

**THE EXPERIENCES OF THE BATSWANA FAMILIES  
REGARDING HOSPICE CARE OF AIDS PATIENTS**

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## DECLARATION

I Matlhodi Florah Makhele, declare that the study on the Experiences of Batswana families regarding hospice care of AIDS patients is my original work. All relevant quotations included in the report have been acknowledged through references. This work has never been submitted at this University or any other University, or any other institution at any other time.

SIGNATURE: .....

DATE: .....

## ABSTRACT

The HIV/Aids pandemic has put significant strain on health care services in the country. The hospitals are no longer coping with escalating number of patients that are admitted. This has led to the early discharge of patients, some of them being sent to the hospices for continued care as they are still too ill to be nursed at home. There are mixed feelings when it comes to taking patients to hospices for care, as this did not use to be the practice among Africans.

Batswana as Africans have a culture that is deeply rooted in the principles of Ubuntu. These principles control the way people behave when caring for one another through thick and thin. According to this culture, an ill person is taken care of at home by the people within the family and the community. Taking a person to a hospital or hospice became an option when people started working to earn a living. They are no longer able to take care of their ill loved ones.

The purpose of the study is to explore and describe the experiences of Batswana families regarding the hospice care of Aids patients in Tlhabane Township in the North-West Province. The objectives of the study include exploring and describing the experiences of Batswana families regarding hospice care of Aids patients, and to making recommendations to policy makers to ensure cultural safety in caring for Aids patients in hospices.

A qualitative explorative descriptive research design that was contextual in nature was followed in order to explore and describe the experiences of Batswana families. Purposive sampling was used as method to select the participants for the study. For data collection, in-depth, unstructured individual interviews were conducted with all participants. Data analysis was done by means of putting the data into categories and sub-categories from the themes that emerged from the findings.

The findings indicate that families of the patients that are being cared for at the hospice experience hospice care as foreign to their culture. These families are also stigmatized, firstly as a result of Aids as an illness, and secondly due to the fact that they have sent their loved ones to the hospice for care. They also observed the differences between the quality of care for patients in hospital and in hospices. The families gain knowledge in the process of taking their ill family member to the hospice, and they understand the benefits of hospice care.

From the findings of this study, recommendations are made to the policy makers to ensure cultural safety at hospices.

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## CHAPTER 1

### 1.1. INTRODUCTION

The focus of the study was to explore and describe the experiences of Batswana families regarding the hospice care of Aids patients in the Tlhabane community in the North-West Province of South Africa.

Batswana as Africans believe that patients must be cared for within their families, not in hospices. Hospices are generally viewed as places where terminally ill patients are cared for. According to (Cameron 2009: 11) a hospice is a place where an individual is cared for in order to ensure that he/she spends the last days of his/her life with minimal pain and maximized comfort. However, among Africans the idea of sending a patient to a hospice is frowned upon as the custom is that people must care for their own until death (Watson, 2004: 51). The family structure is viewed as a place of care, and people bear children so that the children can take care of them during old age and when they are frail and sick. The view is supported by the African philosophy of Ubuntu. Ubuntu comes from a Xhosa idiom which is formulated as follows: "umuntu ngumuntu nga bantu". The literal English translation means "a person is a person through other persons" (Broodryk, 2005:17). It is within this premise that the Batswana people also feel that people must take care for each other through thick and thin. This view ultimately has an impact on one's death, hospitalization or institutionalization. This is further supported in the study by (Masango, 2005: 916), where she asserts that caring involves all the members of the community, family, relatives, tribe and ancestors. In an African community, life is lived in a group, tribe or clan (Masango, 2005:910). (Broodryk, 2005:18) describes it

as a communal way of life where solidarity and collectivism is emphasized and practiced. However, although the Batswana communities may have strong sentiments on family centered care, the living situation has changed drastically. Due to the modernization of society, people are no longer living with extended families. Nuclear families have become a norm. Women are emancipated and they work full-time, leaving the aged and those that are ill alone while they work (Hotep, 2003: 7). This leaves communities with no choice but to send their terminally ill patients to the hospital for care.

However, due to the scourge of HIV and Aids, which is ravaging our communities, the hospitals are no longer coping with the high number of patients that are admitted, especially the terminally ill ones. A study conducted by (Ncama, 2005:1) on Models of community/home based care for people living with Aids, stated that the HIV/Aids epidemic has placed a large burden on public health facilities in developing countries that are already functioning with limited resources. The situation has stretched the hospitals beyond their limits and has shifted the burden of care to the families and communities. Community based care is the central concept in the provision of care in the era of HIV/Aids. It is for this reason that hospice use increased. Hospices have been in existence for many years to cater for diseases such as cancer, but according to (Gwyther and Rawlinson, 2007:4) hospices have only been used to care for Aids patients in South Africa from the 1980's, with an aim of relieving caregivers of the load of care they face. Back then hospices were only used by other population groups than Batswana. The era has come in which black African communities, including the Batswana, are also supposed to send their patients to hospices due to circumstances such as working women and the decline of the extended family

structure. This study aims to explore and describe the experiences of the Batswana families who send their loved ones to hospices for care.

This chapter describes the background, research question, purpose and objectives of the study, an overview of the research design used in the study, ethical considerations, measures to ensure trustworthiness and organization of the study.

## 1.2. BACKGROUND AND RATIONALE OF THE STUDY

As already stated in the introduction, HIV/Aids is a pandemic that has adversely affected the socio-economic status of most countries, including South Africa. In the entire world, 40.3 million people are estimated to be living with HIV/Aids at present. Africa is inhabited by just over 12% of the world population, but it has 60% of the Aids infected population. This is due to the fact that African countries are still underdeveloped. In South Africa there are also a high number of patients living with HIV/Aids, estimated at 5.3 million. South Africa is part of the Sub-Saharan region. It has therefore inherited most of the challenges that this region is facing, including the Aids pandemic. Deaths in these regions are expected to rise sharply until 2010 (USAIDS, 2004:19) as a result of the pandemic and inadequate resources, such as beds in hospitals to care for such patients. This Aids pandemic in Sub-Saharan African countries has reached unprecedented proportions (Giarelli and Jacobs, 2006:1).

The North-West Province is estimated to have 329 000 people with HIV/Aids (Noble, 2007; 2). This province is predominantly occupied by the Batswana communities. The Batswana population occupies the greater portion of the township of Tlhabane, where the study took place. Batswana have several tribes that include Bangwato, Bakgatla, Bafurutshe, Bangwaketse, Batlhaping, Barolong and Bafokeng. The study

concentrated on the Batswana residing in Tlhabane. Rustenburg has only one public hospital, Rustenburg Provincial Hospital. The fact that there is no district hospital in this area has the effect that all patients that are referred from the surrounding districts have to be admitted to this hospital. It caters for all referrals in Bojanala West. The high number of patients admitted with Aids related conditions has resulted in high bed occupancy in the Job Shimankana Tabane Hospital. Bed occupancy in this hospital is about 78%. This is due to the fact that there are several wards admitting such patients. There is a high care ward for the very ill and terminally ill males and females, a ward that admits only males and another one that admits only females, as well as the ward that is called a "step down ward" for patients that are chronically ill, but still too ill to be discharged. Other very ill and acutely ill patients are admitted to the Intensive Care Unit.

The health care facility, which in this case is basically only one hospital, can no longer cope with the need for health services as a result of an increasing number of people migrating to this part of the country to look for jobs. The main cause of migrant labour in this part of the country is the mining industry, which is the major source of employment for the entire province. This has resulted in Rustenburg becoming the fastest growing town in the whole province (Noble, 2007: 3). Much as the development of this town is fast, so is the spread of HIV and the escalating number of admissions in the only public hospital, Job Shimankane Tabane Hospital. Government erected two hospices to facilitate quality care of HIV/Aids patients with the assistance of non-governmental organizations with an aim of caring for the Aids patients that could not be cared for at home. They were erected at Tlhabane and Phokeng. These two areas are about 6 km and 8 km from Rustenburg town

respectively. Families that have Aids patients are advised to take them to these hospices for care.

It was a new thing for the community to accept the concept of hospice care, since it was not known to them. However, there were different views regarding hospice care and its acceptance. Hospice care is a well established approach to palliative care, which enables countless people worldwide to die with dignity through focusing on the patient rather than the disease. It ensures that the patients spend the last days of their lives in an environment where caregivers minimize their pain and maximize their comfort (Cameron, 2009:1).

The Batswana share values and culture with the other African communities. They believe that caring for a person in an institution makes him/her loose his/her sense of belonging and independence. African people, including Batswana, care for all their vulnerable groups of the population, like children, the elderly and even their sick people, including the terminally ill ones, at their own homes (Ott, 2009: 3) It is a taboo for a person to die in a strange environment rather than his/her own home, and therefore terminally ill patients suffering from Aids should be cared for by members of their own families in their own homes. If difficulties are encountered, the significant others as well as the members of the community will in solidarity offer assistance in caring for the patient.

The same thing applies to Batswana residing in Tlhabane. They uphold their beliefs, values and principles. Some of the principles that they uphold is that of Ubuntu, which has generally been described as a worldview of African societies, and a determining factor in the formation of perceptions that influence social conduct. It has also been described as a philosophy of life, which in its most fundamental sense,

represents personhood, humaneness and morality. (Greg *et al*, 2003:319) maintain that group solidarity is central to the survival of communities. In this context it determines how the Batswana society in solidarity responds and behaves towards HIV/Aids as a challenge, and the actual manner in which the Aids patient should be cared for. These reasons cause the community members to feel that their lives can be fulfilled if their ill loved ones can be cared for at their respective homes. However, they have a serious challenge in trying to make this work, because unlike in the past where women did not work and were the centres of care in the homes, they are now breadwinners who leave homes in the morning and only come back in the evening.

According to a study conducted by (Watson, 2004: 51) among the Batswana on perceptions regarding home based care, it was revealed that most people welcomed and preferred the home-based care option as they felt that it is a model that tries to uphold the culture of African communities by caring for the people in their own homes. The same study argues that home-based care could not meet all the needs of patients due to the fact that the home-based caregivers could not be with patients for the duration of the absence of family members, which deprived patients of continuous care. It therefore became necessary that hospices came into being as an alternative means of care.

When the hospice was erected in Tlhabane there were mixed feelings regarding the acceptance of this form of care. The findings of this study aims to explore and describe the experiences of Batswana families regarding the hospice care of Aids patients and to make appropriate evidence-based recommendations to the government

### 1.3. RESEARCH QUESTION

The above-mentioned situation leads to the following questions:

- What are the experiences of the Batswana families in Tlhabane regarding hospice care of Aids patients?
- Which recommendations can be made to policy makers to make hospices culturally safe in caring for Aids patients?

### 1.4. PURPOSE OF THE STUDY

- To explore, and describe the experiences of the Batswana community regarding hospice care of Aids patients.
- To make recommendations for the policy makers within the Department of Health to enable policy formulation that will enhance cultural safety for care for Aids patients in hospices.

### 1.5. PARADIGMATIC PERSPECTIVE

According to (Brink, 2006:22) a paradigm is a discipline's specific method of structuring reality. It is a set of assumptions about the basic kinds of entities in the world, and about how these entities interact. They are untested, but provided in order to guide the researcher's investigations.

For the purpose of this study the researcher's perspective is that of interpretivism. The researcher believes that there is no right or wrong, but all things are interpreted as they occur based on a value system. The researcher does not believe in

measuring the truth, but interpreting, thinking and reasoning out. She also believes that those who are experiencing a situation can give a clearer account of the phenomenon than an outsider, and this fact should be respected. As a point of departure, the researcher uses the following meta-theoretical and methodological assumptions in order that the research objectives can be reached:

#### **1.5.1. Meta-theoretical assumptions**

(Burns and Grove, 2005: 39) maintain that assumptions are statements that are taken for granted or considered to be true. Even if they have not been proven scientifically, they are present in one's thoughts and behavior.

According to the researcher, the following are the interpretations of the terms; man, nursing, health and environment according to her own assumptions.

##### **Man**

It is a person who thrives well among people who are his/her family members. There is a high degree of interdependence amongst family members in sickness and in health. The support of family members is very important. She bases these arguments on the philosophy of ubuntu, which emphasizes values such as love, a sense of belonging and interdependence.

##### **Nursing**

Nursing occurs in a familiar home environment where an ill person is taken care of in a home environment by people who love and care for him/her. Nursing actually occurs in a setting where the patient is free and able to interact with people of his/her

own. A hospice will serve a purpose if support systems and mechanisms are put in place where the patients experience a family structure and sense of belonging.

### **Health**

It is a state in which a person has a good interpersonal relationship with the significant others. It is a situation where people live in harmony with their loved ones within families and communities.

### **Society**

A society is a group of people who share the same values, care for one another in sickness and in health. They help one another to carry burdens of any kind, including disease and caring. It is within communities where problems are discussed and solutions found.

#### **1.5.2. Methodological assumptions**

It is the perspective on the nature of reality that has an implication for the methods used to acquire knowledge. They are the techniques used by the researcher to structure a study and to gather and analyze the information relevant to the research question (Burns and Grove, 2005:742).

The researcher followed a qualitative, explorative and contextual design in order to explore the experiences of the Batswana families regarding hospice care of Aids patients

## 1.6. CONCEPTUAL DEFINITIONS

The following are the definitions of the key concepts that are applicable to this research:

### 1.6.1..Experiences

According to Concise Oxford Dictionary, (2005: 406) an experience is a practical contact with or observation of facts or events. It is an encounter that one undergoes. It is also an event or occurrence that leaves an impression on a person. For the purpose of this study it is the stigmatization and alienation that the families of Aids patients experience. Aids patients experience having Aids in a very specific manner. It is for that reason that the major reason for this study is to explore and describe the experiences of the Batswana community regarding hospice care of the Aids patients.

### 1.6.2. Batswana

Members of a Bantu people living chiefly in Botswana and western South Africa, speaking Setswana (Phuthego, 2008: 9). These people are influenced by the tribal institution of the indigenous law. For the purpose of this study, it is the tribe that stays in Tlhabane.

### 1.6.3. Community

A community is a social group of people sharing a geographical area, normally with shared interests. Beliefs, resources, preferences, needs, risks and a

number of other conditions may be present and common, affecting the identity of the participants and their degree of cohesiveness (Phuthego, 2008; 3).

#### 1.6.4. Aids

HIV is the virus that causes Aids (Auto Immune Deficiency Syndrome) People with Aids are infected with the HIV virus, which is transmitted through bodily fluids (Rigs, 2008: 27). It is a retrovirus that undergoes an unusual biological process in which genetic material in the form of a single-stranded ribonucleic acid (RNA) can be converted to double-stranded di-nucleic acid (DNA). Usually in the normal biological process DNA is made into RNA as a result of an enzyme called reverse transcriptase. It has an affinity for certain target cells with CD4 receptor ties. The virus enters the host's cells and reverses the transcriptase reaction. Later, new viruses are produced that enter the blood stream and infect more cells. Eventually CD4 cells are damaged and immunity is reduced.

#### 1.6.5. Patient

It is a person receiving or registered to receive medical treatment. (Anderson, 2002: 1294)

For the purpose of this study, patient means a person that is HIV infected and is suffering from Aids

#### 1.6.6. Hospice care

Hospice care is a well-established approach to palliative care that enables countless people worldwide to die with dignity through focusing on the patient rather than the disease. It ensures that the patients spend the last days of their lives in an environment where caregivers minimize their pain and maximize their

comfort. According to (Cameron, 2009:1) study, hospice care is under-utilized by many terminally ill patients.

A hospice is a focused, team approach to providing healthcare and other needed services to patients nearing the end of life. The hospice team comprises physicians, nurses, social workers, therapist, pastoral representatives, home health aids, volunteers, and family caregivers. Its mission is to provide comfort and care to patients and their families in a less institutionalized setting and with less strict routines (Strain, 2008:19).

The concept of hospice centers on comprehensive care for the dying and consideration of their special needs. The physical facility may be very extensive or quiet minimal.

## **1.7. RESEARCH DESIGN AND METHOD**

The research design and method will be mentioned briefly and the more detailed discussion will follow in Chapter 2.

### **1.7.1. Research design**

A qualitative, exploratory, descriptive study was done. The rationale for this methodology is that the researcher intended to explore and describe the experiences of the Batswana communities in Tlhabane on hospice care of Aids patients. Exploratory qualitative research is designed to shed light on the various ways in which a phenomenon manifests and its underlying processes (Burns and Grove, 2005:27).

### **1.7.2. Research method**

Research method includes outlining the method of sampling, data collection and data analysis, as well as measures to ensure trustworthiness and ethical consideration. Only a brief outline of these aspects will be given in this chapter: Individual interviews were conducted in order to obtain data.

#### 1.7.2. 1. Sampling

According to (Burns and Grove, 2005:27) sampling involves selecting a group of people to conduct a study. Sampling decisions have a major impact on the meaning and generalization of findings.

The following steps were followed to obtain a sample for the study:

#### 1.7.2.2. Population for the study

The target population consisted of those families of the Batswana population that belongs to the Bafokeng clan residing in Tlhabane around Rustenburg, whose family members suffer from Aids and are being cared for in a hospice.

