HIV/AIDS and this lead to ignorance and HIV/AIDS being a stigmatised epidemic. Due to stigmatisation some people infected with HIV/AIDS can decide not to disclose their status.
HIV/AIDS infected clients are always experiencing a variety of emotions. And some of the respondents who were stigmatised felt isolated, rejected and socially withdrawn.

Disclosure of status is important for one to receive any assistance and accepting one’s status. Majority of the respondents in this study disclosed their status.

Lack of knowledge about HIV/AIDS issues still exist and as a result many people make negative remarks regarding HIV/AIDS. And those remarks have negative impact in some of those infected with HIV/AIDS who then feel sad, hurt, bad and rejected. However, some of the respondents feel sorry for the people making the remarks.

Another conclusion is that it has been established in this study that the majority of the respondents are living in poverty without any source of income whatsoever, depending on the welfare office for food parcels and other social security grants.

Social workers are playing important roles in providing formal social support to clients infected with HIV/AIDS. They also refer clients to other professionals for further service and link them with available resources in their communities.
5.3. RECOMMENDATIONS

The following recommendations are based on the conclusions reached.

5.3.1. Department of Health and Welfare

It is recommended that:

When disability grants are applied, they should be processed speedily as many people infected with HIV/AIDS die before they receive their grants because the application process takes (a long) time.

Food parcels must be available regularly to avoid a situation whereby those infected spent a month or more without receiving any nutritious food parcels. There are many HIV positive and AIDS clients who depend entirely on food parcels from Welfare offices due to lack of income, poverty and having many dependants.

The Department should have more one stop centres to assist HIV/AIDS infected people and orphans and should provide them with cooked meals. Those who are still strong should be encouraged to start projects. It should also continue with public awareness campaigns to inform people about the epidemic as this is the only way to improve people’s knowledge.

A policy that makes a provision for service specialization should be developed and implemented as soon as possible. This would reduce burnout and case backlog.
The Department offers employee assistance programme (EAP) services to social workers and other professionals working with HIV/AIDS infected clients. Working closely with HIV/AIDS infected clients is such a traumatic experience, therefore even social workers need to be debriefed and counselled in order for them to be effective. Presently EAP services within the department are invisible and this makes one wonder that if EAP is there what programmes are put in place to assist social workers as professionals working with traumatic cases. Again a concern is how the programme is marketed to the employees.

5.3.2. Social workers

It is recommended that:

Social workers should move away from generic practice into specialization. Specialization is important if proper counselling and therapy is to be given to the infected clients. Again this will give social workers more time to conduct group work (support groups) with HIV/AIDS infected clients and to monitor cases by visiting clients regularly.

All social workers who work directly with clients infected with HIV/AIDS should receive advanced training on counselling skills so that they provide effective and meaningful service to the infected clients.
5.4. BIBLIOGRAPHY


It affect us all: Know the fact . 2002. Sunday Times.


Soul City: Living positively with HIV and AIDS. 2000.


SEMI-STRUCTURED INTERVIEW SCHEDULE

INSTRUCTIONS:

1. Kindly respond to all questions
2. The interview schedule consists of 5 sections.
3. Mark with an “X” where relevant

NB: All information gathered will be kept confidential.

SECTION 1.
BIOGRAPHICAL DATA

1. Age

1.2. Gender

1.3. Educational level

<table>
<thead>
<tr>
<th>Never attended school</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade R – Grade 6</td>
</tr>
<tr>
<td>Grade 7-Grade 12</td>
</tr>
<tr>
<td>College</td>
</tr>
<tr>
<td>University</td>
</tr>
<tr>
<td>Other, specify</td>
</tr>
</tbody>
</table>
1.4. Marital Status

<table>
<thead>
<tr>
<th>Marital Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
</tr>
<tr>
<td>Married</td>
</tr>
<tr>
<td>Never married</td>
</tr>
<tr>
<td>Divorced</td>
</tr>
<tr>
<td>Widowed</td>
</tr>
<tr>
<td>Other, specify</td>
</tr>
</tbody>
</table>
SECTION 2

DISCLOSURE

2.1. Discuss how you disclosed your HIV/ AIDS status?

__________________________________________________________________

__________________________________________________________________

2.2. To whom did you disclose your HIV/ AIDS status?

<table>
<thead>
<tr>
<th>Family member</th>
<th>Nurse</th>
<th>Community member</th>
<th>Social worker</th>
<th>Other, specify</th>
</tr>
</thead>
</table>

2.3. If not, Why? __________________________________________

__________________________________________________________________

__________________________________________________________________

2.4. Describe how the person you disclose your status to reacted afterward?___________________________________________

__________________________________________________________________

2.5. Explain how you felt after the disclosure?___________________

__________________________________________________________________

2.6. What prompted you to disclose your status? _______________

__________________________________________________________________
SECTION 3

SOCIAL SUPPORT

3.1. Was your family supportive after findings out about your HIV/ AIDS status?

| Yes   |       |
| No    |       |

If Yes, answer 3.2.