#### 1.7.2:2. Sampling method

A purposive voluntary sampling method was used to select the identified population. The population depended on volunteers for participation who complied with the criteria for selection.

#### 1.7.2.3. Sample size

This was determined by the availability of the participants. The researcher did not decide on a sample size beforehand (Burns & Grove, 2005:358).

#### 1.7.2.4. Data collection

The roles of the researcher included obtaining permission from Sub-district Health Manager of Bojanala in the North-West Province to conduct the research. The purpose and aims or objectives were clearly spelled out to the manager. Permission was obtained from the management of the Tshupe Hospice to conduct the research at that institution.

#### 1.7.2.5. Physical environment

In this study, interviews took place in a natural setting. It actually took place in the family member's home environment in Rustenburg. This enabled the participants to relax and feel free to express their experiences, something that is vital for the study.

#### 1.7.2.6. Method

Unstructured interviews were conducted to enable the participants to feel free to share their experiences with the researcher. A thick text was obtained during interview sessions through which the illustrative quote or voice of the participants was recorded.

#### 1.7.2.8. Data analysis

Data analysis entails categorizing, ordering, manipulating and summarizing the data and describing them in meaningful terms (Brink, 2006:170). The collected data was coded. Data was sorted into categories and relationships were developed between

categories. Out of these patterns, the behavior and response of participants was identified (Burns & Grove, 2005:561).

The researcher transcribed the audio-taped interviews. It required labour intensive activity and creativity, conceptual sensitivity and hard work.

### **1.8. TRUSTWORTHINESS**

Chapter 2 of the study includes a detailed discussion on trustworthiness. Guba's model that includes Credibility, Transferability, Dependability and Confirmability was applied for the purpose of this study.

### **1.9. ETHICAL CONSIDERATIONS**

According to (Burns & Grove, 2005:83), the purpose selected for the investigation must be ethical, which means the subjects' rights the rights of others in the setting must be protected. Ethics is regarded as a system of moral values that is concerned with the degree to which research procedures adhere to professional, legal and social obligations to the study participants.

The researcher observed the following aspects throughout the process: obtaining permission to conduct the research from the University Ethics committee, (see annexure A), as well as the authorities of Tshupe Hospice (see annexure B). Informed consent from participants was also obtained (see annexure C) including, maintenance of confidentiality and anonymity, avoidance of exploitation of participants and voluntary participation, as well as respect for human rights and freedom.

## 1.10. ORGANIZATION OF CHAPTERS

Chapter 1: Overview of the study

Chapter 2: Research design and methods

Chapter 3: Discussions of the findings as well as literature control

Chapter 4: Conclusion, shortcomings, recommendations and guidelines

## CHAPTER 2

### RESEARCH DESIGN AND METHOD

#### 2.1. INTRODUCTION

Chapter one provided an overview of the research, including an introduction and problem statement, research objectives, paradigmatic perspective as well as a brief orientation of the research methodology that was followed in this study. In this chapter, the researcher will discuss the process that was followed or the design selected, as well as the methods used.

The purpose of a design is to achieve greater control and thus improve the validity of a study when examining the research problem. Designs are there to meet unique research needs as they emerge (Burns and Grove, 2005:231).

The research design, methods of sampling, ethical considerations as well as measures to ensure trustworthiness will be discussed in detail in this chapter.

#### 2.2. RESEARCH DESIGN

According to (Stommel and Wills, 2004: 32), the research design is a plan according to which the research must be carried out. It determines and provides systems of rules to be followed in the conduct of the study.

- **Qualitative**

A qualitative, exploratory, descriptive study that was contextual in nature was conducted. The rationale for this methodology is that the researcher intended to explore and describe the experiences of the Batswana families in Tlhabane on the care of Aids patients in a hospice.

According to (Burns & Grove, 2005:747) qualitative research is a systematic, interactive, subjective approach used to describe life experiences and to give them meaning.

This approach was chosen in order to be able to describe the Batswana families' experiences. This approach enabled the researcher to collect their narratives based on their lived experiences.

- **Explorative**

An explorative, descriptive study was undertaken as the study deals with people's experiences. Exploratory qualitative research is designed to shed light on the various ways in which a phenomenon is manifested and on underlying processes (Polit & Beck 2005:19). (Brink 2006:64) maintains that the identified problem does not exist in a vacuum; it is embedded in a particular context. This is because the researcher views this problem from a particular perspective, which itself depends on the researcher's philosophical position. This study was contextual in nature,

The experiences of Batswana families on hospice care were explored in order to derive meaning from them. It is for this reason that the study was contextual in nature. Family members freely shared their experiences with the researcher during data collection sessions, and in that way the researcher gained understanding of

what these family members were experiencing during the time when their ill family members were being taken care of at the hospice.

- **Descriptive**

According to (Burns & Grove, 2005:232) descriptive study designs are designed to gain more information about the characteristics within a particular field of study. Their purpose is to provide a picture of situations as they naturally occur. It is a design that has as its main objective to provide an accurate portrayal of the characteristics of persons, situations or groups.

According to (Burns & Grove, 2005:734) a descriptive design is used to identify a phenomenon of interest, identify variables within a phenomenon, develop conceptual and operational definitions of variables, and describe variables in a study situation. An in-depth method was used to describe the experience, meaning and impact of hospice care on human behavior. This approach advocates interpretation and understanding of human experiences, and not only a description. It is believed that people have a physical tie with the world around them, therefore the perception of how the world views them, and how they interact with the world becomes important to them as social beings.

The researcher was able to gain understanding of the experiences Batswana families with regard to hospice care of their Aids patients. During an interview session, the family members were able to describe their own lived experiences.

- **Contextual**

The concept "contextual" describes the uniqueness of the research setting, or the context in which the study took place. It involves the view or the perspective in which the research study took place (Brink, 2006:64).

The study is contextual in nature as only the experiences of Batswana families living in Tlhabane with members with Aids who are being cared for at Tshupe hospice have been explored. The experiences were narrated during interviews.

### **2.3. RESEARCH METHODS**

According to (Burns & Grove, 2005:23) a qualitative research method is a systematic, interactive, subjective approach used to describe life experiences and to give them meaning. It is also maintained that research methods are the techniques used by researchers to structure a study and to gather and analyze information relevant to the research question. Chapter 1 provided a short description of the research method. A more detailed description is about to follow.

#### **2.3.1. Population**

For the purpose of this study, the population used was families living in Tlhabane that have a member of the family who is cared for in Tshupe Hospice due to Aids. The target population was the Batswana of the Bafokeng tribe.

#### **2.3.2. Sampling method**

The researcher selected sample members purposefully. Purposive sampling is sometimes referred to as judgmental or selective sampling as it involves the

researcher consciously selecting the participants who are rich with information (Burns & Grove, 2005: 352).

The researcher included people from different social strata. The name of patients and their next of kin are kept in the hospice register. The researcher consulted this register after agreeing with the person in charge to obtain the names of the patients and their addresses. The purpose was to visit the families that gave consent to be interviewed in their respective homes. The researcher visited nineteen homes with the aim of obtaining consent and conducting an interview. Out of the total number of families visited, only fifteen families agreed to sign the consent for participation. Members of five families were used for a pilot study while ten were used for the actual study.

### **2.3.3. Inclusion criteria**

According to (Brink, 2006: 124) inclusion criteria are the criteria referred to as eligibility criteria, used as the basis for decisions of whether an individual would or would not be classified as a member of the population in question.

The inclusion criteria were:

- The sample was drawn from those that have registered their patients for hospice care for three months or longer as they are in a better position to state their experiences due to their prolonged engagement with hospice care. The researcher was compelled by the prevailing circumstances to consider this short duration due to the fact that most of these patients do not live for a long time after their registration into hospices because they arrive as full-blown Aids patients already.

- The sample also consisted only of family members who consented to participate in the study.
- They also had to consent to be audio-taped during an interview
- They had to be able to communicate in either Setswana or English

#### **2.3.4. The exclusion criteria included the following:**

- Family members whose patients had registered in the hospice for duration of less than 3 months.
- Family members of Aids patients in hospices who did not give consent to be interviewed.

#### **2.3.5. Roles of the researcher**

The roles of the researcher before commencement of data collection were the following:

- The researcher identified and compiled a list of potential participants for the study;
- She explained the importance and significance of the study to the potential participants;
- She emphasized the ways and means of ensuring anonymity and confidentiality throughout the study;
- She outlined the fact that an interview will be the method of data collection and explained how this will take place;

- She explained the availability of the support to the potential participants should they experience any discomfort. This was only an anticipation as none of the participants actually experienced discomfort or emotional disturbance that warranted intervention;
- She arranged an appointment for the interview that suited the interviewer and the interviewee;
- She explained the importance of having a private room in which there will be minimum disturbance. This actually worked well, since only two interviews had slight noise interference. The one from the moving cars from the main road, and the other from the sound of songs from a television. Most of the interviews had no disturbance at all;
- She interviewed all the participants herself.

On the day of the interview, each participant signed a written consent form to voluntarily participate in the study.

#### **2.4. Sample size**

Sample size in qualitative study is determined by the purpose of the study. The number of participants in a qualitative study is sufficient when saturation of information occurs, when additional samples bring in no new information and only redundancy of previously collected data occurs (Burns & Grove, 2005:358).

During the commencement of the data collection process, the total number of patients at Tshupe Hospice was nineteen. The researcher intended to interview one person from each family. Out of the total number of nineteen patients, the families of only four could not be interviewed. Three patients were excluded because they have been in the hospice for less than three months, while family members from the fourth

patient refused to sign the consent form to be interviewed. Fifteen were interviewed and out of that number, five were used for the pilot study. The refusal of family members of one patient to participate in the study might be due to the fact that HIV/Aids still carries such a stigma that affected people are not readily prepared to be interviewed. It therefore means that the sample size depended entirely on the availability of the participants. As the researcher was aware of that challenge and she managed to interview participants in their own homes to minimize the stigma. The relationship of participants with the patients ranged from brothers, to sisters, to mothers and fathers of patients receiving treatment at Tshupe hospice. This makes the population heterogeneous. According to (Burns & Grove, 2005:223) a heterogeneous population has a wide range or variety of characteristics, which enables the reduction of the risk of bias.

They were then entered into the study. The researcher did not decide on a specific sample size. Inadequate sample size can reduce the quality and credibility of the research findings. The depth of the study scope and the clarity of the focus will influence the number of participants needed for the sample (Burns & Grove, 2005:358).

#### **2.5. The role of the researcher during the data collection session**

The manager of Tshupe Hospice was approached as a follow-up on a letter the researcher wrote requesting permission to conduct research in her area of jurisdiction.

On the day of the interview, the researcher visited the homes of the prospective participants that consented to voluntarily participate in the study. She then ascertained that consent forms have been signed before commencement of the

interview. The researcher emphasized the assurance of confidentiality and anonymity to the participants. It was explained to the participants that their names will neither be used on the transcripts nor in the report. Their names will not be attached to their responses in any way. A tape recorder with additional batteries was made available.

Eleven days were used for data collection as the participants were visited in their own homes. In spite of having made appointments with the participants, they were at times not available in their homes when the researcher paid them a visit. She then had to make new arrangements for another visit. As most of the participants were working, the only convenient time for the interview was late in the afternoon or over the weekend.

#### **2.6. The setting/physical environment**

The setting is the location where the study is conducted (Burns & Grove, 2005:342). The natural setting was the most appropriate for conduction of interviews. All participants were interviewed in their own home environments in Tlhabane, Rustenburg. This enabled the participants to relax and feel free to express their experiences, which is vital for the study.

#### **2.7. Data collection method**

Data collection is the process of gathering relevant information needed to address the research problem (Burns & Grove, 2005:733).

Unstructured interviews were conducted to enable the participants to feel free to share their experiences with the researcher. According to Burns and Grove, (2005:539) an unstructured interview is a complex process of collecting data that

occurs simultaneously with data analysis. (Stommel & Wills 2004:285) describe the unstructured interview as the least planned and most flexible procedure of collecting data. It does not have a close-ended response format or use standard set of questions. Individual interviews were conducted. The interaction that takes place determines the success of the study as the study is based on the collected data. The researcher conducted the interview herself. Field-notes were taken. Audio-tapes were used to record the responses of the participants.

A thick text was needed during interview sessions through which the illustrative quote or voice of the participants was recorded. The study consisted of ten members of families that have an HIV/Aids patient that is cared for in the hospice. The following process took place during the interview sessions:

The researcher commenced with a general introductory question that triggered short questions, opened up a discussion, and stimulated participation. The question was: "What are your experiences as a Motswana regarding care of your family members who has AIDS related illnesses at Tshupe hospice?"

- The researcher would make follow-up comments on the answers provided by the participants, and that enabled a meaningful discussion that gave the researcher the information that she needed.
- The interview took place in Setswana so that the researcher could get rich information from the participants that will be answering questions in their own language. A qualified translator assisted in translating the data into English.
- Each interview took a duration ranging between 45 minutes to an hour and half.

Shortly after the interview to allow adequate capturing of data; the interviewer recorded field notes to assist her in analyzing the data, (Burns & Grove, 2005: 540).

Field-notes included the following:

- Descriptive notes that included an account of the events that occurred and the activities that took place during the interview;
- Demographic notes, which covers all information regarding time, place, date, weather and conditions that prevailed on the interview day;
- Reflective notes that form a record of personal thoughts, perceptions or even speculations of incidents and problems that were encountered during the interview were captured. This included impression, prejudice and even feelings.

## **2.8. Data analysis**

It was an ongoing process that did not form a discreet stage of the research process, but it was part of the process throughout from the selection of the research problem until the final report.

(Brink, 2006:171) maintains that analysis involves examination of words rather than numbers. The first step is coding the data, which commences as soon as the data collection process begins. This enabled the researcher to organize the collected data. Categories were then developed. Information from individual participants was compared to determine the final trend.

Data analysis involves synthesis of the data collected and sifting to make choices of the relevant data. In this study, Tesch method of analysis was used. During the analysis process, notes were clarified and interpreted. Intuition, introspection and reasoning were exercised. Data was formed into categories and relationships were

developed between categories. Out of these patterns, the behavior and response of participants was identified (Burns & Grove, 2005:561).

The researcher transcribed the audio-taped interviews. It required labour intensive activity and creativity, conceptual sensitivity and hard work. The following are the generic steps that were followed when data was analyzed:

- Step 1 – organizing and preparing the data for analysis. It involved sorting out and arranging data into different types.
- Step 2 – reading and obtaining the general sense and meaning of the data. Notes were also written on the sides.
- Step 3 – coding was done, after which the data was organized into chunks. These chunks were labeled into categories.
- Step 4 – codes for the description were generated. Small numbers of themes or categories were developed.
- Step 5 – the manner in which the data was represented is described. Narrative passages were used to convey the findings of the analysis.
- Step 6 – interpretation and meaning – the researcher interpreted the data.

Categories, sub-categories as well as themes were derived from the collected data. Only two participants were comfortable to be interviewed in English, while the rest of the participants preferred Setswana. The analysis was done with the transcripts still in Setswana, as the researcher was able to do so.

## 2.9. Ethical Considerations

### 2.9.1. *The principle of autonomy*

- **The right to self determination**

(Burns & Grove, 2005:181) maintain that the right to self determination is based on the ethical principle of respect for persons. According to this principle, humans are capable of self determination and of controlling their own destiny as well as freedom of choice without external control.

The participant were informed about the right to decide whether to participate in the study or not without the risk of incurring any penalty or prejudicial treatment, which includes any explicit or implicit threats of penalty for failing to participate in the study. No participant was coerced to participate. They allowed the researcher to look into the hospice register in order to access their addresses to be able to visit them for interview purposes. This followed the introduction of the researcher to the families of hospice patients

- **The right to full disclosure and informed consent**

The human dignity of the participants was respected. As this research topic is very sensitive and includes a stigma attached to HIV/Aids, participants were adequately informed regarding their privacy. The participants were dealt with in secret without the members of the public becoming suspicious of anything, especially during the data collection process. The researcher visited the family members in the comfort of their own homes. It was therefore not easy for other members of the community to know about the interviews

Informed consent was obtained from the participants. It was then explained to the participant that should he/she decide to terminate participation, he/she may do so without any intimidation. Some of the people who initially agreed to participate in the study changed their minds and did not consent to be

interviewed. The researcher agreed and respected their decision. Interviews were only conducted with those that gave informed consent.

### *2.9.2. Principle of beneficence*

The researcher determined whether the risks to research participation are commensurate with the benefits to society and the nursing profession or not. The risks to be taken by the research participants should never exceed the potential humanitarian benefits of the information and knowledge to be obtained after the study as started. This principle also maintains that the researcher should do well and above all, do no harm (Burns & Grove, 2005:180). The risks were kept to a minimum and the benefits increased as all the findings and results of the study are aimed at improving the lives of the communities.

All measures possible were taken to prevent exposing the participants to stigmatization by the rest of the community members by adhering to professional secrecy throughout the data collection process. Information was handled in the most private possible, way so that it does not end up in the wrong hands. Only the researcher handled the tapes and field-notes.

### *2.9.3. Principle of justice*

The principle of justice includes the subject's right to fair selection and treatment. The researcher's choice should not be motivated by his / her desire for subjects to receive specific benefits that the study might offer. (Brink, 2006:33)

The researcher did not take advantage of the vulnerable group. Among the participants, there were also elderly people who are a vulnerable group as their children are the ones infected and admitted at hospices. One of the participants

was an elderly lady that has recently lost a son that was cared for at Tshupe Hospice. The researcher was able to conduct an interview with minimal discomfort and the participant did not show much emotion.

No harm befell the participants and they were protected from any form of system discomfort as far as it was within the power of the researcher. A support of counseling was in place for those that could be emotionally disturbed.

The right to a fair selection was addressed by the fact that they were given adequate information and allowed to volunteer thereafter. Their right to privacy was protected. To ensure this, interviews were conducted at the homes of the participants. No one will be allowed access to the raw data i.e. audio-tapes or field notes of participants after the interview. Each participant was provided with a code number attached to the field notes to ensure anonymity.

## **2.10. TRUSTWORTHINESS**

Trustworthiness ensures reflection of the true state of the phenomena in qualitative research. It is the criteria of evaluating the data obtained as well as the complex research procedures followed in qualitative studies. The following are the criteria for establishing the trustworthiness of the study, according to (Stommel & Wills, 2004:287):

### **2.10.1. Confirmability**

According to (Stommel & Wills, 2004: 288) confirmability refers to the objectivity or neutrality of the qualitative data once it is obtained. It is a criteria for ensuring data quality. Its goal is to determine whether two or more researchers can agree on the decisions made during a study. In this study, an inquiry audit was be done

by an independent person identified by the supervisor to establish data confirmability. The audit included all documents, comprising raw data like field notes, interview transcripts, and drafts of the final report (Burns & Grove, 2005: 561). The researcher ensured that the necessary audit has been done by an independent practitioner.

#### **2.10.2. Dependability**

Dependability is a criterion for evaluating the quality of qualitative data, referring to the stability of data over time and over conditions, as (Stommel and Willis 2004:288) explains. The supervisor who received all transcripts and listened to the audiotapes conducted an enquiry audit. This also had a bearing on confirmability.

The supervisor introduced an external reviewer who also coded the data in order to scrutinize and audit it with all supporting documents to maximize value of the study. This is another way of ensuring consistency.

#### **2.10.3. Transferability**

According to (Burns & Grove, 2005:561) transferability is similar to generalization or applicability. This is the extent to which the findings of the study can be transferred to another study.

Transferability was be ensured through a thick description of the study and its processes during the enquiry. Sufficient information is available to enable transferability. Purposive sampling was used in the study and a dense description of the experience of the family members of Aids patients was offered. Sufficient descriptive data was provided and the researcher therefore believes that the results can be applicable to different settings.

#### 2.10.4. Credibility

Credibility refers to engaging in activities and procedures for aiding the believability of qualitative research findings (Stommel & Wills, 2004:289). This includes triangulation, prolonged engagement, peer de-briefing and member- checking.

- **Prolonged engagement**

(Stommel and Wills, 2004: 289) maintains that prolonged engagement is the researcher's substantial level of immersion in the research process, so that the researcher becomes fully engaged in the research, establishing a valid and meaningful relationship with the participants. The researcher consequently becomes open to deeper meaning that unfolds during the research process..

The researcher strove towards prolonged engagement in the data collection process and obtained an in-depth knowledge of the culture and the language of the participants. She engaged in an endeavor to build rapport and trust with participants. She invested sufficient time in data collection activities to have an in-depth understanding of the group under investigation. Her engagement with the participants dated back to information sharing about her research topic, requesting consent from the participants, as well as the actual data collection.

- **Triangulation**

Triangulation is the combined use of two or more theories, methods, data sources, investigators or analysis method in the study of the same phenomenon (Burns & Grove, 2005:224). According to (Stommel & Wills, 2004:289), triangulation may also refer to a strategy in which multiple researchers examine the data set separately from each other to validate or provide alternative interpretation of the study results.

Data triangulation was ensured as all responses and information obtained from the participants was perused by the researcher's supervisor, audio tapes were listened to, and later an independent coder was involved in checking the collected data without the interference of the researcher. The coder came up with her own understanding of the data. This ensures its credibility

Triangulation can also involve a session held with an objective peer to review various aspects of the enquiry as a means of strengthening the trustworthiness of the data. It is a process in which the researcher invites the study participants to revise transcripts of their study responses to correct the researcher's interpretation of the meaning of the data (Stommel and Wills, 2004:289).

- **Member checking**

The researcher asked the participants to listen to the tapes with her before they were transcribed to check on the information stored to review or add to the information. This process greatly enhances the credibility of the researcher's interpretation of the information.

- **Peer briefing**

The researcher requested another colleague who is also a researcher to check and explore all aspects of the enquiry. The supervisor and the co-coder also added a great value to ensure credibility (Burns & Grove, 2005:560).

## **2.11. SUMMARY**

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In this chapter, a detailed description of the research design and method, trustworthiness and ethical consideration of the study were outlined. The next

chapter will deal with issues around research findings and a detailed account of literature control.

## CHAPTER 3

### DISCUSSION OF THE FINDINGS AND LITERATURE CONTROL

#### 3.1. INTRODUCTION

The previous chapter offered a detailed description of the research design and methods followed in this research study. This chapter will address the research findings according to the categories, sub-categories and themes. The relevant literature was consulted and used to control the findings of the study.

The objectives of the study were as follows:

- To explore, and describe the experiences of the Batswana community regarding the hospice care of Aids patients
- To make recommendations to policy makers on how to facilitate hospices to render culturally safe care to Aids patients.

#### 3.2. DESCRIPTION OF THE SAMPLE

The sample in this research study consists of ten participants. All the participants were relatives (family members) of Aids patients who were receiving hospice care at the time of data collection. From each family, one member was selected for the interview. They were of different ages, genders, and language preferences, as well as different relationships with the participants. The demographic information of the sample is illustrated in table 2.1

## DEMOGRAPHIC INFORMATION

CRITERION	CHARACTERISTIC	FREQUENCY
Age	20 – 30	30%
	31 – 40	20%
	41 - above	50%
Gender	Male	40%
	Female	60%
Language preference	Setswana	80%
	English	20%
Relationship to patient	Parent	60%
	Sibling	40%
	Extended family member	0%
Status of hospice care	Day care	100%
	Full time care	0%

TABLE 3.1

### 3.3. FINDINGS

This chapter deals with the manner in which data was analyzed. Data analysis is the process of reducing, organizing and assigning meaning to data (Burns & Grove, 2005:733). Big piles of data are transformed into succinct statements that describe, explain or predict something about what the researcher has studied. The researcher

commenced analysis of the data and came up with categories, sub-categories and themes. Thereafter the data and analysis were given to the independent coder along with the copies of verbatim transcripts.

A meeting was held to discuss and reach consensus on the categories, sub-categories and themes identified in the transcripts. Data from the verbatim transcripts was grouped into four main categories and sub-categories. Comprehensive themes were developed strictly from the transcripts in order to portray and convey the experiences of the Batswana families regarding hospice care of Aids patients.

The data was analyzed through Code and Coding, which is a means of categorizing the available information. Data was read and re-read; comments were made in margins for later use. Topics that emerged were given codes, which were written next to each topic to allow for easy retrieval of data. Topics were then turned into categories, which allowed the grouping together of similar data (Burns and Grove, 2005:184). Under each category, sub-categories emerged. After completing the above steps, important verbatim quotations were identified for inclusion into the report.

The main categories identified were:

- ❖ Hospice care as foreign
- ❖ Social stigma associated with Aids
- ❖ Differences in Health Care Practice
- ❖ Knowledge is power

Under each category, sub-categories were identified and these are reflected in table

3.2

### 3.4. FRAMEWORK FOR DATA ANALYSIS

TABLE 3.2

CATEGORY	SUB-CATEGORY	THEMES
1 Hospice care as foreign	A-cultural to Batswana families	<ul style="list-style-type: none"> <li>❖ Family conflict resulting from hospice care option</li> <li>❖ Criticism from extended family</li> <li>❖ Criticism from neighbors</li> <li>❖ Aids care must be kept secret and at home</li> <li>❖ Hospice care and Aids is a form of punishment by God and ancestors for bad behavior</li> <li>❖ Hospice care is a Western practice</li> </ul>
2 Social stigma associated with Aids	Feeling associated with hospice care by family, patient and	<ul style="list-style-type: none"> <li>❖ Feeling of rejection</li> <li>❖ Aids and hospice care are stigmatized</li> <li>❖ Family feeling guilty</li> </ul>

	community	<ul style="list-style-type: none"> <li>❖ Patients' doubts about hospice care</li> <li>❖ Fear of being infected with Aids</li> </ul>
3 Differences in health care practices	<p>Hospital care</p> <p>Hospice care</p>	<ul style="list-style-type: none"> <li>❖ Little empathy at the hospital</li> <li>❖ Hospice caregiver is full of love</li> </ul>
4 Knowledge is power	<p>Positive effects on the Aids patients' emotional well-being</p> <p>Patients. Physical well-being</p> <p>Positive effects on families of Aids patients</p>	<ul style="list-style-type: none"> <li>❖ Counseling is uplifting</li> <li>❖ Emotional symptoms disappear</li> <li>❖ There is improvement physically</li> <li>❖ Counseling restores hope</li> <li>❖ Willingness to advocate for hospice care</li> <li>❖ Relief from burden of physical care of Aids patients</li> </ul>

### 3.5. DISCUSSION OF FINDINGS AND LITERATURE CONTROL

The discussion will be focused or based on the schematic condensation of the relevant data as it appears in Table 3.2. The following discussion will be highlighted by direct quotations from the participants according to the transcripts and accompanying literature control. The major categories that emerged from the interview with participants when they expressed their experiences regarding hospice care of Aids patients are the following:

- Hospice care as foreign
- Social stigma associated with Aids
- Differences in health care practices
- Knowledge is power

#### 3.5.1. CATEGORY 1: HOSPICE CARE AS FOREIGN

It is one of the major categories of the study in which the participants expressed their experiences of hospice care as being foreign to their culture when it comes to caring for patients. According to the (South African Oxford Dictionary, 2005: 496), foreign means something that is introduced or brought in from outside, that is from another country or another culture, in other words something unfamiliar or uncharacteristic. In their study on uncovering the family care giving model, (Wacharasin & Homchampa, 2008:390) indicated that among blacks, hospice care is viewed as a western approach to Aids and cancer care, aimed at rendering end-of-life care, which is foreign and contradictory to their cultural practices. The above arguments are supported by the sub-category that emerged, asserting that hospice care is a-cultural to the Batswana families.

### **A-cultural to Batswana families**

According to the participants, hospice care is not in line with their culture. Batswana like other Africans, are not used to taking their ill loved ones out of the family to be cared for by strangers, like in a hospice. The above findings are corroborated in a study conducted on the African Americans. It has been found that African Americans dislike end-of-life care and have negative perceptions about hospice and end-of-life care as it is foreign to their black culture. This has caused a lot of confusion and misunderstanding in families that lack knowledge on this approach to care. It has also been found that hospice services were utilized more in geographic areas where there were fewer African-American residents, (Chilton *et al*, 2008:40). The above shows that Batswana share the same sentiment as African Americans in their experiences and perceptions of hospice care as foreign. This alone shows that even though the study was done in America among black Americans, remarkably, the black Africans, the Batswana, share the same sentiments. Africans prefer to take care of their patients, including the terminally ill ones, in a home environment. According to (Brack, et al, 2003: 319), in African communities where ubuntu principles are practiced, caring for each other is considered a family and societal effort. Inability to care for the loved ones can lead to disharmony within families even if the option has been discussed and agreed upon. The participants expressed their experiences on hospice care as being a-culturally based form of care, according to the following themes:

- Family conflict resulting from the hospice care option
- Criticism from extended family
- Criticism from neighbors

- Aids care must be kept secret and at home
- Hospice care and Aids is a form of punishment by God and ancestors for unacceptable behavior

These themes will each be discussed separately, including quotes of what the participants said and support from the relevant literature.

### **Family conflict resulting from the hospice care option**

During interviews the participants expressed that they experience that enrolling their loved ones at the hospice has brought conflict in their own families. They verbalized that although they had harmonious relationships before taking their patients to the hospice, some members of the family have started viewing them differently.

One of the participants said:

*"When I took my son to the hospice, conflict and disagreement resulted in the family as though we have never discussed this issue within the family".*

The same participant indicated that she found the actions and expressions of family members confusing and surprising as they were consulted and informed before the patient was taken to the hospice. Family gatherings were also held with extended family members like grandparents, aunts and uncles to discuss the option of taking the ill person to the hospice. The participant was wondering about what happened now that family members seem to have not bought in on the hospice care option. Conflict that had previously not been there emerged after the patient has been taken to the hospice for care.

Families come into conflict after having agreed on the option of hospice care when other people they relate with, for example neighbors and relatives, show disapproval of the option.

Participatory decision-making is a norm in the black culture. This view is supported by (Watson, 2004:52), who maintains that in Botswana, when major decisions such as taking a child to the initiation school, and decisions on health related matters are taken, the family members sit together, deliberate about the issues until a consensus is reached. Watson further shows that in some instances it does occur that the decisions taken yield unexpected results. The decision-makers deny that they were involved in the decisions taken. (Chen *et al*, 2003: 17) share the same sentiments in their study on decisions for hospice care in patients with advanced cancer, where they assert that decisions of care in terminally ill patients should be the result of a collaborative, fully informed decision-making process that includes the patient, family and all concerned. Failure to observe this principle, results in discomfort and conflict.

In most responses from participants it became clear that it was the mother of the patient that was blamed for the decision to opt for this form of care. The father or even the grandmother would start to show some change in attitude towards the mother, even though a consensus was initially reached. During interview sessions, the participants made the following statements:

*"In the beginning my husband did not even talk to me because he believed that I have rejected his son even though he once agreed on that. Maybe it's because he was not in favour of the whole idea from the very beginning".*

Mothers are mostly blamed for the decision of taking a child to the hospice because they are the primary caregivers in families, especially African families. The mother is often regarded as the pillar of the family and a person who is responsible for care. In

this case other family members feel that the mother has drifted away from the culture by taking the ill person to the hospice even after having discussed the issue.

(Johnson *et al*, 2004: 208) also found out that main caregivers are women or girls, amounting for up to 68% of the population in their study on Aids in the household. Even in situations where boys were equally likely to be caregivers, the task was directed to girls. (Madlala, 2005: 34) maintains that the tremendous role played by women as caregivers has made them the leaders as far as union of family members is concerned. That is the reason why any conflict and misunderstanding is directed at them, even when illness and death occurs.

The participants showed signs of frustration as a result of the conflict and misunderstandings spreading from the decision to take their children to hospice for care. Family members still cling to their African beliefs of Ubuntu and caring for patients at home, even if it is no longer possible to do so due to the fact that mothers are working and have to be breadwinners. However, some of the working mothers who participated in this study acknowledged the benefit of the hospice as they are able to cite statements such as:

*"It is not within our culture to subject an ill person to an unfamiliar environment when he needs us badly during an illness. We don't normally do that but I am presently compelled by the fact that I need to go to work and I can't look after my son. I do not have an option and that doesn't have to make us fight."*

This participant expressed a feeling of having taken the option of hospice care for her child based on the fact that she had to work and is therefore able to look after him. Although she acknowledges that the practice is not within her culture she found the hospice as a good option to solve her problems, rather than seeking help from other family members who may also be busy with their own chores.

(Brack et al, 2003: 319) are also of the opinion that this ubuntu worldview of African societies is a determining factor in the societies and within families when it comes to the formation of perceptions that influence social conduct. It therefore means that if the family members disapprove decisions made regarding the option of hospice care, and feel that there is a deviation from the norms, they will most likely cause conflict, as experienced by the participants.

- **Criticism from extended family**

This is another theme that emerged from the sub-category of hospice care as a-cultural to Batswana. It was evident from the interview that even though the nuclear family could agree in consultation with extended family members on taking their son or daughter to the hospice for care, other members of the extended family would show some concern and disapproval. The participants cited that the extended family also has a say in as far as the care of the ill one is concerned. The participants made the following statements to that effect:

*"There is no more relationship between me and my mother in-law as she is against the decision I took of sending her grandchild to the hospice."*

*"At first they didn't understand it. They were totally against it and we suggested that as they are being so difficult and not understanding, they seem to be against hospice"*

*care, maybe they would want to take care of my brother, but they also could not do it due to their commitments"*

*"My decision was mostly criticized by my in-laws as they stated that I came with my own perceptions from my family. That is why I took the child to the hospice"*

The participant was worried because in their culture, the extended family has a role to play in the smooth running of the family, and maintaining peace with them was important to her. Their uncooperativeness has caused her not to care about their relationship anymore, because she has no other option but to take her child to the hospice. That is the reason these words were said:

*"Se sengwe ke gore kutlwano ga e sa tlhole e le teng magareng ga ka le mogadibo wa ka, ke raya ausi wa monna wa ka. Nna ga kena taba le ena. O siame a le jalo. Are mo lapeng ba utlwa ka nna. A re ke go reng ke isitse ngwana wa abuti wa gagwe ko hospice. A re ke ne ke emetse fela gore abuti wa gagwe a tlhokofale ke sale ke dira boithatelo. Maar ga go tshwenye its up to her"*

*"(One other thing is that a good interpersonal relationship does no longer exist between myself and my sister-in-law, that is my husband's elder sister. I do not care about her. She is just fine even if it is like that. She says everybody in the family does as I please. She asks why I took her brother's child to the hospice. She says I only waited for her brother to pass on so that I could remain doing as I please, but it does not matter, it's up to her)".*

In this study the participants show some concern about the reaction of the extended family pertaining to the care of the patients at the hospice. There is usually not much

they can do, and therefore they end up conditioning themselves to the change in attitude of the members of the family, stating that it does not matter anymore. The extended family wants to be involved in the care of the individual ill members according to the culture of this population. They feel that as members of the family they should also be involved in decision making relating to the care of the ill loved one.