3.2. Describe how they support you? _________________________
     __________________________________________________________
     __________________________________________________________

3.2. If you are not getting social supported from your family what are your concerns about the lack of social support. ______________
     __________________________________________________________

3.3. Where do you get formal support from?

| Social workers |       |
| Nurses         |       |
| Doctors        |       |
| Home based care workers |       |
| Other, specify |       |
SECTION 4

ECONOMIC STATUS

4.1. Are you employed?

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

4.2. If you are not employed, what is your source of income?

<table>
<thead>
<tr>
<th>None</th>
<th>Disability grant</th>
<th>Care-dependency grant</th>
<th>Other, specify</th>
</tr>
</thead>
</table>

4.3. Is your above source of income sufficient to meet your basic needs and those of your family?

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

If No, answer 4.4.

4.4. Please explain how you survive__________________________

_________________________________________________________________
4.5. How many dependents do you have?______________________

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td></td>
</tr>
<tr>
<td>4-6</td>
<td></td>
</tr>
<tr>
<td>Other, specify</td>
<td></td>
</tr>
</tbody>
</table>
SECTION 5

HIV/AIDS AND STIGMA

5.1. How do you feel about your HIV/AIDS status? ________________________________

5.2. Do people make remarks, in your presence, that indicate that they are aware of your health status?

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

If Yes, answer 5.3.

5.3. What kinds of remarks?____________________________________________________

5.4. Explain how you feel about those remarks. _________________________________

Thank You For Your Co-Operation
CONSENT FORM

Participant’s Name:…………………………Date…………………….
Principal Investigator: Nghonyama Winnie Tsakani, University of Pretoria, P.O.Box 1791 Thohoyandou, 0950.

Informed Consent.

1. **Title of study:** The impact of social support on people with HIV/AIDS at Vhembe district in Limpopo Province.

2. **Purpose of:** To investigate the impact of social support on the lives of people with HIV/AIDS

3. **Procedures:** I will be asked to answer/respond to questions about the study. The interviewing process will be scheduled at my convenience, and will be conducted in the investigator’s office to minimize the aspect of stigmatization.

4. **Risk and discomforts:** There are no known medical risk or discomforts associated with this project, although I may experience fatigue and/or stress when responding to these questions. I will be given as many breaks as I want during interviewing session.

5. **Benefits:** I understand that there are no known direct medical benefits to me for participating in this study. However the results of the study may help researchers gain a better understanding of how social support can impact the lives of people with HIV/AIDS

6. **Participant’s rights:** I may withdraw from participating in the study any time.

7. **Financial Compensation:** I will not be reimbursed for my participation and any travel expenses.
8. **Confidentiality:** The researcher will record my responses in writing to enable her to have valid and reliable data (transcripts). The transcripts will only be viewed by principal investigator and authorized members of the research team at the University of Pretoria. I understand that the results of this study will be kept confidential unless I ask that they be released. The results of this study may be published in professional journals or presented at professional conferences, but my record or identity will not be revealed unless required by law.

9. If I have any questions or concerns, I can call Nghonyama Winnie Tsakane at 082 738 9151 or 015-9631578

I understand my rights as research subject, and I voluntarily consent to participate in the study, I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

-----------------------------   -----------------------------
Subject's Signature    Date

--------------------------------------
Signature of Investigator
Enquiries: Sinah Mahlangu
Reference: Research & Quality Improvement
11 February 2003

P O BOX 1791
THOHOYANDOU
0950

Project: MWT 895
MS Nghonyama, WT

THE IMPACT OF SOCIAL SUPPORT ON PEOPLE WITH HIV/AIDS AT VHEMBE DISTRICT IN LIMPOPO PROVINCE

1. Permission is hereby granted to Ms Nghonyama to conduct a study on “The impact of social support on people with HIV/AIDS at Vhembe District in Limpopo Province”.

2. The Department of Health & Welfare needs a copy of the research findings for its own resource centre.

3. The researcher should be prepared to assist in interpretation and implementation of the recommendations where possible.

4. Implications: Permission should be requested from institutional management to do research.

Sincerely,

[Signature]

HEAD OF DEPARTMENT
DEPARTMENT OF HEALTH & WELFARE

DEPARTMENT OF HEALTH & WELFARE