(Masango, 2005:916) supports the finding that one may experience criticism from the extended family members the African context supposes that caring involves all the members of the family, relatives, community members and ancestors. The view is that in an African community, life is lived in a group, tribe or clan. There is no individualism and as in other societies. This view also has an impact on one's death, hospitalization or institutionalization. Batswana believe in consulting the elder members of the family in accordance with the ubuntu principle before decisions can be made. There is a belief that they have experience, and have the interest of the family at heart (Hotep, 2003:917). (Masango, 2005:912) also maintains that, the affirmation of your decisions by others is valued. The belief is that no man is an island. The Zulu proverb that says "Izandla zi a gezana" (Hands wash each other). The role of the significant others is important (Mulaudzi, Libster & Phiri, 2009:47).

A study by (Kang'ethe 2009:28) on challenges impacting on the quality of care for persons living with Aids, assert that the families of patients in the study became adamant that their patients should be discharged from the hospice and others from the hospital because people have started viewing them differently ever since they have decided to admit the patient, especially because they did not have other ordinary illnesses, but Aids. Major criticism was directed at the parents of the ill persons.

- **Criticism from neighbors**

This is another theme that emerged during an interview. Participants were worried about the change in attitude and behavior of their neighbors after having noticed that they have sent their loved ones to the hospice for care. Because Africans believe in doing things together, they value the relationships of all people they live with, including neighbors. This is shown by the way people greet each other. They always want to know about the status of one's health. The particular good morning or good afternoon is always followed by "How are you doing?" (re teng le kae?). On explaining the criticism from neighbors, the participants verbalized the following words:

*"They accused me of throwing my child away to strangers who don't even care".*

*"People in my neighbourhood were surprised that I took him to a hospice" and "some people even laughed at me and questioned why I took my child to that place".*

One participant said: *"My neighbours stopped to visit me as they did in the past. Even if one would come, she would not drink or eat anything from my house as if everything was filthy or could infect her. This continued until one of the caregivers from the clinic came and clarified issues around how one gets infected, with some of them."*

**Literature control: Criticism from neighbors**

(Masango, 2005: 912) argues that Africans maintain that people care for one another and one man's problem becomes the whole community's problem. Words of criticism are taken seriously, just like words of acknowledgement and compliments. The study further maintains that, according to the way the African communities lead their lives, they are very concerned about how their neighbors behave towards and think about them. A change in their attitude has a negative impact on them. As they do

things together, if their neighbors are not on good terms with them, they will exclude them on issues that take place in the community. They will no longer be allowed to participate in ceremonies and community events.(Brack et 2003; 320) echo these views and assert that African people are innately social creatures and exist in groups in order to survive and thrive, and conflict is best kept minimal. That is the reason that one participant even welcomed intervention from the caregiver, who brought some relief as the neighbors changed their attitude for the best after understanding more about HIV/Aids. (Gausset, 2008:2) in his study on Aids and cultural practices in Africa, also found that the people in the community looked down on those who have an Aids patient in the family. Those who have sent those patient out of their homes for care, or those who were not actively involved in the care and support of such patients, were rejected. (De Villiers, 2005: 60) maintains that because Africans care for one another and are concerned about the welfare of others, they may either approve or disapprove the behavior of another person, and this has an impact on a person's life as it can result in exclusion and marginalization. In cases of disease there is the bad connotation of being cursed.

- **Aids care must be kept secret at home**

As Aids has so much stigma attached, participants revealed the fact that some people feel that patients should be kept secretly at home and be nursed there without anybody knowing about their illness. The participants made the following statements:

*"In our culture, it is true that, we are used to the fact that we take care of our people or we nurse them at home, its part of our black culture"*

Another participants added by saying:

*“Culturally; we usually take care of them at home. They don't get exposed a lot to the outside world, to other people. I think in our culture is a bit of a stigma. So when they are HIV positive, all of a sudden people think that the signs are showing, that people can see, even though it is not written on your forehead. There is this thing that people can see, so they turn to, people turn to hide you in the house, they nurse you in the house and hide you till the end of your life rather than sending you to the hospital or hospice. We are also aware of the fact that they look down upon us as we have a person with AIDS in our family, they talk a lot about us, quiet a lot”*

In the African view, people are best taken care of at home, that is people with all types of diseases, but most importantly Aids patients due to stigma. The feeling of the participants is that taking a person to a hospice will only expose him/her to the outside world, meaning strangers whose reactions may be unpleasant.

*“Since we are Tswana and we grew up like that, if somebody's sick we keep them in the family, we look after them. But I think that if a person reaches that stage where they cannot be taken care of by people around them is best for them to be taken to hospital where they will get proper treatment and where trained people, professionals will look after them. So in that way, even if it's not in our culture, but there is a benefit. We just need to adjust and we must know that it is just for the benefit of the people that we love.”*

Participants are aware of the fact that neighbors and the community disapproves of hospice care and rather feels that the patients could have been kept at home. However, the participants acknowledge the good that the hospice has brought to them. They are willing to take it upon themselves to deviate from the norm of

keeping an ill person at home, and to take him to the hospice for better care especially when the condition of the patient is no longer manageable at home.

#### **Literature control: Aids care must be kept secret at home**

Families of Aids patients have serious psychological and emotional problems with regard to their Aids patients as soon as it is found out that the patient is suffering from Aids. Their self-confidence as well as their self-esteem is adversely affected. Keeping such patients secretly in their home and not exposing them to the rest of the world to know about their illness, preserves their dignity. Families and patients living with Aids have lost their autonomy, privacy and control. They have a sense of guilt, denial, anger, and have lost their coping mechanisms to combat anxiety, depression and suicidal tendencies. This occurs after the patient has been sent to an institution for care where people will start noticing his illness. It therefore means that to prevent all this from happening a patient is kept and cared for at home, irrespective of the stage of the illness (Dworzanowski, 2002:426). (Burrs, *et al*, 2004:1) share the same insights as they are of the opinion that African Americans have been caring for their loved ones at home since the beginning of time, including the terminally ill and the dying, no exceptions. A study conducted in America by (Char, 2003: 377) on accepting hospice care also reveals that there has been a long standing cultural mistrust between Africans and medical community in as far as terminal illness and care is concerned. This study also addressed issues of cultural sensitivity as it further states that caregivers from different cultural backgrounds may lack culturally sensitive approaches to hospice care, and African American people may view them as insensitive. Due to these reasons they feel that their patients are best cared for at home. The issue of rendering culturally sensitive care is supported by Leininger's trans-cultural care theory, which emphasizes that there is a need for health care

professionals to be culturally sensitive by rendering care that incorporates cultural care preservation/maintenance, cultural care accommodation/negotiation and cultural care re-patterning /restructuring, so that nurses will have knowledge to provide culturally competent care (Vivanco, 2004:4).

- **Hospice care and Aids is a form of punishment from God and ancestors for bad behavior**

There were actually mixed reactions and different views regarding hospice care and Aids as punishment. Some participants viewed Aids as some form of punishment from God while others felt strongly that it was the ancestors. The participants asserted that they view the hospice itself and Aids as a disease to be a form of punishment to those people that were difficult and could not listen while they were advised. A participant actually stated that her son was a very difficult person who lived life as he pleased. Her son failed to listen to her advice and therefore became ill with Aids. It is for this reason that he should be taken to the hospice. This perception frustrates family members. This can be proved by statements uttered by a participant:

*“He spent his social grant on alcohol and cigarettes, so he is better off at the hospice”.*

*“My son was a problem child even before he fell sick, the ancestors are dealing with him as they are now angry, thus he deserves to be put for hospice care”.*

The other participant attributed the illness of Aids to promiscuity, which the word of God is very much against. It is clear that because she could not change her daughter's behavior through advice, she ended up ill, only the hospice can serve her

right. The hospice can now be a form of sanction to her for not taking advice seriously. Anger and frustration made her say these words:

*"My daughter would not listen to me....she went out with several men, and she is difficult, only the hospice got her right"*

The statements that have been uttered by some participants really showed anger at their ill children. They feel that the disease occurred because they did not listen to them as parents and therefore the children became infected with Aids. Other participants attribute the wrath inflicted as punishment on the individual by the ancestors, while others see it as something from God. It is also clear that some of the participants view sending their loved ones to a hospice as punishing their own children for failing to listen to their advice.

#### **Literature control: Hospice care and Aids as a form of punishment for bad behavior**

(Van Dyk, 2005:3) stated in his argument that some black Christians believe that Aids is God's punishment for immorality and sins. Illness as well as hospice care is seen as a penalty to some for their wrong doing. In a study on HIV Counseling conducted by (Meursing & Sibindi, 2000:20) it has been found that Aids is perceived as a dirty disease. It is associated with promiscuity. This misconception that Aids affects promiscuous and sinful people that end up being very ill in homes and hospices brought about condemnation and a belief that it is a form of punishment. The same opinions are echoed by (Chen, et al.2003: 51) and (Schonwetter, 2003: 789) who maintain that hospices are perceived as places that are ungodly and cater for people who are being punished and have given up on life.

The same views have been reiterated by (Duffy, 2005: 14) in his study on suffering, shame and silence, where the findings revealed that HIV is viewed as a disease that results from immoral behavior and which can cause the rest of the people to reject one no one would like to associate with him/her. They went further by stating that in most instances denial causes the ancestors or the witches to be blamed for being responsible or causing the disease as a form of sanction to a person.

The same views are echoed by (Holzemer & Uys, 2004: 166) in their study on managing the Aids stigma. They reiterate that Aids people are stigmatized and said to be punished because others view them as contributors to their own problems and unworthy of care as they brought the situation onto themselves.

- **Hospice care is a Western practice**

Discussions with participants in this study show that there is a general feeling that hospice care is foreign and part of western practices. This is how it was expressed by some of the participants:

*"We don't understand hospice care...it is white culture introduced by the new government, but who cares, I will take my child there for help"*

It is clear that to them, hospice care is Western. Even after having heard of hospice as an option in caring for Aids patient, the issue of trust was still a hindrance. This type of belief was also found in a study undertaken by (Harding et al, 2005: 9) in which findings revealed that 82% of patients in the hospice under study were white, even though the doors were open for all races. This was observed as a reaction of some parents of Aids patients within the hospice.

(Mundell, 2008:7) conducted a study that showed that the blacks in the study, when compared to whites, clearly had less favorable beliefs and attitudes about hospice care. Lack of trust came up clearly in (Char, 2003: 3) a study on accepting hospice care. He shows that in the African American community historically there has been a long standing cultural mistrust between African Americans and the medical community. African Americans feel that it is the white man's practice to take a patient to the hospice as opposed to their home-based care, which works well for them. The findings of (Winston, *et al*, 2005: 151) in their study on overcoming barriers to the access and utilization of hospices, emphasize the fact that hospice care is Western to Africans as it was found to be unable to address their issues around religion, spirituality, as well as cultural beliefs. The procedures within hospices were incompatible and insensitive to the culture of Africans. Batswana, according to their expression do not trust hospices for care as it is Western and they feel that their cultural beliefs as well as customs might not be accommodated.

Much as hospice and palliative care are affordable, sustainable care services, some participants are still skeptical and have second thoughts about hospice care. One of the participants said :

*Culturally it is not allowed" and "hospice care is foreign in our culture...but if the benefits are good, I will take it. Initially I did not really trust hospice care at all for my child"*

One might wonder why they have such remarks and thoughts while their loved ones are being cared for in a hospice. According to their responses it is clear that it is due to the fact that they have no alternative means of care and they are actually aware of the benefits this new means of care has brought in their lives.

The above subcategory describes how the participants view hospice care as foreign and a-cultural. They also reveal painful experiences that participants and their loved ones have experienced due to lack of incorporation of culture in hospice care. These sentiments are supported by proponents who advocate for incorporation of culture in the health care models. Terms such as cultural safety, cultural congruence care and cultural diplomacy have been used and described in literature to show the importance of respecting values, norms and practices of those that are in our care. (Eckermann et al, (1992 : 215)

*"Cultural safety needs to be recognized within the health care system and to be assured that the system reflects something of you – of your culture, your language, your customs, attitudes, beliefs and preferred ways of doing things".*

(Leininger & McFarland 2007: 315) agrees with (Eckermann et al, (1992: 215), when they assert that culturally congruent care must be central to the models of health care. They emphasized that there is a need to ensure that health care practitioners are aware of the cultural needs of their clients to be able to provide quality care. The same views have been reiterated by (Mulaudzi *et al* 2009), who assert that in their daily contact with patients, health care professionals must strive to display cultural diplomacy and principles embedded in the African philosophy of ubuntu.

### **3.5.2. CATEGORY 2: SOCIAL STIGMA ASSOCIATED WITH AIDS**

Social stigma is another category that came out of the study. (Nathan and Gilbert, 2007:3) define social stigma associated with Aids as a feeling of rejection and grief that result from people knowing that one has Aids. This results in a person fearing

knowledge of the results of blood taken for the test. (Duffy, 2005:14) also confirms that stigma was originally a Greek word and referred to bodily signs designed to expose something unusual and bad about the moral status of the particular person affected. As in this case, participants brought to light the fact that they are also stigmatized. A major cause of stigma is the fact that patients are transported to and from the hospice with a vehicle that is labeled hospice and it is a known factor in this community that the hospice, much as it caters for other terminally ill patients, predominantly caters for Aids patients.

The sub-category under this major category was: Family's, patients' and the community's feelings associated with hospice care.

The participants expressed their feelings in relation to hospice care options and among them, the patient, family and community are affected in either similar or different ways.

The following are the themes that fall under this sub-category:

- Feelings of rejection
- Aids and hospice care are stigmatized
- Family feeling guilty
- Patient's doubts about hospice care

Fear of being infected with Aids

- **Feelings of rejection**

It was evident from the interviews that participants stated that their ill patients had a feeling that the families have rejected them when they send them to the hospice for

care. The patients had a feeling that they were no longer wanted in the families and they wanted to do away with them. The family members also felt that it will appear as though they have rejected their loved ones. The feeling was mutual between the patients and their families. Rejection of this nature was mainly due to the stigma of Aids, even though the issue of hospice care also had a bearing on the stigma. This is how it was expressed by a participant:

*"Circumstances forced me to take my child for hospice care as though I am rejecting her."*

*"Our culture does not allow people to be rejected; people are not animals that they should be taken out of their homes and be put elsewhere."*

#### **Literature control: Feeling of rejection**

The feeling of rejection was picked up in some participants during the interviews. This was further emphasized by a study by (Abrams, 2009:1) that reveals the extent of rejection those family members of Aids patients face. It states that, for many, learning their HIV positive status and being put in institutions, resulted in societal and familial rejection, poverty, and in some cases severe illness, rather than facilitating opportunities to access care, counseling and support services due to fear of rejection and ill-treatment.

(Cao et al, 2006: 518) also confirm the issue of stigma in the study of understanding the HIV related stigma and discrimination. They argue that the stigma of Aids is related or associated with the way the disease was acquired rather than the disease itself, and unfortunately it does not only affect the patient but the family as well. (Nathan & Gilbert 2005:18) also became aware of the stigma in their study when

they highlighted that the stigma is real. It creates fear of ostracism and silence, and this is major barrier to obtain assistance and medical attention as they fear that they will be discriminated against and rejected. (Greef et al, 2007: 83) also echo the same stigma related to Aids in their study on experiences of the HIV stigma. They point out that Aids creates outsiders and social boundaries between the normal and the stigmatized. This stigma results in a rejection of the affected and the infected. Much as they are rejected, they are discredited within social interactions. (Carr, 2008:12) maintains that there is a serious vulnerability of Aids people as they are stigmatized and unacceptable to the significant others. The experience of stigma contributes to heightening the patient and the caregiver's stress level (Orner, 2006: 238).

- **Aids and Hospice care are stigmatized**

It also emerged as a theme during the interview session where participants were concerned about hospice care. They stated that the other people such as extended family members as well as the community stigmatize them for having taken their patient to the hospice. It is as though they do not want to care for the patient at home. They highlighted the fact that a hospice car that collect and bring back patients to and from their homes is labeled "hospice". Their neighbors frown at them each time the car is seen at their homes. This is how a participant expressed it:

*"I think the struggle, the main, the main struggle was the issue of being picked up, and the idea of being dropped off with the car written "hospice."*

*"So, it's better, it depends on how you look at a hospice, but I think in our culture, in our black culture, its mostly wrong, its not a good thing too, and again it makes the stigma very alive now."*

The participants expressed their experiences of being stigmatized not only due to Aids itself, but the hospice care option made matters worse. The reason for all that people already presume that one has Aids as soon as one is enrolled in the hospice. This is how one participant actually put it:

*"Now people see you, you are put in an institution and stay there with only people like that. It's in a way stigma on its own"*

*"Well, avoiding it, eeh, maybe we can avoid it, or maybe we can work on it than try to avoid it. I think especially with a hospice, it starts with a very, I mean it starts with this, basically why you are there. It's because of HIV, and because of how people look at HIV. I mean I don't think it just starts about you being in a hospice, it goes back to why you are there and how people view HIV, they just think its some different disease or illness, so that's why the stigma is so huge"*

The stigma is so intense that the participants feel that it is a matter of an attitude that needs to change and they believe that knowledge and understanding will enable a change in attitude, which would lessen the stigma:

*"The stigma is so huge, and maybe if we can change our whatever attitude towards the virus and hospice care or towards the disease, then maybe we can try to know and understand or not to stigmatize it or whatever the way people are doing it today."*

#### **Literature control: Hospice care is stigmatized**

(Abrams, 2009:1) argues that challenges for HIV infected patients includes stigma and the perceived threat of violence as major barriers to acceptable quality of life and to obtaining appropriate care and support. A study by (Rogers *et al*, 2006: 803) also revealed the stigma related to Aids and hospice care. According to them,

women in their study faced rejection and breakage of their marriages as soon as they were confirmed to have Aids. Some were either sent to hospice for care or referred for home-based care. Their love and social lives became seriously disrupted. They further state that for interventions to be successful; urgent attention must be focused on education and empowerment of families as well as patients. This is an aspect that also came up among the participants, as one also mentioned the need for knowledge and understanding on Aids and the concept of hospice care.

In their study on health care seeking behavior (Kruger et al, 2009: 37) discovered that participants expressed that putting a person in an institution means that he is HIV infected. If people know your status, you will be pushed aside by the community to an institution, to a hospice.

- **Family feeling guilty**

The participants as families of the patients that receive care at the hospice have a feeling of guilt. Even though they are working and do not have time to look after the patients at home, they still feel guilty as though there was something they could do to care for the patients. They feel that they are not doing enough, or even that they are not doing the right thing by taking the patient to the hospice for care. During the interview, the participant revealed a sense of guilt as well as anger, which led to anxiety. The following were comments made by the participants:

*P: Ee, e batla e le thatanyana ka nnete, because nako e nngwe e ba e ka re motho o re mo latlhile.*

*(Yes, it really becomes difficult, because at times it appears as though one has disposed him off)*

At times it was as though the participant, due to frustration and guilt, wanted the opinion of the researcher as an individual, to justify the decision of taking a patient to the hospice. The following are the words that were said by the participant:

*For my brother it was like, it wasn't easy, it wasn't fair. You know it was like we are advertising his status in a way by sending him to the hospice, but he got to understand that, what else could we have done?*

#### **Literature control: Family feeling guilty**

(Dworzanowski, 2002: 426) maintains that families and patients living with Aids have lost their autonomy, privacy and control. They are haunted by guilt, denial, anger and they no longer have a coping mechanism to combat anxiety, depression and suicidal tendencies. What intensifies the guilt is the inability to look after the ill person. For these people, intervention is important.

(Johnson *et al*, 2008: 1956) also discovered the guilt and frustration that family members experience due to Aids and due to the type of care the family decides upon, especially if it involves a person outside the family. They maintain that, for Africans, it is a less favorable thing to talk about death and palliative care. This is due to fear resulting from spiritual beliefs and distrust of the health care system.

(Sullivan, 2007:79) also argues that a hospice as an institution may give rise to initial misunderstanding in an individual so much that the decision to take a patient there; results in guilt feelings because of lack of knowledge of what hospices stand for. All these occur as a result of cultural beliefs and practices within specific communities.

- **Patients doubt about hospice care**

During an interview, some participants revealed that patients who are being cared for at the hospice also have doubts about the decisions that have been taken about their care. The reaction of the patient towards the hospice as an option of care also affects the way the family feels. These are some of the comments from the participants:

*"In the beginning it was difficult for him to accept that we are doing it for his good"*

*"He struggled to accept the fact that we've decided to take him there in the first place. It was hard for the family."*

The participant showed signs of relief when she stated that, even though in the initial stage of the patient's care at the hospice, there was a feeling of shame, later acceptance occurred as care continued.

*"At first they feel ashamed of the hospice but with time they accept."*

#### **Literature control: Patients' doubt about hospice care**

According to (Harding *et al* 2005: 23) the term hospice, in Spanish, has a very negative connotation. It implies abandonment, some patients actually felt as though they have been sent to a Leper colony. They have been sent to a place where they will not come back and be part of their families again. Hospice care is viewed as a place that mainly deals with end-of-life care, the patients that are taken there also know that, and it is as though the family has given up on them. They are just put there to wait for their last day to come. This has a negative impact on the patient, especially those that still have hope for cure (Johnson *et al* 2008: 1953).

The study of barriers to hospice use also found out that patients that believe in God's power to heal, also feel that being taken to a hospice means that people have given up on the power that God has. To them this power could result in them being well again, because unlike in a hospital, hospices do not offer vigorous types of treatment and medication that to them can lead to healing (Washington *et al*, 2008: 270). (Char 2003: 380) also asserted the issue of mistrust of modern medicine by Aids patients. The fact that they will only be visited at scheduled times also made patients doubt this option of care. There were also doubts about the type of medications that were administered in hospices (Fitzgerald & Simon, 2001:308).They also feared to be known by other people as going to this institution.

- **Fear of being infected with Aids**

Participants raised their concern during the discussions that as family members, even though they might prefer to nurse an Aids patient at home, they have fear that they might get infected while caring for him at home. Most of the participants are aware of the fact that Aids is infectious. They stated that much as they feel that they want to nurse their loved ones at home, they acknowledge the fact that they might not succeed in protecting themselves from being infected. The participants uttered the following phrases:

*"AIDS is infectious; I don't know how to nurse him at home while protecting myself from being infected"*

*"I don't know how to care for him but at the hospice they will do it right"*

*"Here at home where will I get the protective supplies; AIDS is infectious."*

The participants have a concern that because they do not have the protective devices at home to use while caring for the patient, the whole family can be infected and end up dying.

*"kwa hospice gona ba a tseba gore ba ka kgona go itlhokomela jwang gore ba se ke ka tshwaetsega. Jwale mo gae o tla tsaya kae di-glove tse o di rwalang gore o sireletseg?, Re ka tla ra fela ka lapa?"*

*("At the hospice they know how to take the precautions so that they do not become infected. Now at home where will one get gloves that one can put on to be protected? Otherwise we can all die")*

#### **Literature control: Fear of being infected with Aids**

In a study by de (Figueiredo and Turato, 2001: 638), it was found that when caregivers were informed about the patient's Aids diagnosis, their first feeling was fear that they themselves, or another member of the family, might also become infected die.

(Abrams, 2009: 3) agree with the above author by highlighting that non-governmental organizations such as hospices and home based care initiatives address the problem of fear by teaching caregivers through dissemination of knowledge, introduction of specific skills relevant to care and support of HIV/Aids patients in order to allay the anxiety and fear of being infected. (Duffy, 2005:16) discovered in his study that one participant from a rural community who had Aids actually stated that when she goes to the river to bath, everybody would stop bathing in that river and change to another stream. Some people would even go home without washing rather than washing with her in the river. They feared that she might

infect them. The same concept of fear of being infected was also observed in the family of that same rural woman as the members of her family also refused to share anything with her.

The findings of the study conducted on non-professional caregivers of people living with Aids, revealed that fear of being infected and infecting the rest of the people that one is in contact with was a barrier towards provision of care. Lack of resources was another aspect that made them fearful, as protective devices were inadequate. Fear was also cited as a contributory factor affecting quality of care (Strydom & Wessels, 2006:6). (Kang'ethe 2009:28) supports the above findings when he states that people are afraid of being infected by the Aids people they care for as they had no protective gloves.

### **3.5.3. CATEGORY 3: DIFFERENCES IN HEALTH CARE PRACTICES**

The third major category that emerged during the interview sessions was differences in health care practices. The sub-categories under this category are:

Hospital care, with theme being: little empathy at the hospital.

Hospice care with the theme being: hospice caregivers are full of love.

#### **3.5.3.1. Hospital care**

It is the subcategory that emerged from the category of differences in health care practices. The theme under this sub-category is little empathy at the hospital.

### **Little empathy at the hospital**

Some participants expressed the feeling that as family member, they experienced little empathy at the hospital, less than what they actually expected during the family member's stay at the hospital. Participants also highlighted the fact that patients are discharged early from the hospital, even before they are well enough to go home. These are some of the phrases stated by the participants:

*"My child was very weak and sick but the hospital could not keep her longer to care for her."*

*"The hospital keeps them for just a few days and sends them away; it was tough."*

The participant showed acknowledgement of the fact that there is an explanation of the sub-standard type of care that she saw and attributed it to the fact that the workload at the hospital is sometimes not manageable and patients should then be sent home.

*"At the hospital, patient care is not good... today nurses don't care for patients like our old nurses, maybe they are overworked. We took him out of the hospital because the care was poor and hospital personnel agreed. Someone advised me about hospice care the ward was so full that patients due not get individualized care."*

### **Literature control: little empathy at the hospital**

(Gwyther & Rawlison, 2007:4) did a study on the introduction of hospices. In his study, it has been stated that hospices were first utilized for Aids patients in South Africa in 1980. It was a model of palliative care provision that involved a strong interdisciplinary team comprising of professional nurses, social workers, counselors and volunteers in order to address the problem encountered at the hospitals that

were no longer coping with care of patients as a result of high numbers of patients. Quality of care in these facilities was then compromised. Physical care rather than emotional care was the key priority as a result of the workload the staff encounters. This compelled them to concentrate much of the physical aspect of healing more than any other aspect. This gives the patient and families an impression that hospital personnel do not have empathy. (Sullivan, 2007:79) maintains that for the patient that is terminally ill, provision of support and care to them and their families cannot be adequate after all curative options have been exhausted and the focus is on the acutely ill patients.

(Boyle *et al*, 2001: 196) discovered that hospital care service providers more often than not view patients as diseases or objects rather than persons with unique human characteristics and/or different cultural values and expectations. This can be attributed to the health care demand they are facing. In the same study, a participant who was a mother to an Aids patient described her experience with her son when he was in hospital. She felt that the hospital staff was not adequately taking care of her and did not show a shred of sympathy for him. She had to stay with him and gradually assumed the responsibility for his personal care, particularly, to offer emotional support and empathy.

### 3.5.3. 2. Hospice care

- **Hospice caregivers are full of love**
- Participants expressed the appreciation they have of hospice caregivers. They stated that during their loved ones' illness, they experienced sympathy and warmth at the hospice. They uttered the following words to express their feelings:

*"I lack words to describe the care I saw being given to my child at the hospice"*

*"They received my child with warm hands. The empathy demonstrated by the nurses was formidable."*

*"Nurses at the hospice are dedicated to caring for the sick."*

The participants, according to their responses, were aware of the fact that the caregivers at the hospice have been taught about palliative care and caring for a terminally ill patient.

*"The nurses at the hospice show expertise in caring for all illness conditions especially those who are very ill."*

*"I took my brother to people who can love and show compassion to patients, they are knowledgeable and true caregivers."*

*"I wish all black nurses could go and learn caring from the hospice, their caring is pleasing to the patients and to families."*

#### **Literature control: Hospice caregivers are full of love**

According to (Mc Causland, & Pakenham, 2003: 853), supporting efforts to improve care for patients and families with life-limiting illness in institutions such as hospices, focus on professional and public education, and have expertise, experience and proven community organizing skills necessary for care and support of patients and their families.

(Chen *et al*, 2003: 796) maintain that hospice care has the potential of offering quality end-of-life care while reducing all other hassles involved with care, such as medical costs. It further highlights the fact that it provides accurate prognosis and

better understanding of preferences and values, including targeting towards a specific group in need at a given time. The study on a comparison of the quality of care by (Addington-Hall & O'Callaghan 2009: 190) revealed that their study reflected underlying differences in the needs of patients and their families while in the two settings, that of the hospital and that of a hospice, and the way in which they were addressed. As far as emotional care was concerned, hospice care always came out first in the type of patients that were under study, namely the terminally ill ones. It is in the same study that it was found that respondents that are participants in the study were far more positive about their communication with hospice staff than hospital staff and tended to be satisfied with their involvement in the decision making when the patient was in hospital. Sympathy and empathy was observed by participants regarding the hospice personnel.

#### **3.5.4. CATEGORY 4: KNOWLEDGE IS POWER**

The fourth and last category that emerged from the discussions was knowledge is power.

From the discussions with participants it became clear that their involvement with the hospice has made them more knowledgeable about the way the hospices function, and that has empowered them.

The following are the sub-categories:

-Positive effects on the Aids patient's emotional well-being

Themes: Counseling is uplifting

Emotional symptoms disappear

-Patient's physical well-being

Theme: there is improvement physically

-Positive effect on family of Aids patients

Theme: Counseling restores hope

Willingness to advocate for hospice care

Relief from burden of physical care of Aids patient

I will discuss each theme under sub-categories that have emerged from this category.

#### **3.5.4.1. Positive effects on Aids patient's emotional well-being**

The participant brought to light the fact that Aids patients, after being taken to the hospice for care, improved emotionally as they started to understand their condition further and accepted it.

The following are the themes for discussion under this sub-category:

- **Counseling is uplifting**

This is one of the themes that emerged. The participant expressed their gratitude to hospice caregivers as hospice care had a positive effect on the patient's emotional well-being. They stated that they started observing emotional changes in their patients as they were being counseled at the hospice. These are some of the participant's comments:

*"Counselling helped my child to accept his disease"*

*“Se ke se lemogileng thata ke gore ba ba khansela, ba ba ruta ka mokgwa wa go tsaya ditlharetsa bolwetse, le mokgwa wa go itlhokomela ka dijo, le go itlhokomela gape ka bophele bo o bo phelang, le ka go amogela bolwetse ba gago. Tseo ke dilo tse ke do lemogileng”.*

*(“What I have noticed is the fact that, they are being counseled, they are being taught how to take medication for the illness, the way of looking after what you eat, looking after the life you live and to accept your illness. That is what I have noticed”)*

These are some of her words:

The participant observed the depression that her son was undergoing due to the loss of his lover due to Aids. After sessions of counseling at the hospice, improvement set in.

*“When he learned about his diagnosis he became very depressed, especially after the death of his girlfriend...now I see that he has accepted it; the depression is gone after counseling.”*

#### **Literature control: Counseling is uplifting**

Hospice care, just like a home based care initiative; seem to be very successful in enhancing the human dignity of patients living with Aids through counseling (Figueiredo et al, 2004:101). This enables patients to come to terms with their disease.

(Yankah, 2004: 184) is of the idea that Aids and Aids related diseases drain all the strength in an individual to such an extent that even the mighty and the powerful are

not always able to cope with the disease. Unless emotional care in the form of counseling is resorted to, the physical state of the patient is not likely to respond positively to any form of treatment. This became evident when the patients became uplifted emotionally after sessions of counseling.

In this study, counseling was effective even in a very difficult situation where an already physically taxed patient has lost a girlfriend. Counseling sessions enabled him to accept the illness and over and above that, to accept the loss.

(Skinner and Mfecane, 2004: 158) in their study on stigma, discrimination and implications also found that the impact of identity and coping of a person with HIV is largely dependent on the care and support an individual receives. The expertise in counseling and support of the affected and the infected has the ability to uplift one's spirit and the desire to live.

- **Emotional symptoms disappear**

This theme also emerged during the discussions. The participants showed appreciation to hospice care as their patients started showing improvement in their emotional well-being after they have been taken to the hospice for care. They stated the following words to that effect:

*"After a few days at the hospice, I saw an improvement in his feelings; he could smile" and "a few weeks at the hospice made him re-take his life again."*

*"I could not believe the change in his attitude; he wanted to live again."*

### Literature control: Emotional symptoms disappear

(Mc Causland & Pakenham, 2003: 854), state that care of such patients evokes positive personal qualities such as increased understanding of self and others. Due to the support and knowledge the patient receives at the hospice, their personal qualities improve for the best. The change becomes overwhelming. Patients' emotional well-being is seen to improve day by day as the patient continues to receive care at the hospice. The family members notice that.

(Boyle *et al*, 2009: 197) also managed to uncover the effects of hospice care on emotional well-being of Aids patients. In this study it became clear that mothers of adult Aids' patients, saw how distressed and upset their children were during the time they were still being cared for at home. Both their physical and emotional conditions were deteriorating day by day. They had actually given up on life and refused to eat to hasten death, which was not coming soon. The mothers believe that it is impossible to bring healing to a person who has intentionally stopped to live, in other words someone who has given up on life. After their adult patients were taken to hospice for care, they regained their lives. This is the observation that the participant of this study also made.

In a study by (Rogers *et al*, 2006: 805) the benefits of hospice care in the emotional health of Aids patients also became known. Patients that had given up on life accepted their HIV positive status and became health care promoters that taught communities about Aids and its related diseases.

### 3.5.4.2. Patient's physical well-being

This is another theme that came out of the sub-category of Positive effects on Aids patient's emotional well-being.

- There is improvement physically

Most of the participants expressed their views with regard to the improvement they have noticed in their loved ones after being taken to the hospice for care. Some of the patients were unable to eat and even get out of bed due to pain and general bodily weakness. The participants highlighted that most of the patients were sent to the hospice when they are already very ill, while some were sent there after discharge from hospital still in an unfavorable condition.

These are some of the comments of participants:

*"He was refusing to eat or drink medication ...hospice has helped me, all that is corrected. I am thankful to the improvement I see in my child. Indeed there is improvement on him after receiving hospice care because he could not get out of bed and sit."*

*"He could not even swallow water because of sores in the throat...hospice has changed all that he is able to eat now."*

**Literature control: There is improvement physically**

(Uys, 2002: 101) explains that services at the hospice play an important role in assessment of the clients' needs, and they are given advice as to how to live with the disease. This is true of both physical and psychological problems. It therefore becomes possible for the patients' physical well-being to improve. The same study

further states that, the caregivers are able to offer basic physical care such as mouth care, bed baths, ambulation and health education that could otherwise not be given elsewhere. This improves the physical condition of patients.

A study on service needs of patients with advanced HIV diseases by (Karus *et al*, 2004: 19) also maintain that more efficacious treatment of HIV/Aids disease, improved prophylaxis and treatment for some opportunistic conditions that were previously associated with poor prognosis are better managed in hospices lately. The same study explains that several practical assistance and support on nutrition and personal hygiene is seen to be a priority in the hospice care option. This practice brings about physical improvement in patients. During the interviews, participants in this study, particularly mothers of Aids patients in the hospice, with their observational skills were able to detect the rate at which the patients were improving physically.

The study conducted by (Twycross, 2007:9) on patient care: past, present and future, revealed that the nature of palliative care that is rendered to patients in home-based care and hospice settings; lessen psychological symptoms and improves physical conditions giving rise to opportunistic infections.

#### **3.5.4.3. Positive effects on families of Aids patients**

This is the third sub-category under the category of knowledge is power. Themes that emerged under this sub-category are:

- Counseling restores hope
- Willingness to advocate for hospice care
- Relief from the burden of physical care of Aids patients

I will discuss each theme separately and I will also quote what the participants have said.

- **Counseling restores hope**

The participants, who are family members that are affected by this condition and have patients in hospice, reveal their feelings of appreciation and satisfaction. The hospice care has brought about changes in their lives. They gained a different concept of hospice care. Attitudes of family member are also changed and the ways in which they view hospice care also become altered, according to the participants. This is how the participants expressed it:

*"Being with others suffering from AIDS gave him peace and hope"*

*"Counseling helped us to accept and support our child who has AIDS and even hope that one day he will become better and well"*

The benefits that the participants have noticed in hospice care options, made them content and stopped them from caring and worrying about what other people say about their patients and the hospice. This occurs as a result of the good that came out of the hospice as a form of care to their patients:

*"I have peace of mind...I don't care what people say about hospice care; my brother is getting better and we as a family are all happy"*

*"Improvement on my son's condition; made the family come together and forget all initial conflicts."*

There is this particular participant who lost a son due to Aids while he was being cared for in the hospice. The therapeutic effect that the hospice had on her; enabled her to accept the loss of a son. She did not have any sign of bitterness or regrets:

*"My son died in the hospice, but after the counseling sessions, I felt renewal of my hope."*

#### **Literature control: Counseling restores hope**

(Mc Causland *et al* 2003: 854) in their study highlighted that, in order to provide compassionate, high quality and humane care, it is important for counselors in hospices to not only be aware of physical effects of HIV, but also the psychosocial issues that make patients loose hope and how that affect individuals and families. Counselors have to plan around that and restore their lost hope.

(Karus *et al* 2004: 155) maintain that client that have Aids may be unaware of services that are rendered by hospices and in that case become dependent on their lay friends and people they come into contact with for advice, and depending on the advice they obtain from these people, much can happen. That may either make or break them in the process. Improvement will start setting in when professional counseling at institutions such as hospices commences and hope that was lost gradually becomes restored. (Strydom & Wessels, 2006: 5) also echo the same fact that counseling does restore hope in the lives of the patients and their families. To give support, encouragement and lend assistance to patients and families also restores the lost hope. Restored hope is the fundamental of physical and emotional healing.

- Willingness to advocate for hospice care

This theme also emerged during the discussion with participants that because they have discovered the good effects that the hospice has in their lives, they are willing to make it known to the people in order that they may also know the benefits of hospice care. They seemed to know which avenues to take so that the general public can get the information about hospice care. The participants made the following proposals:

*"I think many people don't really get the idea of hospice. So, I think when people are going around, informing people about HIV AIDS and what is done to prevent it, I think they should also teach people about hospice and hospice care. Maybe if there were in a way, maybe two hospices in the township, maybe it will be better. Now there is one hospice built, maybe it should also be discussed in churches, people should talk about hospice care, let people talk about it and then do something to help out, then it won't be such a stigma, you know. Make the information available to people, teach people so that they learn and become aware, more open minded, so that they become open minded about the whole hospice idea."*

*"All people must learn about hospice care...spread the message through radio, churches and other media."*

A participant was aware that a lack of knowledge and ignorance about hospice is common amongst black people, which is the reason that she actually mentioned them as the target population to get this information.

*"I am personally willing to advocate for hospice care and educate my fellow black people to come out of the darkness of ignorance."*

## Literature control: Willingness to advocate for hospice care

(Foley *et al* 2009: 3) maintain that there are not yet enough hospice services in all nine provinces. It is the aim of the national association that all nine provinces should have associations as well as nine palliative care development teams, making more hospices available. This results from the input that was received from the people that benefit from these services, as they see the service as beneficial and they advocate for their increase and funding.

A mother of an Aids patient in the study by (Boyle *et al* 2009: 197) mentioned that the manner in which her child was treated and made whole again by a hospice, it is her wish that all patients should come into contact with a hospice at one stage or another and live to tell a tale. Her story is that she has seen enough uses and benefits of hospice care. This mother was able to detect what the participants in this study also detected. They had media in mind that could help them to have their voices heard about the good aspects of hospice care.

(Johnson *et al* 2004: 206) also maintain that women who were sole caregivers of patients within families were mainly stressed by activities related to mobility and all activities of daily living. Hospices were introduced to them and their burden was alleviated. Like all the people that acknowledge help, they became ambassadors for this form of care. People knew hospice care through these women.

- **Relief from burden of physical care of Aids patients**

Participants in the study indicated that taking patients to the hospice has freed the family members and enabled them to do other unavoidable duties they are faced with. Most of the participants stated that they are working and are sole

breadwinners; they therefore cannot afford to stay home and take care of patients. They also highlighted that they leave in the morning and only come back in the afternoon. The hospice serves a purpose as patients are also taken there in the morning and are brought back in the afternoon when everybody else is home to continue with after-care of these patients. These are some of the statements mentioned by the participants:

*"I am the only one working...caring for him at home meant I must quit my job and how will the family survive?"*

*"I feel a relief...I did the best for my child. I have no regrets as I am able to look after the younger children because I placed her at the hospice."*

*"Emotionally, I also feel fulfilled as we have been relieved from emotional strain".*

A participant mentioned that taking a patient to the hospice for care, much as it is not according to their cultural practices, had to be done so that they could be released from these practices that do not work for her family. For that matter, she feels that hospices should increase in number as she has seen their uses.

*"My family is released from the bondages of cultural ignorance...there is need for more hospices in our communities as they bring relief to us."*

#### **Literature control: Relief from burden of physical care of AIDS patients**

To some people, hospices brought a glimpse of hope with the advent of palliative care. It has brought a sigh of relief to the people affected by Aids and all the other terminally ill patients. It has taken the burden off them, (Earl, 2005:2).

(Boyle *et al*, 2009:196) in her study also mentions that as the HIV illness progressed and the adult children in her study experienced episodes of serious illness and debility, their mothers became more involved in the activities of daily living, including personal hygiene and nutrition for their ill children. This put much strain on them and their lives came to a halt as they could no longer do anything rather than caring for these children. It took them a long time before they could seek help and when they did, the hospice was the next option. After having taken their children there, their lives changed and they were relieved of the burden of care.

(Strydom *et al*, 2006: 4) maintain that stress among caregivers in the field of Aids manifests itself in a wide range of signs and symptoms, psychological, behavioral and physical. Caring for terminally ill ones becomes even worse. Putting such a person in either a hospital or hospice alleviates all such symptoms and a degree of wellness can be attained.

## **DISCUSSION ON FIELD NOTES**

The researcher kept records of messages and information heard, seen and experienced. A Field note of the first five participants in the research study has been included. They are as follows:

### **Participant 1**

#### **Descriptive notes**

A lady of 61 years of age was visited by the researcher after having made an appointment with her. She has three sons and three daughters. It is one of the sons that is admitted in the hospice. The lady seemed surprised as though she has forgotten about the appointment the researcher made with her. The participant was

with her helper who she has recently appointed. She seemed happy and content about the decision of taking her son to the hospice for care.

#### Reflective notes

*After having taken my son to the hospice I did not have problems. It is a relief to me as I was no longer able to manage caring for my son. He was refusing to take medication at home and he was at times very aggressive. At the hospice he is taken care of by trained people and has a good relationship with them.*

*Neighbors and family members are supporting me in the decision I have made. Some close family members feel that I have rejected my son by taking him to the hospice for care. Personally, I feel that much as hospice care is a foreign means of caring for the sick, it is good for me as it suits my situation. My husband died some time ago, I have no proper resources and food, to care for him, these are only found in the hospice.*

#### Demographic notes

The interview was conducted early at about-09h30 on the 4<sup>th</sup> February 2009 at the participant's home. The researcher and the participant sat outside the house in the veranda of the house.

#### **Participant 2**

##### Descriptive note

The interview was conducted with a woman of 68 years of age, less than 1km away from the hospice. She initially did not show any form of emotional disturbance in spite of having lost a son recently. (Before the interview).

## Reflective notes

*After having taken my son to the hospice, I did not experience any challenge, except the fact that my son passed away recently while being cared for at the hospice. I regards hospice as a great source of help. I was only unfortunate because I took my son late to the hospice while he was already very ill. (Her eyes were shiny due to tears but never shed them until the next question was asked)*

Family members and neighbors never changed the way they relate to me. They even encouraged me that my son will be better. I do not understand the people that use traditional medicine while they are busy taking western medication. It is inappropriate. I was impressed by the fact that patients are being well cared for at the hospice. Exercises are done to encourage them to be mobile, I was just unfortunate. I was also expected to pay R50 for my son's stay at the hospice but he passed way before I could pay. There is no contradiction between hospice care and the Batswana culture. I love hospices.

## Demographic notes

The interview was conducted around mid-day on the 2<sup>nd</sup> of February 2009. Even though the participant has recently lost a son through death, she showed little emotional disturbance. At some stage she looked as though she was about to cry, but she did not.

### Participant 3

#### Descriptive notes

The participant was a woman of 53 years old, who is still working in the nearby factory. She could only be available for an interview late in the afternoon after work. She was more than willing to participate in the study.

#### Reflective notes

*After having taken my daughter to the hospice for care, I cannot say I had challenges. I had to do it. I am working; there is no one to look after my sick daughter. She was admitted in hospital but got discharged while she was still very weak and unable to walk. When she arrived at home she still needed constant attention and care. When I took her back to the hospital, there was no bed available and was asked to get an alternative means of care.*

*At home she refused to take medication. I took her to the hospice where she is able to be fed and be given medication. I am thankful that my daughter is at the hospice. She is able to be cared for while I am at work until 3pm when I come back.*

Other members of the family feel that I have failed my daughter by taking her to the hospice. They feel that it is a way of rejecting her daughter. They are not happy about hospice care at all. I differ with the rest of them as I am in favour of hospices. People do get well there.

## Demographic notes

The interview took place at 18h00 after the participant has come back from work. She seemed distracted most of the time, probably as she was tired from work. Nevertheless she willingly sat for the interview.

## Participant 4

### Descriptive notes

A 59 years old man was interviewed at his home at 11h00 on the 12<sup>th</sup> February 2009. He waited patiently for the researcher and seemed quite keen to be interviewed. Before the interview started, he was very talkative and bubbling with words like a person who wanted company and to lengthen the discussion

### Reflective notes

*I had few challenges after having taken my son to a hospice but they are not significant now. I feel that my son is better off in hospice as my wife has long died and there was nobody to help me in caring for the sick child. There is a reliable means of transport that takes him to hospice and back. He gets proper food. He is actually improving. On admission to hospice, he was not able to walk but now he can due to the care he has received from the hospice.*

*Other members of the family were prepared to let my child rotate among them for care but they later became tired and gave lame excuses not to continue caring for him. They then advised me to take him to the hospice. Other family members actually told me that hospices are for whites but I think that they will come around.*

*I have found great help from a hospice that takes care of my son.*

## Demographic notes

The interview took place on a very hot day under the tree in the backyard of the family with sound of trucks passing from the main road, causing a disturbance, but the interview took place as scheduled even though the conditions were unavoidable.

## Participant 5

### Descriptive notes

A lady of 30 years of age was interviewed as she is the one that has been staying with her ill brother that is receiving care at the hospice. She requested to be interviewed in English.

### Reflective notes

*I am working and therefore there is no one to look after my ill brother. He is transported daily to the hospice like the other entire patient receiving care there. The transport to the hospice is the cause of the problem in the community. The car fetching patients is written in big letters, "Tshupe Hospice." It enables all people to know that the patient transported is having AIDS. I wish that the letters should be removed. Some neighbors have supported me in her decision while others think that I have rejected my brother. Such neighbors have distanced themselves from the family and the way they relate to us has changed. Those that are enlightened are supporting the idea of a hospice for my brother. I wish that people should have an open mind as far as hospices are concerned as they are useful*

## Demographic notes

The interview was conducted inside the family house in the evening at 19h00 in the kitchen. Noise from the television in the sitting room could be heard but the interview was successfully conducted. The participant was very calm and fluent in English.

### 3.6. CONCLUSION

Realization of data analysis on the experiences of Batswana families regarding hospice care of Aids patients was discussed in this chapter, followed by the discussion of research findings. The findings included four main categories, hospice care as foreign, social stigma associated with Aids, differences in health care practices as well as knowledge is power. These findings were enriched with direct quotations from the transcripts as verbalized by the family members of Aids patients. The findings were supported by the available relevant literature for confirmation. Chapter 4 deals with findings, recommendations, limitations as well as conclusions.

## CHAPTER 4

### CONCLUSIONS BASED ON FINDINGS, RECOMMENDATIONS AND LIMITATIONS

#### 4.1. INTRODUCTION

The previous chapter provided a detailed discussion on findings of the study and the supporting verbal responses from the participants as well as the supporting literature. This chapter will highlight the researchers conclusions based on the findings, recommendation as well as limitations that the researcher encountered.

#### 4.2. CONCLUSIONS BASED ON THE FINDINGS

The objective of the study was to explore and describe the experiences of the Batswana families regarding hospice care of Aids patients. The experiences were gathered by obtaining data through in-depth interview of the family members of Aids patients that are being cared for at the hospice. Data was then analyzed, relating it to the relevant literature. Four main categories emerged as findings of the study namely; hospice care as foreign, social stigma associated with Aids, differences in health care practices and knowledge is power. The findings were supported by literature.

Conclusions will be discussed separately according to the categories as follows:

##### 4.2.1. Conclusions regarding Hospice care as foreign

Responses from participants revealed the fact that the concept of hospice care is foreign to the Batswana.

A sub-category of hospice care as being a-cultural to Batswana families emerged. Conclusions in relation to this will then be discussed along with the themes that emerged.

#### **A-cultural to Batswana families**

The participants stated that they as Batswana have believed in caring for their own family members who are sick or terminally ill at home. The home is viewed as a centre of care. Batswana have been caring for their loved ones at home since the beginning of time, just like all the other African communities, as it was also found among African Americans in the literature. However, with the introduction of modern medicine the situation changed and they started sending sick people to the hospital. Although they are now used to hospital care they experience hospice care differently and they view it as a practice that is not within their cultural practices.

The participants highlighted the fact that, they are now working to earn a living and that made it difficult to continue caring for their ill loved ones. When the issue of hospice care became known to them, they had to take their patients to the hospice for care. To the mothers who were primary caregivers and also expected to work, it became a relief. This brought about mixed feelings in families as some were for the idea of hospice care while others were not. This resulted in conflict within families. To combat divisions and misunderstanding, family members had to sit around the table and intensively talk about the hospice issue. Prolonged discussions and deliberations had to be held before an agreement could be reached, that is, before the other members could be convinced that a patient should be taken to the hospice for care. It has become clear that even though the family members were consulted, they seemed dissatisfied as time went on based on the fact that there were criticism

from significant others such as extended family members and relatives. It was also interesting to note that literature shows that African Americans also experienced confusion and misunderstanding in the use of hospice care for their HIV/AIDS patients.

Extended family members also showed concern as the participants described it. It was clear that the mothers were being blamed as people that were central to decision-making about care of their children. Unpleasant words were directed to them. They felt that they were viewed as people that have drifted away from the culture of families by taking their children to the hospice for care. Mothers – in-law are the people that showed concern and disapproval. The mothers experienced the reaction of family members as surprising and unexpected as they were consulted before the decision could be taken. Discussions and consultations is a way of life among the Batswana. Decision-making is based on consensus. The advices of the elder people in the family are often respected. There is a belief that with their experience on life, they can give better advice. In this study, though they were consulted, they still showed dissatisfaction as evidenced by the responses of the participants.

Batswana live like all Africans, who believe that problems are shared in communities. The affirmation of the significant other is important. It is therefore not surprising that the participants experienced criticism from neighbors as painful. When one person is going through any circumstance, all the other members become equally affected. It is for this reason that neighbors are also involved in the disapproval of hospice care for Aids patients. They are not regarded as intruders, but as concerned individuals. In this study, they resented the concept of hospice care to such an extent

that they started to distance themselves from the family concerned and even refuse to eat or drink anything from their homes. Literature also supports the issue of involvement of neighbors in the care of patients and the reason for their concern. It states that Africans exist in groups so that they can face the challenges together and conflict should be minimized by all means. It further emphasizes the fact that if there is no harmony among people, they exclude one another in activities and ceremonies held in communities and this becomes unpleasant for the excluded ones. Although some of the participants verbalized that that they do not care what neighbors are saying as hospice care works for them, it was also clear that they still find criticism and disapproval of the people they live with painful as they needed them to understand their situations and show empathy.

It became very clear from participants that some view Aids and even hospice care as a form of punishment. Some mothers stated that because their children did not change their bad behavior when they reprimanded them for their wrong doing, they should be put in hospices as they deserve that. Promiscuity and doing just as they wished are mistakes that the mothers stated. Aids itself is viewed as a punishment by God or ancestors for one's transgressions as one mother said that her child has angered the ancestors and God. Some literature also associate Aids with immoral behavior and state that it is a dirty disease for which one must be put away from the others. That alone shows a sign of misunderstanding of the concept behind the availability of hospice care.

Some participants felt that hospices promote the western way of doing things. They have a perception that hospice care is something new that it is not according to their culture that came as a result of the new government with its principles. The finding

was supported by literature that was asserted that hospices are unable to address issues of culture, religion and spirituality of African communities, resulting in mistrust of western care methods. Even if circumstances were like that, some people continued using hospices as they have observed the benefits thereof.

Participants expressed the feelings that some family members feel that Aids care must be kept secret at home. This occurs also as a result of the fact that Africans used to care for their patients in a home environment and again because there is stigma attached to Aids itself. They are not against taking care of patients at home, but they are of the opinion that this can only be possible at a certain stage of the disease, but as it progresses, the patient should be taken to a place where experts will be able to render the health care service like in a hospice and in that way, they will be deviating from the norm and they are prepared to do that. The fact that caregivers are working also has an impact on the decision of caring for patients at home. Literature attributes the feeling of taking care of patients at home to the African's lack of trust in medical communities and their practices. It also brings to light the fact that when Aids patients are cared for outside home, they are seen by the rest of the people and the issue of stigma becomes a problem.

#### **4.2.2 Conclusions regarding social stigma associated with Aids**

The families of the Aids patients feel rejected and marginalized. The people they have previously lived happily with, do not even visit them anymore.

A sub-category of feelings associated with hospice care by family, patient and community emerged. Conclusions in relation to this will then be discussed along with the themes that emerged.

## Feelings associated with hospice care by family, patient and community

Families of these patients with Aids that were sent to the hospice, felt rejected for having taken their loved ones to this centre, because the people changed their attitudes towards them, and this occurred after they have taken their patients to the hospice. It is not only the family members that became affected by hospice care, even the patients showed signs of doubt about the hospice care issue mainly due to the fact that the car used to transport them to the hospice has the label for the hospice. Literature support this view as stigma and alienation also befell women that were ultimately left by their spouses after finding out that they were HIV positive and were supposed to be taken to hospices for care. They were rejected.

Participants asserted guilt feelings in patients and family. Guilt feelings in the family is worse, they are the ones that decide to opt for hospice care option. Even if their decisions are based on reasons of work and lack of time to care for these patients, they still felt as though they have abandoned them. This is caused by the reactions of the people they live with as there is lack of understanding on the relief the hospice has brought in people's lives. According to literature, lack of knowledge and understanding of what hospice stands for, can cause a lot of misunderstanding and disharmony in families, as it will be as though the family does not care.

It became clear from participants that, in the first instances, patients were not ready to accept hospice care as an option as they were having doubts. They only started accepting it later when they felt changes in their lives, that is; when they started improving. Indeed improvement did take place at the hospice on patients whose family members were interviewed. Initially patients felt as though the family has given up on them. Available literature also supports the issue of a hospice as being a

place where people go when they have given up. It has also been mentioned that patients who believe in God's healing power do not like hospices as a place of care because they have a belief that people that are sent to the hospice are awaiting death and cannot heal.

It became clear from the findings that family members had fear of being infected by the virus during the care of the patient at home as they do not know precautionary measures. They also do not have the protective devices that would protect them from contracting the disease. To the participants, taking the patient to the hospice would prevent the rest of the family members from being infected with Aids. Much as the desire for care is evident in the family members, so is fear for infection. This was further supported by literature in which a participant mentioned that people around her could not bear the thought of sharing anything with her, even water, due to fear of being infected. People would abandon the river in which she bathed and would rather go home without bathing than going into the same river with her.

#### **4.2.3. Conclusions regarding differences in health care**

Participants expressed their experiences that, hospital care and hospice care are different. They had an opportunity to witness both the care rendered at the hospital and that which is rendered at the hospice. They have observed care at the hospital while their patients were still receiving care at that facility, before they were discharged, and they are subjected to hospice care at present as their loved ones are still receiving care there, except for the one whose son died recently in hospice.

The sub-category that emerged under this category is hospital and hospice care. They will both be discussed concurrently and compared according to the responses of the participants.

## **Hospital and hospice care**

At the hospital patients are discharged early, even before they are well and ready to go home. They are discharged while still very weak. It actually came out clearly that there is less love, compassion and empathy at the hospital than at the hospice. The hospice caregivers are more compassionate and caring. Participants assume that this is due to the fact that they have been taught to care for the terminally ill and the dying in a special manner. It is for that reason that palliative care of patients in this facility gives one peace of mind. People at the hospice become well and their state of health improve. It is clear that hospice care does not hasten death, but may actually yield extra time, which might be particularly important to patients and their families, as it may allow some people to use the end of life as a time of resolution and closure. Health care at the hospice is rendered on a small scale and patients receive individualized care, while a lot of patients at the hospital are being cared for by fewer nurses. Hospices caregivers are said to be displaying expertise, experience and proven community organizing skill. Families of patients receiving care at the hospice observed this.

### **4.2.4. Conclusions regarding the fact that knowledge is power.**

It is clear from the participants that having sent their patients to a hospice for care; they gained knowledge and understanding about hospices that they did not know before then.

Sub-category that emerged under this category includes the following:

- A positive effect on the patient's emotional well-being
- Positive effects on the patient's physical well-being

- Positive effects on families of Aids patients

These sub-categories will be discussed individually below.

#### **Positive effect on the patient's emotional well-being**

Participants confirmed that patients that receive care at the hospice are able to receive the most relevant and appropriate counseling that eventually uplifts their spirits. It is during this time when their spirits are uplifted that the emotional symptoms, such as stress and depression, starts fading. Counseling and support at this institution is done in such a way that it brings about restoration of hope to both patients and families. When hope becomes restored, there is a change in attitude of both the patient and the family towards the illness. The family members accept the status of the patient and are able to cope with it. The patients start taking charge of their lives again and become willing to live again. According to the available literature, counseling that is available in the hospice enables a patient to take charge of his life again as they are enabled to come to terms with their illness. It also states that care of patients in a hospice enable them to understand themselves and their illnesses better.

#### **Positive effects on the patient's physical well-being**

As soon as the emotional symptoms are alleviated, the physical ones such as inability to eat and get out of bed also become alleviated. Those that refused to eat start showing the desire to do so. Prophylactic treatment is available at the hospice and also hastens improvement. Literature confirms that in a hospice, needs analysis is done and care that is individualized can be planned for and implemented. This

results in improvement of the patient. The opportunistic conditions associated with Aids are said to be minimal during hospice care session.

### **Positive effects on families of Aids patients**

Participant expressed their willingness to advocate for hospice caregivers, stating that they are the best caregivers. There is a need to make hospice care known to all so that they can all know its benefits. Most people are still clinging to the cultural beliefs that hospice care is for other population groups, but the participants are willing to change the people's mindset regarding hospice care. They assert that it has brought some relief of physical care of patients on families that are otherwise unable to care for them at home due to commitments such as work, which is unavoidable. This is the benefit that both patients and their families enjoy. Patients are able to be cared for while their families are at work and the family members are able to work while the patients are being cared for at hospice, then come back in the afternoon to continue with after-care of these patient at home in the evening. Literature also supports this benefit of hospice care to family members as it states that mother became so actively involved in the care of their children, so much so that their lives only revolved around their care and could not do anything beyond that, until such time that a hospice became known to them and they took their ill children there.

Gradually the Batswana families and communities have realized that hospice care is there to stay. It was evident in this study as conflict and misunderstanding became resolved as the difficult and uncooperative extended family members came to realize that hospice care is bringing physical and spiritual healing to the sick.

Based on the findings, it was concluded that, although patients were not comfortable in the beginning with hospice care, they later accepted it due to the benefits that they saw in it.

#### 4.3. RECOMMENDATIONS

The following recommendations for are made based on the conclusions drawn from the study:

The findings showed that culture is an integral part of rendering care. For hospice care to be successful the cultures of individuals must be incorporated. The issue of cultural safety must be incorporated in hospice care by ensuring the following:

- **Recommendations for policy makers**
- Adaptation of cultural issue to the hospice model. For example the role played by the significant others such as neighbors', extended families and the community at large.
- Education to the community to enable them to understand the value of hospice care. The community should be taught about the uses of the hospice, including the fact that it renders service to the Aids patients.
- Integration of patients who are suffering from different types of terminally illnesses to avoid social stigmatization associated with HIV/Aids, for example patients suffering from cancer.
- The community should also be taken through a session in which they are taught and advised on correct attitudes and respect for the next person's decision, including decision to utilize a hospice for care in order to minimize

stigma and mistrust attached to hospice care, and instill an understanding that hospices are not used as a form of punishment of the ill people but to render service aimed at improving their health status.

- Intense education should be given about HIV/Aids to the community through the community radio stations and health education sessions at the clinics. This will address the desire of the participants to advocate the use of hospice to all community members. Literature has also revealed that people still lack knowledge about Aids and hospice care. Families of patients with HIV/Aids, fear to be infected while caring for these patients, therefore information sharing and education should be structured around mode of transmission of the virus to the next person.
- There should be transparency pertaining to both hospital and hospice cares in relation to the expectations as the two institutions differ, even though they both render health care services. Participants showed preference of hospice care over hospital care, though the contexts of the two institutions differ. This will be addressed through education that will take place in the clinics and through local radio stations, so that the hospital can still be viewed to be a good centre of care in situations where it is needed.
- Counseling of patients and families at the hospice should be re-enforced as it has shown to improve both the physical and emotional well-being of patients and communities. Hospice personnel should be commented on that.

#### 4.3.2. Recommendations for nursing research

- A research project that will investigate the perception of the Batswana community in relation to hospice care should be done so that the views of the community can be known in relation to the experiences of the families that were explored in this study. Knowledge of both parties, community and families, could be of value to the policy makers.
- Another study that should explore the experiences of patient receiving care at the hospice would also increase the knowledge base of hospice care option in Batswana as a community. The findings thereof would also assist policy makers.

#### 4.4. LIMITATIONS OF THE STUDY

The limitations of the research as experienced and observed by the researcher throughout this project are as follows:

- The fact that Aids is a sensitive issue and highly stigmatized, made it very difficult to get participants to freely give information or to actually participate in the study. Some were quite reluctant. The researcher had to make additional efforts to convince the administration officer to give residential addresses of patients to the researcher so that she could visit the respective homes and make appointments for the interview.
- By virtue of the fact that the families are dependent on the services of the hospice, they might not have given a true reflection of their experiences with the fear that they might lose the services they get even though the researcher has promised them confidentiality in the interview. This is only

human nature, especially if one is entirely dependent with no other option to resort to. They might have said only the things that they think the researcher wants to hear.

- Only members of the family have been interviewed in this study. With subsequent researches, the population should also include the other community members to state how they feel with hospice care as the Batswana community.

#### **4.5. SUMMARY**

The researcher chose this research problem as a concerned person, with her own African values and beliefs, her mind rooted in an African foundation, she had her own view of hospice care. Her observation taught her that the hospice in Tlhabane is not well utilized because the community does not like the hospice care option, or they are denied access to it. She became very objective throughout the study and did not allow her values to cloud her judgment. After intense data collection and analysis, it became evident that much as hospices might have originated from other cultural systems other than African, they have been well accepted and welcomed. It is clear that with more than one cultural group living together, they are bound to adopt traits from one another and cultural diffusion will always have an impact on their norms and values, more so that hospices could bring such relief. It also became a learning curve for the researcher.

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ANNEXURE  
A



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Prof F Mulaudzi

29 August 2008

Dear Prof Mulaudze

**ETHICS APPROVAL OF PROJECT**

The North-West University Ethics Committee (NWU-EC) hereby approves your project as indicated below. This implies that the NWU-EC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title: THE EXPERIENCES OF THE BATSWANA FAMILIES REGARDING HOSPICE CARE OF AIDS PATIENTS																	
Ethics number:		N	W	U	-	1	0	0	3	4	1	-	0	8	-	A	1
		Institution			Project Number						Year		Status				
		NWU			100341-08						2008		A1				
Approval date: 31 July 2008		Expiry date: 30 July 2013															

Special conditions of the approval (if any): None

**General conditions:**  
 While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- The project leader (principal investigator) must report in the prescribed format to the NWU-EC:
  - annually (or as otherwise requested) on the progress of the project.
  - without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the NWU-EC. Would there be deviation from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-EC and new approval received before or on the expiry date.
- In the interest of ethical responsibility the NWU-EC retains the right to:
  - request access to any information or data at any time during the course or after completion of the project
  - withdraw or postpone approval if:
    - any unethical principles or practices of the project are revealed or suspected,
    - it becomes apparent that any relevant information was withheld from the NWU-EC or that information has been false or misrepresented,
    - the required annual report and reporting of adverse events was not done timely and accurately,
    - new institutional rules, national legislation or international conventions deem it necessary.

The Ethics Committee would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the Ethics Committee for any further enquiries or requests for assistance.

Yours sincerely

Prof MMJ Lowes  
(chair NWU Ethics Committee)

27-JUL-2008 SAT 10:27 TEL:

NAME:

P. E

TSHUPE HOSPICE  
2872 MOTSATSI STREET  
TLHABANE 0299  
TEL-FAX: (014) 565 3493

Mrs. M.F. Makhele  
3017 Unit 3 Tlhabane  
0305

Dear Madam,



RE: GRANTING OF PERMISSION TO MRS. M.F. MAKHELE TO CONDUCT A STUDY

Tshupe Hospice in Tlhabane is granting permission to Mrs. M.F. Makhele to do a study on the Experiences of Batswana families regarding hospice care of AIDS patients within the community of this hospice.

Her study recommendations will be of assistance to the families of patients in this organization and the community at large.

Yours sincerely



.....  
Administrator

TSHUPE HOSPICE  
2872 MOTSATSI STREET  
TLHABANE 0299  
TEL-FAX: (014) 565 3493

ANNEXURE C

INFORMED CONSENT

I, ..... On this day  
of..... of..... 2009, hereby consent to:

- Be interviewed by Mathodi Florah Makhele for a research project titled: **The experiences of Batswana families regarding hospice care of AIDS patients.**
- Be available for follow-up interview if necessary
- The interview be audio-taped and
- The use of data collected from the interview by the interviewer in a research report as she deems necessary.

I also acknowledge that the researcher has discussed all relevant information with me regarding the aims and objectives of this study as well as the way in which ethical issues will be observed.

.....

.....

.....

(Interviewee)

(Interviewer)

(Date)

## ANNEXURE D

### INTERVIEW TRANSCRIPT

#### PARTICIPANT 1

R: Good afternoon Sir.

P: Afternoon

R: I am Mrs. Makhele from University of North-West. Remember we made an appointment the other day so that I could come and interview you concerning your brother who is in a hospice.

P: Jaa, I remember

R: You remember, OK. Will you spare me some minutes so that we could have a talk over it?

P: OK.

R: Does it mean that the person who is in the hospice is your brother, or sister?

P: He is my brother.

R: Your brother, OK. I just want to share with you your experiences as a Motswana, if your twin brother, you said, being in a hospice, I know that hospices are new in our culture as blacks, so I just want you to share your experiences with me pertaining to that.

P: Oh. I know that they might be new n in our culture, and its something that we cannot change. Since we are Tswana and we grew up like that, if somebody's sick

we keep them in the family, we look after them. But I think that if a person reaches that stage where they cannot be taken care of by people around them is best for them to be taken to hospital or hospice where they will get proper treatment and where trained people, professionals will look after them. So in that way, even if its not in our culture, but there is a benefit. We just need to adjust and we must know that it is just for the benefit of the people that we love.

R: I understand that you say you are benefiting from the hospice care.

P: Yes.

R: But how would you have preferred things to be done?

P: In terms of our culture, you know as you said, you are aware of the fact that it is new and foreign to us as blacks. If you were to have it otherwise how would you have had it? Eer. Culturally what was being done in cases like these, before hospices were there.

P: Oh, you mean like way back before they introduced hospices?

R: Yes I mean that and ideally, how would you have had it?

P: Jaa, e....let me think of it. I think maybe back then, they did not have hospices back then. People were being taken care of at home. And was AIDS, I mean, were people sick the way they are today, back then?

R: They were sick but AIDS was not there way back then, but they used to cope in one way or the other. So, how do you think could have been the case particularly with your twin brother that is in the hospice, if you were to abide by your culture?

P: Eeh, I think if that is the case, if we were to abide by our culture, we don't have any hospices. There wouldn't be hospices. My brother wouldn't be in a hospice. We would, you know, put our heads together and people who are around, any family member sit and take care of my brother, even me, even whoever, whoever has the time. I mean, because with our black culture where it's so foreign, I mean there wouldn't be any hospice. I mean that's how it is in our culture there is no hospice. A person gets sick, they stay at home, we look after them, because they believe they have been... they've been looked after by the people who love them. That's how our culture is, so... there wouldn't be any hospice. I don't know if that answers your question.

R: To a certain extent it does answer my question. But, eeh further more I just want to find out, do you know the concept of Ubuntu as far as, eeh, African culture is concerned.

P: I think I know. I do have my own interpretation, maybe I don't know if it is the same as what you have in mind. Jaa, I think I know because...

R: Can I have it?

P: Can I say it in African language?

R: Yes you can.

P: I think Ubuntu for me is maybe "Motho ke motho ka batho" I don't know if that's right.

R: Yes

P: Jaa, yes, so I do know that concept

R: So how does this Ubuntu cater for people in the situation in which you find yourself, now that you've got a brother in a hospice, how could Ubuntu back then be of value in caring for your brother?

P: You mean back then where there were no hospices

R: Yes.

P: I think back then actually it was very easy because, I mean back then, there were no hospices and then, when a person gets sick, they just stay at home it was very easy because, I mean my brother is gonna be looked after by a family member, or you know a relative or something like that. So its not foreign for Afamily member to appreciate another family member, like in hospices, we still have to enforce that, eeh... I mean Ubuntu, "motho ke motho ka batho." I mean back then it was just a person in your family. You don't have to enforce anything or do whatever. Maybe that's why back then, like it was very easy because they were looked after by the people at home. Now it's a hospice. It's somebody they are not even related to. It's difficult for you or for them to grasp that concept ya Ubuntu. Jaa.

R: Jaa, OK, I understand. So according to you, do you think as Africans in the condition in which you find ourselves right now, can we still be able to practice the Ubuntu concept in caring for the sick? Is it still possible?

P: I think I shouldn't say... or we shouldn't say that it is not possible and rule it out that it can never happen, that, I mean...We obviously know that people know that the Ubuntu we had back then, obviously it has changed now that if we work.., if we work on maybe morality and other things, that do affect Ubuntu

R: Ee.

P: Maybe we can still go back and have the same Ubuntu that we had back then because other things happened, and that Ubuntu, people are slowly losing it. As much as, it has been preached and staffs like that, we are losing it. We should work on our morality, our values as black people we can still go back to Ubuntu

R: Eee. OK. Can we please go back to issue of stigma attached to HIV because you have a brother there in hospice and also touch issues around stigmatization in a patient put in an institution? Maybe let's start with putting a patient in an institution. Doesn't it have a social stigma in your culture as Batswana.

P: I think it does, it does the same thing as old age homes in a way. Old people are being taken to old age home but they.. in a way personally feel that, eeh, they have been a burden to you or whoever is around, that's why they have been taken there. But if they look at it in the other way, like I have said initially maybe its just being...you being caring and saying that I can't take care of him and give him, some better care than you could. So, it's better, it depends on how you look at it, but I think in our culture, in our black culture, it's mostly wrong, it's not a good thing too, and again it makes the stigma very alive now.

R; Ee.

P: Now people see you, you are put in an institution, there with only people like that. It's in a way stigma on its own

R: Uh, OK. Sir... and I would like to thank you for your time, but one last question that I would want to find out, still on the stigma again. Is there anyway that we can, we can run away from the stigma pertaining to a person being put in an institution like a hospice. Is there a way that we can avoid that stigma?

P: Well, avoiding it, eeh... maybe we can avoid it, or maybe we can work on it than try to avoid it. I think especially with a hospice, it starts with a vey very,...I mean it starts with this, basically why you are there. It's because of HIV, and because of how people look at HIV. I mean I don't think it just starts about you being in a hospice, it goes back to why you are there and how people view HIV, they just think its some different disease or illness, so that's why the stigma is so huge, and maybe if we can change our whatever attitude towards the virus or towards the disease, then maybe we can try to, or not to stigmatize it or whatever the way people are doing it today.

R: So, lastly, what I've just gathered from you is, the stigma is not much about the hospice but it's much about AIDS itself.

P: Yes, jaa

R: OK, thank you very much for your time sir.

P: OK.

R: Bye

P: Bye

### PARTICIPANT 3

R: Dumela ntate.

P: Agee mama, le kae?

R: Re teng, lena le kea?

P: Ee ka nnete.

R: Nna ke mme mma Makhele, ke tswa ko North-West University , jaana ka ga ke dirile appointment le wena, gore ke tlo go bua le wena. Ee go nale brother wag ago ko hospice. Ee ke tlo go botsa gore maitemogelo ke a feng ka batho ba ba isiwang ko di-hospice ba tshwerwe ke bolwetse ba HIV / AIDS?

P: Ee ka nnete nna ka mo ke ileng ka sheba dintho ka teng, ke bona e kare ntho e, e tliša bobeterenyana mo saeteng le la rona because motho o o leng mo bolwetseng, a tshwerwe ke bona bolwetse bo, o batla motho oe leng gore o ipha nako e ngata le dintho tse ngata, le tlhokomelo e leng gore ba ba fa yona, ga se e e leng gore re ka ba fa yona re le mo gae. Ke a utiwisisa gore tše dingwe tsa dintho, rona re le mo gae, o tlamegile motho oo ga o mo sheba , tsela e o mo shebang ka yona e be ele gore le wena at the same time o kgone gore o itshireletse, ka tsela enngwe ka baka la gore batho ba ba leng koo rona ga re ba tlhokomela re ba tlhokomela ka tsela ya sé-Afrika, ga nke re sebedisa tse o ka reng ka nako e tlang le wena o fitlhele e le gore le wena o sireletsegile , bolwetse bo kgona gore bo go fetele ka mantwe a mangwe.

R: Bo go fetele.

P: Ene gape tse dingwe tsa dintho, ke dintho tse tsa meriana, ke nagana gore ga re le mona, mo gongwe nka fitlhela ke tsere ke mabaka ke be ke lebala go mo gopotsa gore a nke meriana ya gage. Athe ga a le koo, gona ko dihosipice tseo, ke gore ba kgona go tshwara nako ya gage ke gore a kgone go nwa dipilisi ka nako e rileng, a seke a nwa dipilisi a sa ja. Rona ga re le ko gae, ga a re ga ana takatso ya dijo, go fella moo.. ga go na ntho e nngwe ,re tla be re mmolella gore a phomole. Ko dipetlele tseo ba ka kgona gore ba mo eletse. Ene gape ga re kgone gore re nne le go kgothatsa ga kalo., anthe ga a le koo, ba kgona gore ba mo kgothatse a amogele boemo bo a leng mo go bona. Jaanong tsatsing le lengwe o ka fitlhela ele gore ka tsatsing leo, ke...ke...ke betere mogo ena or ka gosane ke tla ke tennwe ke tsa ka, ke be mmolella mantsewe a a leng gore ga go kgonege gore a kgothale. Maar ga a le koo o fumana e le gore ba a tshwana, le ena ka moo a kgone gore a amogele bolwetse boo. Le batho ba ba ba tlhokomelang ke batho ba e leng ba gore ba fumane thuto, ba rutilwe le gore motho o tla kgona gore a be le mamello eo. Le ga a ka tenwa ke tsa ko lapeng, a seke a phisetsa mo go ena.

R: Ke a utlwa rre, ke ne ke batla go itse gore aa selo se hospice, go isa motho, a ga se thulane le setso ga re le Batswana?

P: Ja mama, ke...ke..gore ga o shebile o ka nagana gore di a thulana because nako e nngwe rona re na le gore re nne re se ke ra sheba fela meriana e ya sekgowa. Ene re na le tumelo mo...mo... merianeng e ya mo fatshe mo, maar re kile ra bona gore mo bolwetseng bo, ko...ko kae kae batho ba ba ngata ba kileng ba felella bale mo matsogong a rona, so, ke dumela ko..ko..ko..mo dilong tseo tse..tse..tsa ditlhare tsa..tsa..sepetlele seo ba kgona gore ba be betere ka gore sa pele melemo ya bona ba kgona gore ba e je ka nako e e tshwanetseng, e batla e le betere mo go e ye rona because rona re dumela gore motho re mo phehele dipitsa, re mo etse eng,

jaanong o kereya e le gore nako enngwe bolwetse bo re makaditse gona jaanong. Empa fa e le gore mo go reng gaba sa kgona go fola, re tsamaya re qakega, that's why re re go betere ga ba le moo, re kgona go bona diphetogo ka nnete.

R: Ee.

P: Eeh

R: No, ke a utlwisisa rre gore tota go ya ka wena dihospice tse dina le thuso. Jaanong ne ke re botho, botho, selo se re se bitsang ubuntu, botho ba rona batho ba ba ntsho, a re ka se ke ra makallwa ke batho ba merafe e mengwe go bona re isitse motho wa rona ko dihospice, gore a yo tlhokomelwa ko teng?

P: Ee, e batla e le thatanyana ka nnete mme because nako e nngwe e ba e ka re motho re mo latlhile, so, ke ka moo go..go leng botlhokwa go re o ka re batho ba...ba...ba...ka fumana, ke gore thutu, e be gore ba kgone gore ba rutiwe ba.. ba.. ba...be le kitso ya gore ke mabaka a feng a e leng a a gapeletsang gore motho a ye koo. Le teng motho ga a le mo tlung, ke nnete re..re..re..bona e kare re a mo kgathalla, maar ka nako e nngwe e nna e kare re mo latlhetse matsogo, o kare re mo latlhile, anthe ga go jalo ka baka la gore ga gona thuso gore motho re dule le ena mo ntliong a be a tlo tlhokofala, anthe mola nkebe re mo isistse a ka bo a kgona gore a be le bophelo bo bongwe ka mo ntlong re shebile gore o ka re a ka ba beterenyana. Metlheng e ga e sa tihole e le metlheng ela ya pele, ke ka moo ke ileng ka bua kare metlheng ya pele o ne o kgona gore o tsamaye o ile go cheka setlhare ko..ko..ko thoteng o be o kgona go tlo phehela motho a fola. Mme malwetse a jaanong a re makaditse le rona, ke ka moo re tlamegang gore ga motho a lwala re mo isa. Ga re bone e ka ba ntho e kgatlanong ga kaalo ne.

R: Ke a utlwa gore tota di a thusa di-hospice. Ee jaanong go ya ka dingwao tsa rona, motho re ne re mo tlhokomela mo ntlung, aba a..a tlhokofalla mo lapeng kgotsa a fola, maar jaanong ga o lebeletse, o ka khona go dira jalo gona jaanong?

P: Ga ke dumele ga ..ga.ga kalo mma. Ke gore..ke gore , ee, ke gore go tla ya le gore bolwetse ke ba mofuta mang. Pele re ne re re motho ga a gotihola, re dire jwang, re mo phehele a be a fole, mme gona jaanong ke malwetse a leng gore ga a phekolege.

R: Ee.

P: Mo e bileng ele gore, ntlha e nngwe a kotsi, a a fetela, so that is why, wa bona mo go rona o tla fitlhela e le gore Ma-Afrika ka botho ba rena, re batho ba e leng gore re a seketsa, ga ke rekile ntho e nnyane ke tlo e berekisa le mo letsatsing le le latelang. Ga re sebedisa ntho tse e kang magare, re a a bea, re boye re a sebedise, ga se ntho e e kareng re a e latlha. O mongwe oa a baya o mongwe o a a sebedisa. Re tshelana malwetse, o fitlhele e le gore lapa kaofela le wela ka mokoting o le mongwe

R: Le fetetswe ke bolwetse.

P: Wa bona. Ga e le ko dipetlele tseo o fitlhele bana le disebediswa tse di lekaneng. Ntho e tla sebediswa ke ena a le mong. Ene gape ntho e e leng teng ke ka moo ke reng pele re ne re kgona, gona jaanong re a tshoga, go na le mo re tsamayang re tshoga teng, ke ka moo.... ke ka moo ke reng gare ba fe kgothatso e e leng gore ba ka e fiwa kwadipetleleng tseo. Koo re tsamaya re fela pelo, gape ntho e nngwe e e leng teng, ko dipetlele ba ka bona bobeterenyana, empa ga re bona motho a dutse re mmona a ntse a ota, tota go sena tswelopele, re tsamaya re fela pelo, ra bara

palelwa ke kgothatso eo, anthe ga a le koo, re mmona a ntse a kaonafala, re tle re tie moyeng, re kgona le go mo kgothatso le go feta moo. Ee..

R: Jaanong seo ke maikutlo a gago, rre. Ee. Jaanong ke ne ke botsa gore ba lelepa ba bangwe, ba lelapa ba bangwe ko ntle gagago, maikutlo a bona ke a feng, ga le isitse molwetse ko hospice?

P: Ke gore ba...ba...bangwe ba batla ba utlisisa. Ka gore ga re tshwane ka dikelello kaofela, mme ba ba bangwe ba kile ba kwata ba re motho o e ka re re mo latihile re mo neile ko badichaba. Re le lelepa re tle re leke gore ka nako e nngwe re ba tshaisetse gore gagolo selo seo se dirang gore... gagolo seo di dirang gore re mo ise koo ke eng. Mme re ba tshwantshetsa ka batho ba bangwe kwa ntle gore di mosola gagolo. Motho ga a le koo o nna le diphetogo gagolo go feta ga a le mo gae, ebe re simolola go utlisisa le ga e le gore qalong ne basa utlwisise. Ga motho o mo tshaisetse o mmontsha mabaka a be a utlwisise bogolo ga a bona motho a kaonafala.

R: Ee.

P: A le koo

R: Jaanong maikutlo a molwetse o o teng ko hospising ena,.. o experientia jang bophelo?

P: Gagolo gagolo, wa bona, hospice ke yona e e leng gore e nka karolo e ngata gagolo fo feta moo, ka gore ka ga ke kile ka cho gore ga a bona ba bangwe o bona pholo ka gore ga dutse a le mongwe, o kgona go nagana a its'hola, a etsang, athe ga a le koo, a kopana le ba bangwe o kgona go amogela gore a se gore bo diretswe ena, athe ke ntho e ka tshwarang mang kapa mang.

R: Ee.

P: Moo o kgona gore a kgothale. . gape moo ke kileng ka bua gore o dula le nna abuti wa gage, ga ke tlhaga ka tennwe ke tsa ka, e ka re ge ke tlo kopana le ena, ke be ke mmotsa mantswe a e leng gore ga a monate, a mo dira gore a nagane ka mokgwa o mongwe. Ga a le koo o dula le batho ba ba dulang ba mo fa kgothatso ka metlha.

R: Ee.

P: Le ena o ba betere ga a le moo o bona go na le phapang e ngata gogolo. O kgona gore a amogele le ena boemo bo a leng mo go bona.

R: Jaanong seo se raya gore re le batho ba ba ntsho re tshwanetse re simolle re nagane ka mokgwa o mongwe ka di-hospisi tse.

P: Ka nnete mama. Ke ka moo ke kileng ka cho ka re, ekare, ekare o ka re go ka ba le thuto e itseng e ka fitlhang mo go rona batho ba ba ntsho gore batho ba kgone go bona botlhokwa ba gore go baneng batho ba tshwanetse ba isiwe koo gore ba kgone ba kereye tlhatlho eo. Ka go re ka mo gae re batho bao ba tshwanentseng go bontshana ona mabaka. E kare batho ba ka fumana yona tlhatlho eo ya gore ke go baneng batho ba tshwanetse go ya koo, ba kgone go itse gore ga ba le koo ga se gore re ba tshapetse matsogo, re ba latlhile. Ke gore di a sebetsa ka nnete dilo tseo.

R: Ee

P: Ee

R: Ke lebogela nako ya gago rre.. Ee information e o mphileng yona e tla felela magareng ga ka le wena. Ee. Ke ya go e dirisa

P: Ke lebogile gagolo mama

R: Dankie.